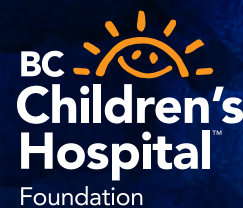


FALL 2021

SHINE



Looking back, moving forward

How reflecting on
the history of
childhood cancer care
is helping us
blaze new trails

Also in this issue

40 years of smiles

Taking back control from epilepsy

Closer to COVID-19 protection for kids



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CONTENTS

2 THEN & NOW

6 DEVOTED LEADER LEAVES LASTING LEGACY

7 TAKING BACK CONTROL OVER THEIR LIVES

8 LATEST STRIDES

10 ADOPTING A BRIGHTER FUTURE

11 ONE BOWL AT A TIME & A GOOD CAUSE

12 40 YEARS OF SMILES & OUR NEW BOARD CHAIR

13 REWRITING THE STORY FOR CHILDREN



A TIMELINE OF TRANSFORMATION

Social reformer Frederick Douglass once said, "If there is no struggle, there is no progress." When I reflect upon this quote, I immediately think of ways this principle has rung true in the decades-long quest to specialize our healthcare for children.

As recently as the last century, children received the same healthcare as adults. Equipment, programs and clinical care designed specifically for kids were a foreign concept. Survival rates for many childhood diseases were also much lower than they are today.

Over the decades, leading experts in BC reimagined what healthcare could look like for the youngest members of society. And yes, there were struggles. It wasn't easy to obtain the right resources, expertise and financial support to bring a new future to bear. But with the support of compassionate and determined British Columbians—individuals and organizations—these visionaries breathed their dreams to life.

In this issue of Shine magazine, you'll read about how this exact movement took place in the care of

children with cancers. I'm inspired by oncologists and researchers who considered the low survival rates unacceptable—and pressed upwards to improve treatments and change outcomes. Along the way, dedicated members of the community rallied by their side with hopeful determination.

I'm also moved by the stories of thoughtful donors who have joined our quest to conquer childhood illness. Some joined us many years ago; others more recently, but each of them have played an important role in the timeline of transformation in children's health.

You too are part of this timeline—and the legacy we are continuing to build together to reimagine the future of child health. I am so thankful for each of you.

With gratitude,

Malcolm Berry
President & CEO
BC Children's Hospital Foundation

Then & Now

From a dismal past to a daring future for childhood cancer care

ACCORDING TO A MEDICAL TEXTBOOK WRITTEN IN THE 1930s, CHILDHOOD LEUKEMIA WAS AN UNTREATABLE CONDITION THAT WOULD INEVITABLY LEAD TO THE CHILD SUCCUMBING TO THE DISEASE.

Dr. Rebecca Deyell, pediatric oncologist and investigator, Michael Cuccione Childhood Cancer Research Program (MCCCRP) at BC Children's Hospital, was given that textbook by her grandfather, a family doctor. Flipping through the book was like looking back in time at the recent history of treatments for childhood cancers and seeing how dismal the health prospects used to be for children with cancer. "This was my grandfather's textbook," said Dr. Deyell. "It really wasn't that long ago."

Even up to the 1950s, surviving childhood cancers was a nearly hopeless prospect. With survival rates between 10 and 15 per cent, the vast majority of children diagnosed with cancer did not make it.

Gradually over the years, medical researchers developed treatments that steadily pushed those survival rates higher. With the creation of treatments like chemotherapy, radiation, and bone marrow and stem cell transplantation, more children were able to survive their cancer—but not without paying a price.

Many of the treatments for cancer were very harsh, hurting the patients even when cured. Some children suffered from devastating long-term side effects such as heart damage, hormone problems and permanent hearing loss. The very treatments meant to heal often harmed the kids, who grew into adults still dealing with the negative impacts of treatment.

WE'VE COME A LONG WAY, *BUT IS IT ENOUGH?* With donations from generous British Columbians and organizations throughout the years, researchers at the MCCCRP at BC Children's Hospital have made enormous advancements in therapies. Today the survival rate for children with cancer is approximately 80 per cent, a testament to medical experts at BC Children's and around the world who have developed new and better ways to treat childhood cancers.

