



Shine

Spring 2024

Connecting the Dots

Unravelling the intricate web that ties the immune system to the toughest childhood illnesses

ALSO IN THIS ISSUE

Innovative approaches that are reimagining pain care

A revolutionary leap forward in cardiac surgery is helping newborns in BC

The transformative power of small actions in kids' health journeys

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

Return undeliverable Canadian addresses to address above.

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Managing Editor: Ali Omelaniec

Writers: Lauren Erdelyi, Miriam Mortimer

Creative Director: Terry Lin

Graphic Design: Jennifer Pratt

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Solving medicine's greatest mysteries



Big strides in children's health come from humble beginnings. Often, it starts with a boldness to venture into realms where the knowledge may be scarce, yet the potential for breakthroughs is vast.

Consider the immune system, for example. While we recognize its role in defending against invading infections, we're only beginning to realize how its functions extend far beyond that. At BC Children's Hospital, a fearless team is dedicated to changing our understanding of this highly complex system and the role it plays in everything from asthma to childhood cancers.

Pain is another realm that has long eluded medical professionals. For decades, it was misunderstood in pediatric care. Yet, we know that the lasting imprint unaddressed pain can leave on a child's health is profound. That's why a revolution is unfolding across our campus, as bold thinkers in research and medicine adopt novel approaches to tackle pain in children.

In this edition of *Shine*, you'll also learn about a breakthrough that's transforming cardiac surgery for the smallest patients, alongside initiatives that are providing comfort for children and families throughout their healing journeys. These advances

simply wouldn't be possible without you. Your support empowers health care providers to dare to pursue new frontiers as they unravel the greatest mysteries of children's health.

With gratitude,

Malcolm Berry
President & CEO
 BC Children's Hospital Foundation

Diving into the unknown

Inside the quest to unravel the mysterious world of the immune system

Think about your immune system for a moment. You might envision an internal defense system that protects you from common illnesses like the cold and flu. That's, of course, true—the immune system is constantly on the lookout for invading germs, bacteria and other organisms. Yet, that doesn't even begin to scratch the surface of its importance.

Along with fighting infections, the immune system performs many beneficial functions—like guarding against cancer cells and helping to repair damaged tissues. However, it also has a shadowy side. When not functioning properly, it can lead to the development of chronic conditions such as diabetes, asthma and celiac disease. And a growing body of research has linked it to mental health issues like depression.

In short: the immune system is inextricably intertwined to virtually

every aspect of our health, whether good or bad.

DEMISTIFYING THE IMMUNE SYSTEM

Despite its significance, the immune system has long been shrouded in mystery—considered second only to the brain in complexity. That's partly because it isn't tied to a specific organ, such as the heart or lungs. This vast network of cells, tissues and organs can be found virtually everywhere within our body, from our toes to our head. And that means there are a multitude of ways that it can impact a child's health.

While we are only beginning to understand these connections, one thing is clear: this knowledge will revolutionize how we treat the biggest health challenges facing children. Led by Dr. Kyla Hildebrand, a dedicated team of clinical immunologists—including Drs. Catherine

Biggs, Elliot James and Stuart Turvey—assess children each year at BC Children's Hospital. Their expertise isn't only sought after by clinicians across the hospital seeking to diagnose perplexing conditions; it's also garnered international attention, with children's hospitals around the world turning to the team to answer tough questions.

“Our patients live with rare conditions,” explained Dr. Hildebrand. “Some children do not yet have specific diagnoses and our team is working to discover novel genes that may allow for precision treatments and therapies.”

Although their influence is already significant, their aspirations for the future are even bolder: they are determined to connect the dots that link the immune system to a host of other conditions, from atopic disorders to immune dysregulation.

PICTURED ON COVER
Caleb, age 6, diagnosed with chronic granulomatous disease—a rare genetic disorder that hinders the immune system's ability to fight off bacterial and fungal infections.

“We’re working to launch a bold new precision immunology initiative, where we’re bringing experts across the campus together in new ways to understand the immune system’s role in different childhood diseases and ultimately ensure every child has the best immune system possible to fight big health challenges.”

