Spring 2025

The Journey Beyond

Finding calm waters in a sea of medical complexity

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Navigating the currents of change



Medical advances have shattered what was once unthinkable.

Many children who faced seemingly insurmountable illnesses are now defying expectations and dreaming of futures their families were previously told wouldn't be possible.

This didn't happen overnight. It came from decades of determined work—researchers spending hours in labs pursuing tough questions, families participating in life-changing trials and clinicians refusing to give up when standard options failed. Together, this has transformed the outlook for many once-devastating conditions.

Yet success brings new challenges. Some treatments have developed faster than the systems built to

support these children's ongoing health needs. Many families facing enormous health challenges now find themselves navigating complex journeys without proper maps or guides.

BC Children's Hospital's centre for health complexity, a visionary facility now under construction that will transform care for children with complex and chronic health needs. Within these pages, you'll also discover the remarkable power of small: kids whose courage defies their size, young siblings who become fierce advocates, medical experts whose small steps forward became big advances, and donors whose gifts add up to create lasting change.

This issue of Shine takes you inside

The medical landscape has shifted. For some conditions that once offered little hope, we've moved beyond it being only a question of survival. Now, it's also about the journey ahead-and the dedicated people who are determined to chart a course through waters no one has navigated before.

With gratitude,

Plalulm Berry

Malcolm Berry President & CEO BC Children's Hospital Foundation

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Unknown waters

Where medicine created possibilities, a new centre offers a compass for the journey ahead

> Two decades ago, certain diagnoses meant near-certain outcomes. Children with complex neuromuscular disorders rarely lived to see kindergarten. Premature infants with underdeveloped lungs wouldn't survive past their first hours. Rare neurological conditions left families with few answers-and even fewer treatments.

Medical science has since redrawn these boundaries. Revolutionary advances—ranging from genetic sequencing to targeted therapies and life-sustaining technologies—have turned some fatal conditions into chronic ones. Many children who once faced insurmountable odds are now growing up, defying expectations and living longer lives.

Yet many families find themselves adrift in unknown waters without maps, guides or clear paths forward. For them, survival of their child marks only the beginning of an isolating journey they're navigating alone.

MEDICINE'S UNEXPLORED DEPTHS

Breakthroughs in pediatric medicine over the decades have altered the trajectory of countless young lives. Dr. Hal Siden, medical director with the new BC Children's Hospital centre for health complexity (currently the Slocan Site Redevelopment Project), explains that these triumphs created new challenges.

"There's now a large number of children whose treatment stretches across their entire lives," he said.

"The problem is that we haven't built systems to support them and their complex health needs."

These children—roughly 9,000 across BC and the Yukon-exist in a population defined as having health complexity. They represent less than 1% of just over one million children in the province, yet account for more than one-third of all pediatric hospitalizations and one-third of health-care dollars spent on children. About 2,500 of these children have the highest levels of health complexity across the province and territory.

They live with complex, chronic conditions affecting multiple organs. Many require assistance with basic daily function, including mobility, feeding and communication. They may face vision, hearing or developmental challenges. Their well-being often depends on sophisticated medical technologies-tracheostomies, feeding tubes, mobility devices and portable ventilators. They are in and out of clinics, hospitals and therapy programs at BC Children's and in their communities.

NAVIGATORS WITHOUT TRAINING

The toll on their families is enormous. Parents spend sleepless nights next to the beeping sounds of monitoring machines as they carefully give medications on precise schedules. Their calendars fill with specialist appointments while their homes transform into miniature intensive care units. Siblings step into caregiving roles far beyond their years.

"Boxes of medical supplies line my hallway closets, emails between therapists and specialists are ongoing, I give handover to the nurse who will tend to my daughter overnight," said one parent centre—through funding from the BC Government and a \$60-million fundraising initiative from BC Children's Hospital Foundation—will launch an entirely new approach to supporting children with complex medical needs.