As far as we've come over the past century, there's still a challenging road ahead. Currently, of the approximately 130 kids in BC diagnosed with cancer each year, one in five will not survive long-term—that's a classroom full of kids.

"For the hard-to-cure cancers kids need new treatments and new approaches so that the story of relapses and kids dying of cancer will hopefully one day be history."

— DR. ROD RASSEKH, PEDIATRIC ONCOLOGIST AND INVESTIGATOR, MICHAEL CUCCIONE CHILDHOOD CANCER RESEARCH PROGRAM

Some young cancer patients suffer relapses, making it much less likely they will survive. Other kids have tough-to-cure cancers that require more specialized approaches—children like Ellie.

ELLIE'S STORY

It was the last day of 2017 when Racyne found a lump on the neck of her two-year-old daughter Ellie. The family from Osoyoos learned, after they arrived at BC Children's Hospital, that Ellie was suffering from a malignant rhabdoid tumour—which has only a 20 per cent chance of survival longer than five years after diagnosis.

Due to the rarity of this type of cancer, there was no standard treatment. Dr. Deyell checked the medical literature and the biggest case series she could find had only 26 kids, of which only one survived long-term. After extensively researching different treatment options, Dr. Deyell came up with a plan: six total rounds of chemotherapy, surgery to remove the tumour and 25 radiation treatments.

After seven and a half months in the hospital, Ellie and her family were finally able to go home. It's been almost three years since then, and there's no evidence of disease so far.

Racyne and her family are deeply grateful Ellie is currently among the small percentage of kids who are surviving this rare condition, and they're hopeful that some day every child with cancer will not only survive, but thrive.

The generosity of donors is what allows researchers to continue pursuing breakthroughs for future treatments, so we can help more kids like Ellie. We're grateful for recent leadership donors—the Hudson family, Donald's Fine Foods, and Donald and Julia Leung—for their passion and vision to build a better community and improve health care for children fighting cancers across British Columbia.

HOPE ON THE HORIZON
WITH YOUR HELP

Innovative areas of research are leading to promising new treatments.

"We're going to a new level of personalization," said Dr. Kirk Schultz, pediatric oncologist/hematologist and investigator with the MCCRCP at BC Children's, "trying to identify the molecule changes, genetic changes within the cancer, and targeting it in more specific ways to increase cure rates and get safer cures with fewer complications."

Right here in BC, we have world renowned pediatric oncology researchers who can tackle these challenges. BC Children's is home to a unique collaboration of experts that is unlike anywhere else in the world.



Dr. Kirk Schultz



Ellie with Dr. Rebecca Deyell

CAR T-cell
therapy

A PROMISING PATH FORWARD

One exciting area of research is focused on CAR T-cell therapy, a highly innovative approach to personalized medicine that can offer hope to kids whose hard-to-cure cancers haven't responded to other available treatments.

The Michael Cuccione Foundation, a BC-based global leader in raising support for childhood cancer research, has made a tremendous commitment to raise \$10.5 million for this novel area of research.

We've made so much progress in treating childhood cancers since that 1930s textbook Dr. Deyell received from her grandfather. With your support researchers can get closer to developing safer treatments for childhood cancers, so new textbooks written in the years to come can describe effective ways to cure childhood cancers, save lives and give children their childhoods back.

"I want to see increased research," said Dr. Deyell. "I want to see clinical trials that are designed for these rare kinds of tumors. I want to see results of targeted therapies. This work is critical. And none of it would be possible without donor support."

"We can't accept the status quo, we need to take it to the next level. What if we could do more for children with cancer?"

— DR. REBECCA DEYELL, PEDIATRIC ONCOLOGIST AND INVESTIGATOR, MICHAEL CUCCIONE CHILDHOOD CANCER RESEARCH PROGRAM

Dr. Asa Johal,
front left,
with family

Devoted family and business leader leaves lasting legacy

Dr. Asa Johal immigrated from India to Canada in 1924 as an infant; from humble beginnings he arrived with big dreams and a strong sense of family. Those values became foundational guide posts for personal and business endeavours as Dr. Johal developed into a visionary and philanthropist. Through the challenges and successes of life, Dr. Johal would go on to create a legacy that will live on for years to come.