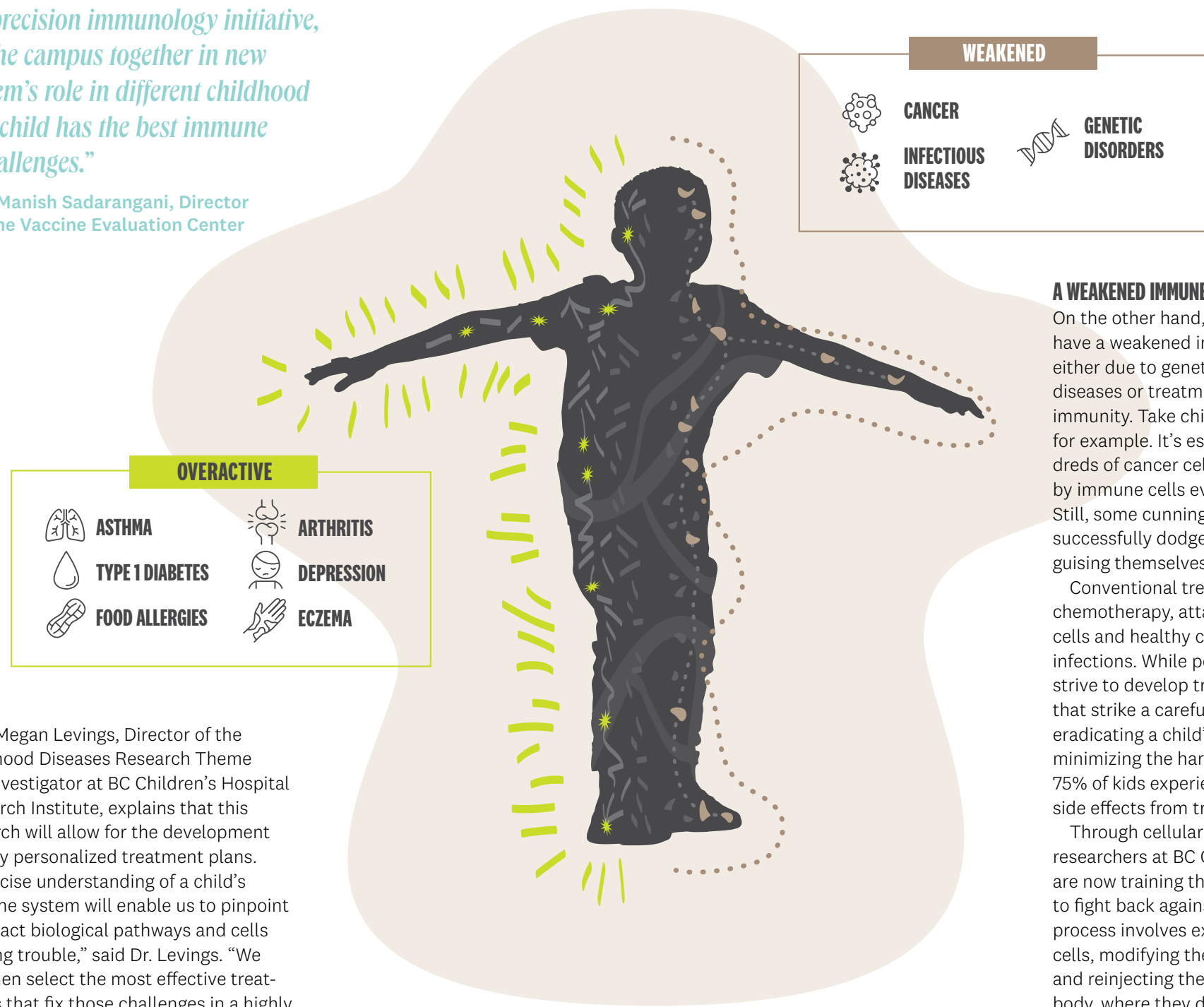
— Dr. Manish Sadarangani, Director of the Vaccine Evaluation Center

AN OVERACTIVE IMMUNE SYSTEM

The immune system is important for keeping us healthy and fending off infectious diseases, but it can also cause serious health issues when it goes awry. For some children, it can be too aggressive and cause conditions like asthma, eczema and food allergies. This occurs when the immune system mistakenly recognizes a harmless substance, such as pollen or peanuts, as a threat and carries out a full-blown attack against what it considers to be an invader. In other children, the immune system accidentally views the body as the enemy and attacks the very cells it exists to protect, leading to autoimmune conditions like inflammatory bowel disease.