IN SEARCH OF A CO-CAPTAIN

"We talk extensively about coordination of care for kids and families with health complexity. But you can't just navigate a ship—you need a captain and crew," Dr. Siden explained. "Unfortunately, almost every family I meet feels forced into that captain role without training.

"You can't just navigate a ship—you need a captain and crew. Unfortunately, almost every family I meet feels forced into that captain role without training. Most don't have the health care knowledge, nursing expertise or medical background to handle this level of complexity."

in the recently published report by BC Complex Kids.¹ "Alarms go off, reminding me to silence the feeding pump, check her heart rate, or determine if the oxygen concentrator needs to be turned up. I am constantly on alert for anything to happen—emergency bag ready to go by the front door."

"Each day revolves around their child's care needs." Dr. Siden added. "They're waking up at dawn to catch ferries for appointments, spending their entire day at the hospital, and then repeating it all over again the next week."

These families coordinate care between dozens of specialists. Each one focuses on a specific aspect of their child's health, but no one oversees the complete picture. That will soon change. In 2028, a groundbreaking new facility will open its doors: the BC Children's Hospital centre for health complexity. This \$309.9 million

Most don't have the health care knowledge, nursing expertise or medical background to handle this level of complexity." cessing specialized care adds another

- Dr. Hal Siden

The new centre aims to change this dynamic. Each family will have a dedicated team—including a nurse, social worker and logistics navigator-that will coordinate their child's care, help manage appointments and improve access to services within and beyond the healthcare system. An innovative electronic platform will enhance collaboration between providers and families, ensuring critical information isn't lost in transition.

Medical crises don't always adhere to clinic hours. The centre will offer real-time support when families need it most. "If families need help on weekends or evenings, they'll have someone they can call immediately," said Elizabeth Stanford, who is leading the clinical planning for the centre for health complexity. "That simply doesn't exist right now."

A SMALL POPULATION. WITH A MASSIVE IMPACT

35% OF HEALTH-CARE DOLLARS FOR CHILDREN GO TO THOSE WITH HEALTH COMPLEXITY

30 to 40% **OF HOSPITAL BEDS AT BC CHILDREN'S** ARE OCCUPIED BY **KIDS WITH HEALTH COMPLEXITY AT ANY**

 $\sim\!9,000$ CHILDREN IN BC AND THE YUKON LIVE WITH HEALTH COMPLEXITY

For those living outside Vancouver, ac-

layer of difficulty. Some families travel

hours each way for appointments. The

costs of transportation, accommoda-

tion, meals and time away from work

compound the already heavy burden

these families carry. Often, travel isn't

possible given the complexity of a

child's health condition and the dis-

The centre's design confronts this

reality through technology and training.

Consult rooms will feature interactive

systems allowing specialists, community

physicians and family members to par-

ticipate in a patient's care simultaneous-

"With the press of a single button,

ly, no matter where they are located.

we'll connect instantly with medical

metres away," said Dr. Siden. "If we're

teams or families hundreds of kilo-

tance required.

BRIDGING VAST DISTANCES

GIVEN TIME

Top: The three-storey building will offer a warm, welcoming environment with abundant natural light and inviting outdoor spaces

Bottom: An interior ramp-made possible only through donor support-connects multiple floors, enhancing accessibility for all families



teaching a parent in the centre how to use a feeding tube, family members at home can learn alongside them. Bringing together all these people through technology and making it as seamless as possible is one of our bold goals."

A HARBOUR FOR HEALING

The emotional toll of raising a child with complex health needs can be as overwhelming as the logistical challenges. The centre will offer specialized counselling addressing ongoing griefwhether mourning the loss of typical childhood experiences, managing caregiver stress or fighting the isolation that

often accompanies rare conditions. One of the centre's key features will be its 16 family suites, which provide short, pre-planned overnight stays, when needed, for children and their families during care transitions or when learning new adjoining rooms—one for the child and one for caregivers and family—with a

a teaching kitchen, purposeful art and a space designed specifically for siblings. **CHARTING A NEW COURSE, TOGETHER** With few existing models worldwide, BC Children's Hospital is creating a new care techniques. Each suite will have two map that could set new standards of care for children with complex health needs globally, and possibly inform fully accessible bathroom. adult care models as well.

