Fall 2019

SHINE

BC Children's Hospital Foundation

Embracing mindfulness

Discover how one of the first pediatric mindfulness centres of its kind is helping youth better cope with challenges

IN THIS ISSUE

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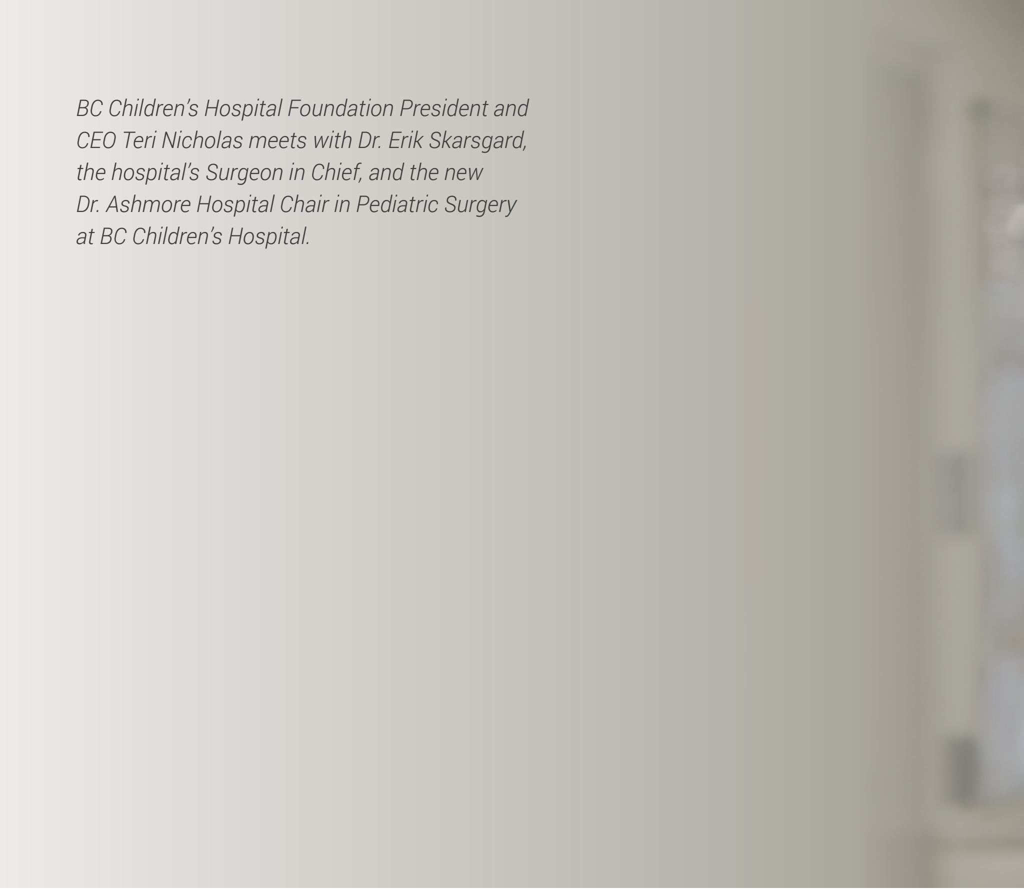

BC Children's Hospital Foundation President and CEO Teri Nicholas meets with Dr. Erik Skarsgard, the hospital's Surgeon in Chief, and the new Dr. Ashmore Hospital Chair in Pediatric Surgery at BC Children's Hospital.

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NEW FRONTIERS

As a supporter of BC Children's, you already know that it's the only hospital in BC devoted solely to the care of kids. We're also fortunate to have some of the brightest minds in medicine caring for kids and searching for new discoveries that will transform the care they receive.

In this issue, you'll read about how we are helping to pursue new frontiers in child health, with the support of donors like you. We're working to bring next generation technologies to kids and families who are searching for answers about unexplained genetic conditions. We're also helping to improve access to critical, life-saving resources across BC to better control type 1 diabetes, a serious, lifelong disease.