Many current treatments for these conditions suppress the entire immune system, which leave children vulnerable to serious infections and other severe side effects. Determined to develop a better way, researchers at BC Children’s are racing toward a future where kids receive highly tailored treatments that fight only the cells that act out of line, sparing all healthy ones. Achieving this will require that they first gain a comprehensive understanding of every child’s immune system.

Dr. Megan Levings, Director of the Childhood Diseases Research Theme and Investigator at BC Children’s Hospital Research Institute, explains that this research will allow for the development of truly personalized treatment plans. “A precise understanding of a child’s immune system will enable us to pinpoint the exact biological pathways and cells causing trouble,” said Dr. Levings. “We can then select the most effective treatments that fix those challenges in a highly individualized, patient-specific manner.”



A WEAKENED IMMUNE SYSTEM

On the other hand, children may also have a weakened immune system, either due to genetic conditions, diseases or treatments that suppress immunity. Take childhood cancer, for example. It’s estimated that hundreds of cancer cells are eliminated by immune cells every single day. Still, some cunning cells manage to successfully dodge detection by disguising themselves as healthy ones.

Conventional treatments, such as chemotherapy, attack both cancer cells and healthy cells that fight infections. While pediatric oncologists strive to develop treatment plans that strike a careful balance between eradicating a child’s cancer and minimizing the harm it causes, 75% of kids experience life-long side effects from treatments.

Through cellular therapy, researchers at BC Children’s Hospital are now training the immune cells to fight back against disease. The process involves extracting a patient’s cells, modifying them in the laboratory and reinjecting them into the patient’s body, where they divide and attack cancerous cells with remarkable precision. Not only can this reduce



Dr. Megan Levings

the side effects of chemotherapy, but it also has the power to prevent future relapses as the manipulated cells continue to live in the body.

Cell therapy also holds promise for a range of conditions beyond cancers. For instance, children who have undergone heart or kidney transplants must currently take immunosuppressants that suppress the immune system, ensuring that it doesn’t recognize the organ as foreign and begin to attack it. But what happens if they develop a severe viral infection? In some cases, they may need to temporarily stop taking these powerful medications to fight the virus. Although it’s still in its early days, researchers are exploring the potential of injecting immune cells that could eliminate the virus, so kids could continue immunosuppressants.

“For years, cellular therapy seemed like a distant dream,” said Dr. Levings. “Now, it’s becoming a reality, especially in the fight against cancer. We’re also on the cusp of applying this groundbreaking therapy to a wide range of autoimmune and transplant-related diseases.”

The immune system plays a crucial role in a child’s overall health.

1.8 trillion cells
MAKE UP THE IMMUNE SYSTEM

THE IMMUNE SYSTEM REMEMBERS AN ENEMY FOR **decades**

80+ illnesses result FROM THE IMMUNE SYSTEM ATTACKING THE BODY

20+ DISEASES ARE PREVENTED BY VACCINES THAT BOOST THE IMMUNE SYSTEM

DEEPER INTO THE IMMUNE SYSTEM’S DEPTHS

The immune system is truly extraordinary. As one of the most sophisticated systems in the body, its 1.8 trillion cells work together to protect children from not only infectious diseases but also countless other health threats in ways we’re only beginning to comprehend. Through their bold efforts to untangle these many connections, visionary medical minds at BC Children’s are poised to transform how some of the toughest health challenges are confronted.*

Tackling pain: THE BODY'S 5TH VITAL SIGN

Whether it's the sharp sting of a needle, acute discomfort that follows surgery or the persistent aches of chronic migraines, pain is a common experience for many children who visit the hospital.

Although most pain can be reduced or even prevented entirely, assessing pain in kids is highly challenging for several reasons. For one, babies and children with developmental differences may be unable to express discomfort. Pain is also a personal experience that often can't be observed, making it even more difficult to measure. And finally, it's highly subjective—what hurts for one child may be experienced differently by another child.