The centre's physical design features a three-level accessible ramp in the atrium that replaces traditional staircases. Built with sustainable mass timber and flooded with natural light, the centre will include welcoming recreational spaces,



What makes the centre truly groundbreaking is how it was conceivedthrough direct collaboration with nearly 400 individuals who intimately understand these challenges, including former patients, parents and caregivers, siblings, clinical and non-clinical staff, operational leaders, community health and service providers, and Indigenous partners. Families have tested mockups of child and family suites, and Indigenous advisors have helped create culturally safe spaces, including All Nations spaces, ceremonial areas and a healing garden with plants of medicinal significance.

For thousands of children with health complexity and their families, the journey ahead remains daunting. But in a few years, many families won't have to navigate it alone. Medical advances that created this population of children once seemed unthinkable. Building a system that supports their journeys is the next frontier-one that's about to be crossed.₩

SPRING 2025

A future rewritten



In 2015, the words that shattered Alisha and Josh's world came as they sat at BC Children's Hospital with their fivemonth-old son: "Emmett has spinal muscular atrophy, a fatal neuromuscular disease." Their son might only live to see his first birthday—or his second, if they were fortunate.

"I was shocked. Numb," Josh recalled. "It felt like watching someone else's story unfold. I was no longer the person who walked into that room. I changed forever that day."

What the family couldn't know at that moment was that science stood on the precipice of a breakthrough decades in the making—one that would not only transform their son's future but also redefine what was possible for an entire generation of children.

FROM FATAL TO TREATABLE

Spinal muscular atrophy (SMA) affects one in 10,000 newborns, attacking the motor neurons in the spinal cord that send signals to muscles. When these neurons are lost, muscles waste away, robbing children of their ability to breathe, feed, sit, walk and talk.

"Historically, it was one of the most devastating disorders in pediatric neuromuscular diseases," explained Dr. Kathryn Selby, a pediatric neurologist at BC Children's Hospital who cared for Emmett. "The vast majority of babies with SMA have the most severe form, and death within the first two years was the most typical outcome."

The pivotal breakthrough came in 1995 when researchers finally pinpointed SMA's genetic culprits—the SMN1 gene and its backup, the SMN2 gene. This critical discovery opened the door for researchers to pursue precise treatments targeting the gene defects. Decades of exhaustive research, setbacks that became stepping stones and relentless determination had converged at exactly the moment Emmett needed it most.

"

Time is muscle. Once symptomatic, the outcome is significantly impaired. Every single day matters. - Paige Bellan-Northrup



A GLIMMER OF HOPE

Hours after his parents received the devastating news, Dr. Selby told them about a groundbreaking clinical trial at BC Children's that could potentially make a difference.

Two months later, Emmett began receiving nusinersen, the first of what would eventually become three approved disease-modifying therapies for SMA. Nusinersen was administered directly into the spinal fluid, through a spinal tap. He required four loading doses in the first two months, followed by maintenance doses every four months for life.

The improvements began subtly. First, Emmett's hand strength improved. Movement in his arms followed. But the true breakthrough came at 16 months when, lying on his mother's chest, he did something unimaginable: he craned

his neck and locked eves with Alisha. By 18 months, he could hold his body upright in a sitting position-a milestone never before seen in a child with Type 1 SMA.

RACING AGAINST THE CLOCK

The clinical trial Emmett participated in revealed something both promising and urgent: timing was everything. Children treated earlier showed better outcomes.

pre-symptomatically will walk, run and play," said Dr. Selby. "That number drops to just 25% for those treated after symptoms appear. The children, like Emmett, who participated in these initial clinical trials were essential in gaining this knowledge that now helps countless other children affected by SMA."