You'll also learn about pioneering advances in child health, including the first virtual hearing clinic of its kind in BC, new resources to help kids diagnosed with asthma stay out of the hospital, and BC Children's new Centre for Mindfulness—one of the first of its kind at a pediatric hospital anywhere in the world.

I am also excited to share that a new Hospital Chair—the second at BC Children's—has been established, and will be held by Surgeon in Chief Dr. Erik Skarsgard. This is one of the highest honours BC Children's can give to its clinicians or scientists, and provides them with guaranteed support for their pioneering work today and for generations to come. The Dr. Ashmore Hospital Chair in Pediatric Surgery at BC Children's Hospital, named in honour of its first Surgeon in Chief Dr. Phillip G. Ashmore, will help transform care in pediatric surgery.

This progress has been made possible through the help of supporters like you. Your generosity is helping to achieve new advances. Advances that will improve and save children's lives.

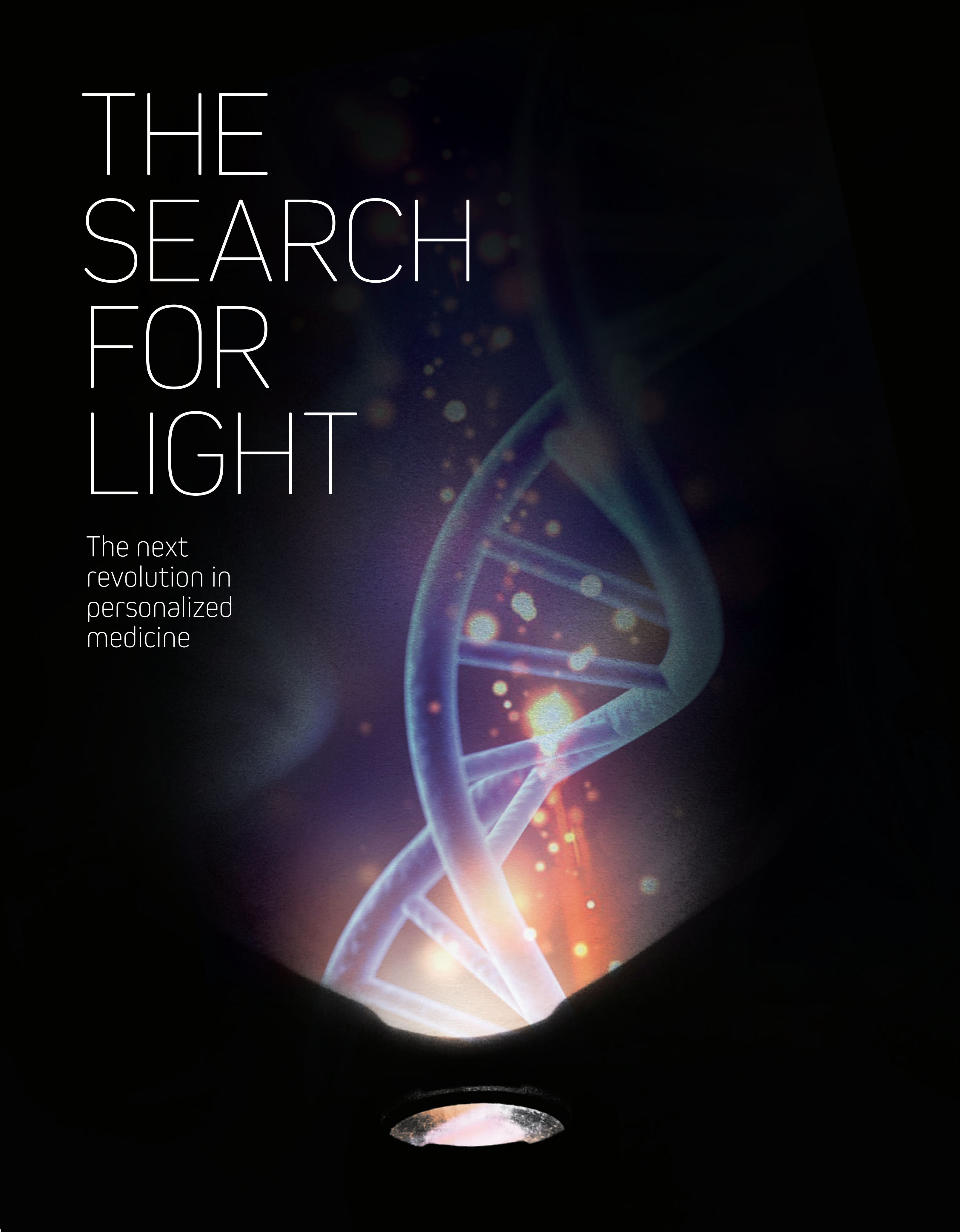
We thank you for joining us as we embark on these new frontiers.