At age 14, Dr. Johal left school and began working at a local sawmill. It was the first step towards accomplishing his dream—to one day own a lumber mill. Perseverance, integrity and a strong work ethic drove the industrialist to start his own independent lumber company in the mid 1960s. Terminal Forest Products would go on to become one of the largest lumber companies in British Columbia.

As Dr. Johal's business grew, so too did his family and their strong desire to support the community around them. Along with his wife, Kashmir, Dr. Johal demonstrated the importance of philanthropy to his family and employees, giving generously to many organizations and communities, including BC Children's Hospital Foundation for the past three decades. He believed deeply in supporting initiatives that continued to elevate health care for BC's kids and strived to improve the lives of those being cared for by the hospital.

Thirty years ago, in 1991, Dr. Johal was presented with the Order of BC and the Order of Canada, a well-deserved accomplishment for a man who made remarkable contributions to the province of BC while staying true to his cultural roots and important values.

In July 2021, Dr. Johal passed away at the age of 98. Those who had the privilege of knowing him recall his incredible spirit, drive for excellence and passion for helping others. His and his family's generosity will continue to transform the lives of BC's kids for years to come.

Taking back control over their lives

Each year approximately 15,500 Canadians are diagnosed with epilepsy, which often marks the start of a difficult and complicated health journey. Two epilepsy patients, young women living in BC, decided to take back control and determine their own path forward.

Jacqueline was in Grade 9 when she and her family were playing in the pool and she jumped into the water—and never came up. Her family rescued her and discovered she had a seizure, the first in her life. Not long after she had a second seizure, and at BC Children's Hospital she was diagnosed with epilepsy.

Grace was also diagnosed with epilepsy at BC Children's, although her seizures were of a different nature. "Mine were myoclonic jerks, so basically I would drop things, throw or buckle a leg," said Grace.

Of the thousands of Canadians who learn they have epilepsy—an average of 42 people diagnosed each day—44 per cent are five years old or younger. Treating epilepsy is difficult because its causes aren't well understood, and the condition can take a heavy toll both on the patients' physical and mental well-being.

The families of Jacqueline and Grace are close friends with philanthropist Ali Pejman, who has first-hand knowledge of epilepsy. Together they



Grace (left)
and Jacqueline

joined the Pejman & Friends Epilepsy Fellowships and Research Initiative, a partnership that provides funding to both BC Children's Hospital and Vancouver General Hospital—the cornerstones of epileptic care in BC.

The funding supports ground-breaking research and training of the next generation of medical superstars in the epilepsy field, with the ultimate goal of transforming care for the thousands of Canadians living with epilepsy today.

There's still much that's unknown about epilepsy. By joining the Pejman & Friends Initiative, Jacqueline and Grace are taking action and refusing to let epilepsy take over their lives.

"You don't let it control you," said Jacqueline. "You control it."

LATEST STRIDES

A closer look at how supporters like you are making strides in research and clinical care possible.



THE POWER OF PARENTING STYLE

Thanks to a recent scientific study, we're learning that the way a parent responds to a child's needs can affect more than just the child's behaviour. The study provides evidence that a secure attachment parenting style can potentially benefit a child's cognitive development and immune system, even among infants as young as three months of age.



Parenting style effects can be observed in infants as young as **three months old**

Researchers from BC Children's Hospital and the University of British Columbia's Faculty of Medicine examined how the attachment style between a mother and toddler can alter a child's DNA on the molecular level.

They explored two different attachment styles. The first was secure attachments, in which babies used their parent as a secure base for exploration and a safe haven from stressful situations. Insecure attachments, on the other hand, involved infants whose parents were withdrawn, didn't respond consistently or

provoked fear when the child sought comfort or safety.

"This study illustrates the potential biological consequences of early adversity, but also demonstrates the resilience associated with positive parenting," said the study's lead author Dr. Sarah Merrill, a postdoctoral fellow in BC Children's Hospital's Kobor lab. "These molecular differences indicate that positive parenting has potential benefits when it comes to a child's immune system and their cognitive development."

A GUT REACTION TO A NEW TREATMENT POSSIBILITY

It starts with fatigue, diarrhea, fever and stomach pain, and could possibly lead to arthritis, skin disease, osteoporosis (bone density loss), kidney stones, increased risk of developing colorectal cancer and other complications. This is inflammatory bowel disease (IBD), an umbrella term for gastrointestinal disorders that includes Crohn's disease (CD).