"Over 90% of children treated

This understanding galvanized a movement for universal newborn screening, which began in BC in October 2022 and has expanded across Canada. Today, every baby born in this country is screened for SMA, allowing for intervention in the vital window before symptoms emerge. The implications of this are profound. Children who might have faced progressive disability or death are now receiving treatment early, and their prognosis is significantly improved.

A DIFFERENT STORY

The transformation in the past decade has been remarkable. Most children with SMA are diagnosed and treated within their first few weeks of life. They'll reach milestones—sitting up, standing and even walking—that were unimaginable just a few years ago. Many may never fully grasp the alternative path their lives could have taken.

For Alisha and Josh, watching Emmett recently celebrate his 10th birthday felt like witnessing the impossible. Today, he participates in chess club, sings in the choir, writes his own stories and spends weekends playing power soccer.

Children like Emmett are living proof that those who dare to challenge medical boundaries can, in fact, rewrite the future. Through its donor-funded Clinical Trials Super Hub, BC Children's Hospital is driving similar advances for conditions once thought untreatable—each one carrying the potential to create more stories like Emmett's.₩

BRINGING THE LAB HOME

"We've typically thought that bringing children into the lab and assessing them for a given condition would give us a window into their lived experience," said Dr. Tim Oberlander, a developmental pediatrician and researcher at BC Children's Hospital. "But that only gave us one snapshot—a point in time—that wasn't a very accurate way to understand how children think and behave in their daily lives."

This challenge particularly affects the way researchers study children with complex health needs, who have long been underrepresented in research. Families in rural and remote communities struggle with travel to clinics. Some children's conditions are too complex for a single trip to BC Children's and individual differences between patients further complicates gathering meaningful insights from one measure.

A CLEVER APPROACH

This led Dr. Oberlander and Dr. Katelynn Boerner, a clinical psychologist and researcher, to develop a new approach for collecting data that moves away from traditional research settings and



Stress levels, sleep patterns and daily activity tracking these indicators is vital for understand-

ing what daily life is like for children with health

complexity. The challenge? Traditionally, this data

has been captured during brief appointments,

which often provide an incomplete picture of

health and aren't accessible for many families.

into approaches that capture many measures of real world life in a home setting. In 2021, they established the Living Lab at Home, a community-based platform that studies the everyday experiences of children and youth with developmental and behavioural disabilities.

The Living Lab at Home integrates self-reported experiences with

innovative technology. A smartphone app captures daily emotions and social interactions, wearable devices monitor physical activity and non-invasive saliva samples measure stress-related biomarkers. All technology has been co-developed alongside families and young people with lived experience of developmental, psychiatric and medical complexity.

REIMAGINING WEARABLES

Standard wearables can prove unsuitable for children with complex health needs. For instance, a child with significant neurological impairments might find wrist-worn devices uncomfortable

> or even distressing. The team is addressing this challenge by rethinking what wearable technology can be, asking questions like: What will children actually wear in daily life? How do we make it comfortable? And how can the information we get from a wearable truly help?

"We're in an era of enormous innovation," explained Dr. Boerner. "From activity monitors measuring daily body movements to smart socks tracking heart rate and vests that monitor vital signs, we're on the cusp of seeing a surge of new technologies deliver health insights from home."

The team is exploring innovative alternatives beyond

conventional designs. "I envision a future where we'll have a lab that creates our own custom-designed clothing with sensors seamlessly built into fabrics," said Dr. Oberlander. "We're also exploring the potential of 'nearables'-devices installed in a room that can measure health indicators without requiring the child to wear the technology."



medical needs.*

"We're in an era of enormous innovation... we're on the cusp of seeing a surge of new technologies deliver health insights from home."

- Dr. Katelynn Boerner

EMPOWERING FAMILIES THROUGH DATA

Beyond collection, the Living Lab at Home transforms how families interact with health data. "Simply gathering data isn't good enough," Dr. Boerner emphasized. "Families also want to access it, understand it and use it to improve their children's lives." To address this need, the lab puts health information directly into families' hands through a custom-designed app. "We're hoping this can help them evaluate interventions in real time," she noted. "Whether it's starting a new medication or trying a different therapy approach, having continuous data allows for more informed decisions."