Teri Nicholas

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

THE SEARCH FOR LIGHT

The next
revolution in
personalized
medicine



IMAGINE THAT, IN THE MONTHS AFTER YOUR CHILD IS BORN, THEY DON'T HIT ANY OF THE USUAL DEVELOPMENTAL MILESTONES, LIKE ROLLING OVER OR CRAWLING. AS TIME PASSES, YOUR FEARS START TO MOUNT AS YOUR CHILD BEGINS TO SUFFER FROM MORE DEBILITATING SYMPTOMS, SUCH AS SEIZURES AND VISION LOSS.

You visit specialist after specialist, only to be told each time that they don't have an answer. After months—even years—of searching, you are still left in the dark.

Several hundred of our province's kids and families with unexplained genetic conditions experience journeys like this each year. Individually, these conditions are very uncommon—but with an estimated 8,000 known rare diseases, these conditions collectively affect a large number of children and their families.

"When these kids and families come into our hospital, they are desperate for an answer to the challenges they are facing," said Dr. Wyeth Wasserman, executive director of the BC Children's Hospital Research Institute.

These families embark on exhausting "diagnostic odysseys"—journeys that involve dozens of specialists who try endlessly to find out what's going on. The answers often lie in their genes—and specifically, mutations that occur within them. But with tens of thousands of genes in the human body, pinpointing the precise mutation that's causing a condition is no small job. And it's one that can often involve countless tests or painful procedures.

"Every test is an invasion in the life of a child, whether it's a blood draw, muscle biopsy or spinal tap," added Dr. Wasserman. "So, you try the most likely problem first—the one that has the best chance of an answer."

Yet this approach has been unlikely to yield answers. To get a handle on why, it helps to understand how genetic testing technology has evolved throughout the years.

CRACKING THE GENETIC CODE

Decades ago, health care providers were essentially in the dark when it came to finding the underlying causes of genetic conditions. But thanks to scientists' work in mapping out the entire human genome, new technologies emerged that enabled experts to search for the causes.

This was a huge step forward, but the problem with these early tools was that they could only zero in on one gene at a time. It was like trying to find a small object in an immense dark room with the help of just a flashlight. More often than not, the process was unsuccessful.

Diagnostic tools improved, but not quickly enough. Months could still be spent looking at a gene, only to discover that it was the wrong one.

"Families without a diagnosis truly suffer," explained Dr. Stuart Turvey, Professor and Canada Research Chair in Pediatric Precision Health, who sees many kids with rare genetic conditions. "We don't know what the future holds for their child. It's a feeling of being completely lost."

THE WHOLE PICTURE

But soon, more families will have a path forward.

With the support of donors, BC Children's is working to bring the latest revolution in personalized medicine into the hospital: next generation technologies. In one single test, clinicians can peer into the entire genetic makeup of a child and see every gene at once.

This is transformative for a host of reasons. For kids and families, it means less time searching, fewer painful tests and reduced stress. Above all, it means more answers that come faster, which can be profound. Knowing the problem can, in the best cases, inform personalized treatments that are targeted to a child's DNA—which may even lead to cures.

In cases where there are no proven treatments, a diagnosis can open the door to resources that help families better manage conditions. Many parents also find it life changing to simply have a name for what's causing their child's symptoms. It gives them the chance to connect with others around the world who have similar medical problems, alleviating the isolation that comes with a rare genetic condition.