A LASTING IMPRINT

For pain to be acknowledged, addressed and treated in kids, it must be understood. Yet, this hasn't always been the case. Only decades ago, it was believed in some places around the world that a newborn's nervous system wasn't mature enough to feel pain. As a result, infants underwent invasive procedures, like open-heart surgery, with little or no anesthesia.

The collective understanding has come a long way since then. It's now recognized that even the youngest patients experience pain just as intensely as adults, and its repercussions can reverberate throughout their lives. Unaddressed pain can impact a child's physical, social and emotional well-being—altering the wiring of the brain, heightening their sensitivity to future pain and leading to an increased risk of mental health issues like anxiety and depression.

PIONEERS IN PAIN CARE

Recognizing the crucial role of these early experiences, BC Children's Hospital has made it a top priority to understand pain and ensure every

child is as comfortable as possible. Pain is even viewed as the fifth vital sign across the hospital's campus, as a measure of health status that's equal in importance to a child's blood pressure, temperature, pulse rate and heart rate.

Last year, BC Children's was recognized in a big way for these efforts. It became one of only 15 children's hospitals worldwide to receive ChildKind certification that recognizes excellence in pediatric pain care—an achievement supported and sustained by the efforts of the PainCare 360 team, as well as many dedicated health care professionals, staff and a community of donors.

Over the past few months, health care professionals have been working tirelessly to push the boundaries of pain care even further. Surgeons are harnessing world-leading techniques to minimize discomfort, such as using cold temperatures to temporarily freeze the nerves that transmit pain signals to the brain. Researchers are pursuing clinical trials to explore alternative treatments for chronic headaches. And talented

clinicians are turning to innovative techniques, including virtual reality and medical hypnosis, to alleviate anxiety and fear that contributes to the pain experience.

A BETTER FUTURE

To many, pain may seem like a small yet fleeting discomfort in kids. But with the potential to shape the trajectory of their entire lives, its impact is massive. By transforming a child's earliest experiences and optimizing their comfort, experts are making a real difference in addressing and preventing long-term chronic pain and mental health conditions that hold too many of today's kids back from reaching their full potential.*





Last fall, something remarkable took place at BC Children's: for the first time in Canada a tiny, modified pacemaker was placed inside a newborn's heart. This immediately sparked new hope for babies with severe heart conditions—babies like Jonithin.

Historic surgery a big win for tiny hearts

When Jonithin's mother Caitlyn was almost 30 weeks into her pregnancy, physicians in Williams Lake determined her baby's heartbeat was too slow. The team at their local hospital knew they had to act fast to save Jonithin, so he was delivered prematurely and transported to BC Children's Hospital by air ambulance.

Caitlyn and her husband Peter were beside themselves with worry, but Jonithin was where he needed to be. Dr. Shubhayan Sanatani, head

of cardiology at BC Children's, had recently received a special exemption from Health Canada to use a modified pacemaker on an infant with a low heartbeat. He had seen it work in the U.S. and was inspired by its potential. "We knew this could save lives like Jonithin's," said Dr. Sanatani.

Jonithin easily met the criteria for the exemption: he had a complete heart block. His dangerously low heartbeat was caused by a lack of communication between his heart's atria and ventricles. To survive, Jonithin's tiny heart needed an equally tiny pacemaker. Dr. Sanatani reached



"We knew this could save lives like Jonithin's."

— Dr. Sanatani

out to the cardiac surgery team to set things in motion.

The task would be complex, but experts at BC Children's are equipped to operate on hearts the size of a walnut. What's more, the world-class cardiac surgery team had recently brought in experts like Dr. Mohammed Al Aklabi, head of cardiac surgery. Dr. Al Aklabi has had a transformational impact on the hospital's cardiac surgery program. "He's enabled the delivery of surgical repairs to certain patients where previously there was thought to be no surgical pathway forward," explained Dr. Erik Skarsgard, surgeon-in-chief at the hospital. "The outcomes have been life-changing for families." Jonithin's family would be no exception.