Making sense of this vast amount of data across multiple dimensions will eventually rely on artificial intelligence to uncover meaningful patterns. With this home-based approach, research is now happening where lives actually unfold—transforming how experts understand and improve the health of kids with complex

Plastic surgery: shaping a hopeful new future for kids

To the average person, the words "pediatric plastic surgery" might raise an eyebrow. But visit BC Children's Hospital, and you'll find it's a critically important area of care that uses reconstructive surgery to enhance form and function for kids. The end goal: to improve a child's quality of life—and sometimes, even save it.

Approximately one third of the hospital's plastic surgery patients are part of the Cleft Palate and Craniofacial Program, which has been running since the 1960s. Others have severe burn or hand injuries. For these kids, plastic surgery is a key part of their healing journey.

But for a smaller group of children, advancements in plastic surgery have been the deciding difference between life and death. Take craniosynostosis, a devastating condition that causes a baby's skull to close before their brain has finished forming. This premature closure prevents the skull from growing along with the baby, and in the past, was fatal in severe



or complex cases. Today, these babies have a new chance at life.

What's been the difference maker? "Advancements in distraction osteogenesis," said Dr. Doug Courtemanche, investigator and plastic surgeon at BC Children's Hospital. This procedure involves cutting the bone and inserting a device, which slowly pulls the two pieces of bone apart. New bone can then grow and fill in the gap. Using distraction, plastic surgeons can perform the lifesaving work of changing jaw structures, as well as growing and reshaping skulls. The team at BC Children's was the first in Canada to adopt a new resorbable technology that improved how this care was provided.

The hospital's ambitious plastic surgery division continues to stay at the forefront of its field in part because of its heavy focus on research and education. Though a small team, they've trained over 30 pediatric plastic surgery subspecialty fellows, and, in the last dozen years, have published over 80 papers. "We're investing in the next

generation of plastic surgeons so that we continue to advance the quality of care we're able to provide," said Dr. Courtemanche.

"Plastic surgery can really transform a child's life. And the more you can help a child fit into their world and find their niche, the more they're able to live their life fully. That's what makes this work so important."₩

"The word plastic comes from the Greek word plastikos, which means to shape. When we say plastic surgery, what we really mean is reconstructive surgery." - Dr. Doug Courtemanche

Small rises to mighty roles The remarkable power of sibling caregivers

They memorize medication schedules while learning multiplication tables. They become fluent translators when words fail their siblings. They provide a calming presence during stressful medical procedures.

For children with disabilities and chronic health conditions, one of their most powerful advocates is among the smallest—their sibling. These young caregivers perform essential behindthe-scenes roles, yet their contributions aren't always fully understood or recognized.

"What appears to many as just a caring moment is actually a caregiving role," explained Rhiannon Satherley, manager of Sibling Support Services. "Siblings share one of life's longest relationships. Nobody knows you like a sibling does. They're your peers-they understand your fears and worries, and they see you at both your best and worst."

Without proper support and acknowledgment, sibling caregivers may feel isolated and overlooked. Research has revealed some may even develop mental health challenges that can persist into adulthood.

Recognizing a sibling carer's vital role, "It's so important to have a separate Sibling carers also need their own

BC Children's Hospital opened the Sibling Support Centre and Services to offer a space for respite and play. Thanks to incredible support from the Sauder family, the Centre will be renamed the Sauder Sibling Centre in 2025. Here, kids can simply be kids—whether that means reading a book, playing video games or creating art with volunteers. world for siblings outside of that patient care journey where they can have fun and meet other kids who may be going through the same experience," Rhiannon added. "Because often, when they leave the centre and that door closes, they shift back to being sibling carers." supports in their caregiving role. This understanding prompted BC Children's to launch the Young Sibling Peer Sup-



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port Network this year-made possible through a generous gift from the Canadian Centre for Caregiving Excellence, a program of the Azrieli Foundation.