WITH NEXT GENERATION TECHNOLOGIES, WE CAN:

- Reduce painful tests and time spent searching for a diagnosis
- Enable families to get the resources and support they need
- Open the door to earlier interventions and targeted treatments
- Provide a clearer picture of a child's future health journey

LIGHTING A PATH FORWARD

More than 400 guests will come together at this year's ***33rd Annual Crystal Ball Gala*** to support next generation technologies. This will lead to faster diagnoses and targeted treatments for many, helping end the diagnostic odyssey for hundreds of kids and families across BC.

"The clarity of information that comes out of these technologies represents a transition point for these families," explained Dr. Wasserman. "They go from the mystery and misery of the odyssey, to understanding and knowledge. There's hope."

FROM PROMISE TO PRACTICE

These technologies won't be entirely new to BC Children's Hospital. For the last several years, top minds at the hospital's on-site research institute have been studying their potential to diagnose complex genetic conditions. Hundreds of children have been given access to them and remarkable success stories have proven their power to change lives.

And now, BC Children's Hospital is ready to bring these tools out of the research realm and into real-life clinical practice—helping ensure that any child who could benefit from them, will benefit.

When the technologies arrive at BC Children's, they will transform care for kids and families with unexplained genetic conditions. And that's just the start. The hospital has bold plans to use next generation technologies to improve care across all areas of child health, from cancer to heart disease.

LATEST STRIDES

Here's a look at a few recent discoveries and advancements that have been made possible through the incredible generosity of donors like you.

STATE-OF-THE-ART GENEROSITY

We are so grateful for the immense generosity of an anonymous donor's recent gift of over $1 million that brought a new neuronavigational system to BC Children's. This system uses the latest advances in technology—like robotics, 3D image guidance and state-of-the-art laser technologies—to improve health outcomes and reduce complications for kids undergoing neurosurgeries. This equipment will be the first of its kind in Canada in a pediatric setting. The first surgeries using this innovative technology will begin soon, and we can't wait to share more.

MORE THAN MEETS THE EYE

Amblyopia, or lazy eye, is the most common visual impairment in kids. It's long been defined as a condition that affects just one eye, occurring when the brain favours one, which causes the other to weaken.

But recent research has revealed that this definition may need to be revised. By studying kids with the disorder, Dr. Deborah Giaschi, an investigator at BC Children's Hospital, discovered that both eyes appear to be affected. And beyond impacting a child's ability to see clearly, it's affecting their reading ability, hand-eye coordination and depth perception—all of which aren't currently assessed by physicians.

Though in its early days, this research may change how the disorder is treated. That's because the standard treatment for lazy eye—placing a patch over the strong eye to train the affected eye to work harder—doesn't address the other areas that are impacted. And it's why Dr. Giaschi is also exploring an innovative new treatment that taps into the power of video games. While wearing virtual reality goggles, kids play games that use both high or low contrast images, which require both eyes to work together in order to play successfully.

"More work needs to be done, but the hope is that when a child is diagnosed with lazy eye, we'll be able to see who should be treated with patching—and who has these other things going on and could benefit from playing games," Dr. Giaschi explained.

Dr. Giaschi's research has been made possible through the support of several organizations and donors, including The Whitearn Foundation.

REACHING KIDS ACROSS BC

British Columbia is home to a million kids, and size-wise, it's bigger than the states of Washington, Oregon and California combined. **Child Health BC,** an initiative of BC Children's, is a provincial network of experts working to ensure children from all corners of the province have access to world-class health care.

Two recent advancements by Child Health BC, which is generously supported by lead benefactor Save-On-Foods, are described here, and are among the many ways the provincial network is transforming how specialized health care is delivered across BC.

KEEPING KIDS OUT OF THE HOSPITAL

An asthma diagnosis can be overwhelming. While there is no cure, symptoms can be managed with proper care—which families get a crash course in once diagnosed. But still, many parents worry that they won't be prepared to recognize or manage an asthma attack when it happens.

In collaboration with Child Health BC, Dr. Claire Seaton, a researcher and pediatrician at BC Children's Hospital, developed a new video to help families. It provides information on how to manage the disease with confidence and prevent serious attacks from happening.