Following a successful surgery, Caitlyn and Peter were overwhelmed

with relief: their son could breathe on his own, and for the first time, he was hungry and able to keep food down. He was recovering quickly. At the end of November, Jonithin was cleared to return home to 108 Mile Ranch, where he could finally meet his two older siblings. The family is thrilled to be together in one place.

Jonithin still needs doctors to monitor his heart and pacemaker, and to keep a close eye on him as he grows. "Most of my pacemaker kids I see once or twice a year, and in between that they're running around, they're active kids, they're doing lots of normal-kid stuff," Dr. Sanatani said. Thanks to this historic achievement, Jonithin will be one of them.

Congenital heart disease affects 1 in 100 babies. Unsurprisingly, the Children's Heart Centre at

BC Children's Hospital is a very busy place. Dr. Al Aklabi estimates the cardiac surgery team has performed over 500 surgeries in the last two years alone. "Forty of these cases were extremely complex," said Dr. Al Aklabi. "Previously, those 40 children would have had low chances of survival, or would have lived with significant challenges."

Much of this progress has been made possible through donors, who have empowered the team with new, critical pieces of surgical equipment, research funding and a dedicated cardiac surgery suite. And with continued support, experts are making mighty strides in advancing care for babies and children with heart challenges. In many ways, Jonithin's groundbreaking surgery is just the beginning.★

Hospitals can be intimidating for a sick child. That's where Child and Youth Therapeutic Services come in, supporting patients through programs like child life, music therapy, pet therapy and therapeutic clowning.

Helping kids be kids

The teams' evidence-based work has a remarkable impact on patient well-being, and through even the smallest actions, can transform patient experiences.



Getting familiar with a procedure

CHILD LIFE

Child life provides kids with the support and information they need to process their experiences in-hospital. From teaching breathing exercises to walking a child through a practice MRI, a child life specialist can be a game-changing member of a patient's medical team.

"One of the best things about kids is their imagination. But in an unfamiliar environment, that imagination can make hospitals and procedures more challenging. Child life specialists use the child's language, play, to help patients process and cope with hospitalization." — Gloria, child life specialist

Spending time with a new furry friend can help reduce stress for patients, families and staff. The pet therapy program has over 35 teams of cuddly pets and their humans who've gone through months of support and training in preparation for their hospital visits.

PET THERAPY



A hug from a furry friend

"Sometimes the parents are almost as happy to see the dogs as the patients are. It gives the whole family a few moments of normality, where they can simply enjoy talking about pets and giving some love." — Kim, and Marvin the dog

It's incredible how music can rapidly change the mood in a patient's room. Music therapists harness the power of music to bring the "familiar" into an unfamiliar hospital setting, through singing, playing instruments and even technology-assisted songwriting. This helps create a safe space for self-expression and emotional processing.

"I've had parents say to me that this is the first time they've seen their child be the person they know and recognize at the hospital. It's so important to be able to do that, and I am so proud of what we get to do here." — Carol, music therapist

MUSIC THERAPY



The wonder of music

Through the power of donors, Child and Youth Therapeutic Services can continue to improve overall outcomes for patients at BC Children's in their own unique ways. One of the team's most recent achievements was expanding child life's presence throughout the hospital, including the Leducor Children's Emergency. Looking to the future, the team is dreaming big about how much more they might accomplish to improve the lives of patients and families.

"I'm so grateful to be part of the journey of these children who need such intensive care, to be there for their ups and downs, find moments of fun, comfort and kindness and help them and everyone remember they are, above all, still kids." — Natasha, child life specialist*



Honouring a visionary thinker in Zach's memory

When a child is diagnosed with cancer, they embark on a journey with their family filled with fear and uncertainty. It's in these darkest moments that the dedication of their health care team shines brightest, bringing hope when it's needed most. Recognizing the difference this commitment makes firsthand, the Zach Prince Foundation gave a generous gift to BC Children's Hospital in honour of Dr. Rod Rassekh, a pediatric oncologist.

"Rod's skill, curiosity and ability to make every patient feel like his only charge has immensely contributed to raising the level of excellence that has always distinguished the care and support the Division of Hematology/Oncology/BMT provides its patients and their families," said Dana Prince, who along with Zach's mother, Elana, co-founded the organization in memory of their son.