This first-of-its-kind program in North America provides monthly virtual peer support sessions for children aged 8-11 who have siblings facing medical complexities and/or disabilities, at no cost to families. The space allows them to connect with other sibling caregivers, share their experiences and develop coping skills in a supportive space. The innovative online format ensures accessibility for families throughout BC, the Yukon and Alberta, regardless of their geographic location or transportation limitations.

"By recognizing sibling caregivers as individuals with their own unique needs, we're helping them better navigate their challenges," Rhiannon said. "The network provides a space where siblings can feel seen and supported, empowering them through what can sometimes be a lifelong journey of providing care."*

Every journey needs a navigator

A chat with Kat Broad

In care teams across BC Children's Hospital, there's one role that's getting a seat at the table more and more frequently: social work.

We sat down with Kat Broad, professional practice lead for social work at BC Children's and Women's Hospital, to talk about the field and what it means to help families on their health journey.

Q: WHAT MAKES SOCIAL WORKERS UNIQUELY EQUIPPED TO SUPPORT KIDS AND FAMILIES?

A: At its core, social work is about facilitating relationships-with our patient, their family, their medical team and their broader community. That's why we're uniquely trained to take on many roles: clinical counsellor, case manager, resource navigator, advocate and systems navigator are just a few. Because social workers provide psychosocial care, it's also critical that we assess the individual needs of each child. This isn't just in relation to their medical challenges, but within the context of their life outside the hospital. It's very much big-picture work.

"As social workers, providing support starts with meeting families where they're at, in their interpretation of what health looks like." – Kat Broad

Q: HOW HAS THE ROLE OF SOCIAL WORK EVOLVED OVER THE YEARS?

A: There's now a clearer understanding of how social determinants of health—non-medical factors like poverty, housing or distance from a hospital—can impact a child's health outcome. Social workers specialize in identifying and addressing these issues, so we are necessary to make sure kids get the support and care they need in order to thrive. Over the years, we've started to take a leadership role in centering children and their families in care.

Q: WHAT ROLE WILL SOCIAL WORK PLAY AT THE CENTRE FOR HEALTH COMPLEXITY?

A: Being a parent or guardian caregiver under these circumstances is more than a full-time job, and can be overwhelming. We're trained to support these exact situations, which is why social work will be at the heart of the centre's care. Each family will have a dedicated social worker to help with resource coordination and navigating health systems, which will help provide some relief. These families are on very difficult journeys—some children don't have a diagnosis, or a clear path forward. As social workers, we're there to help them navigate the unknown.*



6th Floor, Cardiac Post-Operative Unit, Teck Acute Care Centre, BC Children's Hospital August 29, 2024, 5:26 PM "The day this photo was taken was the first day in weeks that we saw Jasmine smile. Under her kimono she still was covered with surgery bandages and drainage tubes. She couldn't even walk unassisted, nor eat food yet, but her smile lit up our day. I think that was the day when we thought things would be okay. We could breathe again.

Jasmine has a very complicated heart. We knew before she was born that she only had two chambers instead of four. By the time she was a week old, doctors told us she wouldn't survive without surgery—but even if they operated, her chances were only 50/50.

She's had three open-heart surgeries now. The last one was just last August. What was supposed to be a two-week hospital stay stretched into two months. She had tubes in her stomach, a strict diet and spent most days in bed. It was exhausting, terrifying. But in the middle of all that, people made a difference. The doctors, the nurses, the cleaning staff—they treated us with such kindness. Some of the nurses became like family."

YOUR D Donate today to get your donation matched by the Sauder family.* You can make a gift through the donation form in this magazine, or by visiting MakeUsMighty.ca/double

Isabella, age 7, diagnosed with a rare kidney cancer that affects children.

*Until June 15, 2025, the Sauder family will generously double all one-time and monthly gifts for the first 12 months; up to a cumulative total of \$500,000.