"This video is an easy and accessible way to learn about asthma," said Dr. Seaton. "Families can view it anytime, anywhere and show it to their child's other caregivers."

In addition to the video, an interactive online course was created to support health care providers across the province. This training will help them properly diagnose and treat asthma, including in emergency situations, so that kids and families receive earlier and better care.

Visit the video at Bit.ly/pediatric-asthma-video

A FIRST-OF-ITS-KIND HEARING CLINIC

When a child receives a cochlear implant—an electronic device implanted in the inner ear that allows them to hear—they need to have it reprogrammed regularly to ensure it's working optimally. This requires several visits each year to BC Children's, the only place in the province able to perform the procedure. For kids and families who don't live close by, this can be time-consuming, expensive and stressful. There's now a better option for those who live in Prince George, an 8.5-hour drive away.

Together with Child Health BC, BC Children's recently opened a virtual care hearing clinic there—the first of its kind in Canada. Patients simply visit the clinic, where they can connect with an audiologist at BC Children's via video call to have their implants virtually reprogrammed.

This may just be the start of bringing this type of virtual care to families in BC. The goal is to set up two or three similar clinics across the province over the next two years.

HOPE

FOR A LIFE SENTENCE

Nineteen thousand.

That's about how many needles 14-year-old Jayden Gill has had to use throughout his life to manage his type 1 diabetes. It means he's had to prick his body five times a day—every day—since he was two and a half years old to check his blood sugar levels and receive insulin injections.

As a child, those needles were a normal part of Jayden's life. Although a day never went by when he could avoid them, he took it all in stride.

That all changed when he reached adolescence and took on the responsibility of managing his condition himself.

And that's when the feelings of frustration and exhaustion began to seep in. He noticed more and more how different his life was from those around him—and he started asking himself, "Why me?"

FOR MANY KIDS WITH TYPE 1 DIABETES, THEIR DISEASE CAN FEEL LIKE A LIFE SENTENCE.

In the spring of 2018, when Jayden was 13, he quietly stopped his blood sugar monitoring and insulin injections. When his parents asked him if he was still taking the daily actions needed to care for himself, he said he was—but behind the scenes, he wanted to see if he could function normally without them.

Weeks passed, and Jayden became really sick. He would vomit for hours at a time, and complained of excruciating stomach pains.

Things got so bad that Jayden had to be rushed—twice—to BC Children's for ketoacidosis, a life-threatening condition that could lead to a coma or even long-term brain damage if not caught in time.

That was a wake-up call for Jayden. For the first time in his life, he caught a glimpse of how grave things could become if he didn't manage his disease carefully.

Jayden is one of 2,500 kids in British Columbia with diabetes. Ninety per cent have what he has: type 1, a serious, lifelong condition that currently can't be prevented or cured and can lead to devastating consequences if it's not managed closely.

Ketoacidosis, which Jayden experienced, is only one of the possible complications of the disease. Others could include heart or liver disease, amputations or even blindness.

This real possibility can put stress on families. Unlike type 2, which can be at least partially managed through lifestyle changes like diet and exercise, the only way to manage type 1 diabetes is to continuously maintain the right levels of insulin, an essential hormone to produce energy for the body.

It's no wonder that for many kids with type 1 diabetes, their disease can feel like a life sentence.

Families affected by the condition require specialized care and support to ensure their kids stay healthy. Thankfully, today there are many advancements in technology and care that can ease the burdens of type 1 diabetes that weren't around even just a decade ago.

These include devices like glucose monitoring sensors, which can monitor blood sugar levels without needles simply by waving a smartphone over it, and insulin pumps, which deliver insulin to the body without injections.

But a key part of treatment is understanding and getting specialized support for daily management of the disease. For families close to BC Children's, this support is relatively easy to get.

But for families who live further away, it's not so simple. Because of the burdens of cost, travel and time, they don't always get the care they need when they need it.

This is troubling because research has shown that the further away a child with type 1 diabetes lives from expert care, the worse off they are. In a province that spans nearly one million square kilometres, this is a bleak picture. But it's one that experts at BC Children's are determined to change.