One trait that distinguishes clinicians like Dr. Rassekh is their dedication to building lasting connections with patients. "For me, it's the children who make working in oncology so rewarding," said Dr. Rassekh, who is also shaping the future of care as a researcher with the Michael Cuccione Childhood Cancer Research Program. "Whether we're having a meaningful conversation, playing a video game or simply sharing a laugh, these seemingly small moments make an enormous difference during challenging days."

We are so grateful for the health care providers who constantly go above and beyond, as well as the long-standing support of the Zach Prince Foundation. Their endowment has provided more than \$930,000 in support of oncology education, training and programs at BC Children's.*

A chat with Dr. Sharon Smile

“We are determined to optimize the care we provide, ensuring that everyone who requires it receives the support they need.”

— Dr. Sharon Smile

There are plenty of factors that contribute to BC Children’s being ranked among the top 10 children’s hospitals in the world. A significant one? Its ability to attract the top medical minds and empower them to unleash their full potential. **Dr. Sharon Smile** is one of these outstanding health care professionals. Recently appointed as the Division Head for Developmental

Pediatrics and a Hospital Chair for Developmental Pediatrics, Dr. Smile brings a wealth of experience. She was previously a developmental pediatrician at Holland Bloorview Kids Rehabilitation Hospital and a clinician investigator at the Bloorview Research Institute. We spoke with Dr. Smile about her ambitions for developmental care and more possibilities fuelled by donor support.

Q: WHAT ADVANCES IN DEVELOPMENTAL PEDIATRICS ARE YOU ESPECIALLY EXCITED ABOUT?

A: Technology is showing incredible promise in transforming pediatric rehabilitation care. For example, we’re exploring the potential of using virtual reality in our acute rehabilitation unit to create immersive and engaging physical therapy experiences, which can enhance children’s upper-limb function, balance and activities of daily living.

Q: WHEN YOU IMAGINE THE FUTURE OF DEVELOPMENTAL CARE, WHAT ARE YOU MOST OPTIMISTIC ABOUT?

A: I’m excited about our goal to embed and integrate research into care—and to implement strategies that support early diagnosis and meaningful interventions for neurodevelopmental disorders, such as autism spectrum disorder and cerebral palsy. I also look forward to working collaboratively with other divisions—including adolescent medicine, neurology, orthopedics and child psychiatry—to break down clinical and research silos. Our ultimate goal is to create integrated health services that are centered around the child, youth and family, while also optimizing subspecialty care and community services to ensure the best possible outcomes for our province’s children and youth.

Q: HOW ARE EQUITY, DIVERSITY AND INCLUSION BEING INTEGRATED INTO YOUR APPROACH TO CARE?

A: Our initial focus is on identifying children and families who aren’t currently accessing our programs and clinics—and understanding the reasons behind this. We’re also committed to implementing equitable and inclusive recruitment practices for new staff, ultimately striving for a team that reflects the diversity and rich cultural knowledge of the population we serve. This isn’t work that has a finish line. Rather, it’s a daily commitment to examining the care we provide and identifying ways to ensure that everyone who needs our services accesses them.*



T8, Capstone Mining Oncology/Hematology/BMT Outpatient Clinic, Teck Acute Care Centre BC Children’s Hospital, Feb. 2, 2024, 10:20 AM.

“Almost five years ago, we walked through a different set of hospital doors to bring our girl Hallie into the world. Today, we walked into BC Children’s to explain to her how she can change her little sister’s world as a bone marrow donor.

At her appointment today, Hallie learned about the bone marrow and immune system, and how her body could save her little sister Navy’s life. She surprised us and asked some really good questions. She shared her fears and was met with reassurance. She was asked if she wanted to be Navy’s hero—and she said yes.

Tomorrow Hallie turns five, and I couldn’t possibly be more proud of her. She is not only Navy’s hero, but mine and Daddy’s too”

— Charlene, Hallie and Navy’s mom

Small is MIGHTY.



Xavier, age 5, diagnosed with B-cell acute lymphoblastic leukemia—a cancer that affects the blood and bone marrow.

MakeUsMighty.ca