During Jayden's second hospital visit for ketoacidosis, he met Dr. Shazhan Amed, head of the Division of Endocrinology at BC Children's. This was a turning point for him.

"Jayden just gravitated towards [Dr. Amed] and they created a bond," said Kam Gill, Jayden's mother. "She was very straight with him, but she was also very caring and gave him the exact encouragement and education he needed to manage his condition."

Jayden is doing remarkably well now. His family credits Dr. Amed and the BC Children's team for developing a sustainable plan to help Jayden and his family manage his condition—and for being a lifeline when they needed it most.

Dr. Amed and her team are driven to do more for all kids in BC.

> THE GOAL IS TO PROVIDE SPECIALIZED CARE AND SUPPORT TO FAMILIES IN BC WHO NEED IT, NO MATTER WHERE THEY LIVE.

As the diabetes team at BC Children's tackles this gap, they are looking at ways to expand what they're already doing—like partnering with health care teams in communities across BC—to ensure they have the education, tools and latest technologies they need to provide the same level of specialized care close to home.

But that's not all. Experts here are looking at ways to expand use of technologies that are making virtual care possible for more patients, enabling them to stay in close contact with families without always needing face-to-face clinic visits.

They're also working to improve access to the latest diabetes management technologies and training on how to use them. These resources will help reduce the daily burdens and stressors families face living with this complicated disease.

These are no small goals—but they're ones that Dr. Amed and her team, with the help of donors, are making their mission.

Ultimately, they're not only hoping to reduce complications and improve health outcomes for kids with type 1 diabetes, but to see them live the healthiest lives possible.

Jayden (middle) meets with Dr. Shazhan Amed (right) and Erica Vance, registered nurse (left).

A NIGHT TO TRANSFORM DIABETES CARE

Donors make transformative health care possible. This year, more than 440 guests at the *11th Annual A Night of Miracles*, our South Asian gala, came together on November 2 to raise critical funds to help revolutionize type 1 diabetes care throughout the province.

Q&A

BEING MINDFUL: HEALING FOR THE WHOLE PERSON

Dr. Dzung Vo, (pictured left, along with mindfulness participant Mckenna) is the director of BC Children's new Centre for Mindfulness, which launched this past June with the help of donor support. As one of the first mindfulness centres at a children's hospital globally, its ultimate vision is to create a culture of mindfulness at BC Children's that will help kids, teens, families and health care providers here and around the world. We sat down with Dr. Vo to learn more.

Q What is mindfulness?

A To get the full essence of mindfulness, you have to experience it for yourself. But as a definition, I usually refer to a slightly adapted explanation from mindfulness pioneer Jon Kabat-Zinn:

Mindfulness is paying attention in a particular way, on purpose, in the present moment, without judgment and with unconditional love. I've added the last part as a reminder that "heart qualities" like compassion, caring and acceptance are vital to the healing power of mindfulness.

To simplify it further, when you're wishing things in the past had been different, you can end up depressed. When you worry about the future, you can get anxious. Mindfulness is about living in the present moment, and not giving power to the past or future. It's a way of life, and a concrete tool for coping with life's challenges. If you've observed young children in awe and wonder at a beautiful beach or forest, you've seen mindfulness in action.

Q What benefits have you seen in youth who have practiced mindfulness?

A I've worked with adolescents for many years at the hospital to help them use mindfulness in coping with struggles like depression, anxiety and pain. With one teen, her use of mindfulness ended years of depression and anxiety by changing her relationship with her chronic pain. In paying close attention to it, she recognized the ebbs and flows of her pain and learned how to ride the flows. That's just one example of how mindfulness has helped change lives.

Q You've described the Centre for Mindfulness as a potential game-changer here at the hospital. Tell us why.

A The Centre for Mindfulness is one of the first of its kind at a children's hospital globally. That's huge because we have the chance to create a culture of mindfulness throughout the campus that will not only help youth, families and health care providers as they cope with the challenges they face, but to also become a model and inspiration for other pediatric hospitals around the world. That's our ultimate goal.

Q In the meantime, what are the Centre's short-term goals?

A We're expanding existing mindfulness initiatives at the hospital to create a culture of mindfulness. We're educating hospital staff through initiatives like webinar trainings and lunch-and-learns. And we're also working to expand mindfulness education resources to help more youth, parents and health care providers here at the hospital.

Q What difference has donor support made in the Centre's work?

A The Centre for Mindfulness was only made possible through donor support—and without it, we wouldn't exist today. With the Centre's dedicated team, resources and partnerships in place, we're empowered to take the next steps in pursuing our vision and helping to transform care.

In addition to leading the team at the hospital's new Centre for Mindfulness, Dr. Vo is also the head of the Division of Adolescent Health and Medicine at BC Children's.

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 a few passionate members of our community who are making a difference, all in their own amazing ways.

SPREADING THE LOVE

For more than a third of their lives, Monica and Tom Brennan of West Vancouver have been helping kids in one of the sweetest ways: making jam. The couple started selling homemade preserves and donating proceeds after their granddaughter, Emily, had several operations at BC Children's in her early years.

"We started selling jams, marmalades and chutneys because we wanted to give back for all the help the doctors and staff gave to our family," Monica said.

As word got out, the popularity of the Brennan's jam quickly spread—enabling them to donate more and more each year. To date, they've raised over $20,000 for BC Children's Hospital.

KIDS HELPING KIDS

She may just be 11 years old, but Sia Sidhu is no stranger to philanthropy. For the last five years, she's been supporting charities through events that run the gamut from hot dog stands to ice cream sales.

This year, she decided to host 'Sia's burger shack' at her home in Surrey to raise money for neuromuscular disease—a condition that two of her cousins suffer from. Her efforts raised a remarkable $9,200 for BC Children's Hospital.

"We can all make a difference with a small act of kindness," Sia said. "My hope is that by doing these fundraisers, I can bring a smile to a sick child's face."

108,000+

THAT'S HOW MANY DONORS CAME TOGETHER LAST YEAR TO COLLECTIVELY HELP REDEFINE WHAT'S POSSIBLE AT BC CHILDREN'S HOSPITAL.

TACKLING RARE DISEASES THROUGH RESEARCH

Teresa Sutherland's son, Gabriel, was three years old when he was diagnosed with a rare condition called eosinophilic esophagitis, which has no known cure. But even with treatment, Gabriel's health fluctuated considerably throughout his childhood.

Determined to help where she could, Teresa asked her son's physician at BC Children's, Dr. Vishal Avinashi, how she could help make a difference. Dr. Avinashi told her about novel research that was happening on site—and after meeting with hospital experts and BC Children's Hospital Foundation to learn more, Teresa decided to generously support the initiative through the Foundation of her family's business, Amacon.

"I want my son to have the best quality of life he can—and a long life," Teresa said. "It makes me feel good that I can do something to help kids with the condition, and hopefully move closer toward a cure."

Last year, Kamiah was one of thousands of kids who were treated at BC Children's. By donating to The Snowball Fight for Kids, you'll help fund vital equipment, life-saving research, and the highest level of care for kids across the province.

Donate today to help kids like Kamiah get back to being kids.

snowballfightforkids.ca

Get in the holiday spirit at Festival of Trees events in Victoria and various communities across the province. Tour the beautifully decorated trees and donate to vote for your favourite. Visit **bcchf.ca/fot** to find a location near you.

Help kids like Coralie keep fighting.

Your Will can help do that.

Discover more.
604.875.3679
bcchf.ca/legacy

BC Children's Hospital Foundation

Help kids get back to being kids.

Last year, more than 93,000 kids visited our hospital. Evelyn was one of them. Diagnosed with leukemia in March, Evelyn has since visited the hospital every two weeks, staying four days at a time, undergoing treatment. By donating to The Snowball Fight for Kids – a virtual snowball fight powered by donations – you'll be helping to fund life-saving research and treatment for kids like Evelyn across the province.

Donate at snowballfightforkids.ca

Evelyn | Vancouver

60 appointments in 6 months

BC Children's Hospital™ Foundation