Canada has one of the highest rates of pediatric IBD in the world, with approximately 650 children under 16 diagnosed with IBD every year. And the fastest growing age group of children with IBD is kids under five years old.



Approximately **650 kids** under 16 are diagnosed with IBD every year in Canada

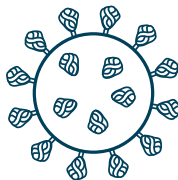
The gold standard treatment for CD is a liquid-only diet called exclusive enteral nutrition (EEN), which does help some patients but is not effective for up to 30 per cent of patients with CD.

Researchers with the Gut4Health team at BC Children's Hospital recently investigated a new EEN formula, with added fibre, and received encouraging results. They are now planning a clinical study with the hope that this treatment will eventually pave the way to better outcomes for kids with IBD.

The Gut4Health initiative has been made possible through the generous support of Mining for Miracles, the BC mining community's longstanding fundraising campaign in support of BC Children's Hospital.

A STEP CLOSER TO PROTECTING KIDS FROM COVID-19

A new study, co-led by researchers at BC Children's Hospital, is currently underway in Canada, monitoring the safety and effectiveness of COVID-19 vaccines in kids and adolescents. Since the pandemic began, hospitals across Canada have gathered information on how COVID-19 affects children and youth. This study, supported by the Government of Canada through the COVID-19 Immunity Task Force and Vaccine Surveillance Reference Group, will continue to build on this critical information and provide evidence for vaccine effectiveness and safety.



The study will provide evidence for **vaccine effectiveness and safety** in kids and adolescents

"As COVID-19 vaccines are rolled out to those aged 12-17 and potentially younger children in the near future, we will analyze whether vaccination is associated with fewer children and youth being admitted to the hospital with COVID-19 and fewer severe cases of the disease," said Dr. Julie Bettinger, an investigator at BC Children's Hospital and data center director for the Canadian Immunization Monitoring Program ACTive (Impact).

As research—and the school year—continues, this study will help provide important data about how to best protect kids and youth across Canada and ensure children across the country stay healthy and safe.

Adopting a brighter future

A wise person once wrote, “Give a little love to a child, and you get a great deal back.” No one embodies this sentiment more than Trevor and Jennifer Barkman, who embarked on a journey of love with four young children.



Since 2009 the Barkmans have lovingly adopted four high-risk babies, all of whom have developmental and health issues. BC Children’s Hospital is a steady partner in the care of all four boys, helping the Barkmans build brighter futures for these children.

Jonathan, the first child they adopted in 2009, was born HIV positive and with fetal alcohol spectrum disorder (FASD). Two years later the family welcomed Matthew, who had a deletion of the X chromosome that resulted in poor vision and hearing, and was unable to walk or crawl.

In 2014 the Barkmans adopted Jonathan’s half-brother David, who was also born HIV positive and had FASD and learning disabilities. Isaac, Matthew’s half-brother, joined the family in 2018, bringing

with him a chromosome deletion that resulted in hearing, vision and mobility issues.

Throughout this roller-coaster journey, Jennifer and Trevor received steadfast support from their families, as well as doctors, nurses and specialists from BC Children’s Hospital.

Matthew alone has visited BC Children’s almost 100 times for tests and surgeries, during which he received extensive treatments that improved his quality of life. “We like to joke that Matthew has a specialist from his toenails to his hair,” said Trevor, “and everything in-between.”

Trevor’s parents, Ken and Betty Barkman, are so inspired by the incredible care their adopted grandsons received that they became regular monthly donors to support BC Children’s Hospital.

With help from experts at BC Children’s, Jennifer and Trevor have created new, hope-filled lives for their boys. “We see only a part of what they have to deal with on a daily basis,” said Ken and Betty, “but we know that they have dedicated their lives to making sure that Jonathan, Matthew, David and Isaac have the best care that they can give them.”

Helping sick kids one bowl at a time

With a child’s scraped knee, the “boo-boo” can be cured with a kiss and comforting words. But for kids with cancer it’s not so simple—treatment requires months or years of care and lots of hardships along the way.

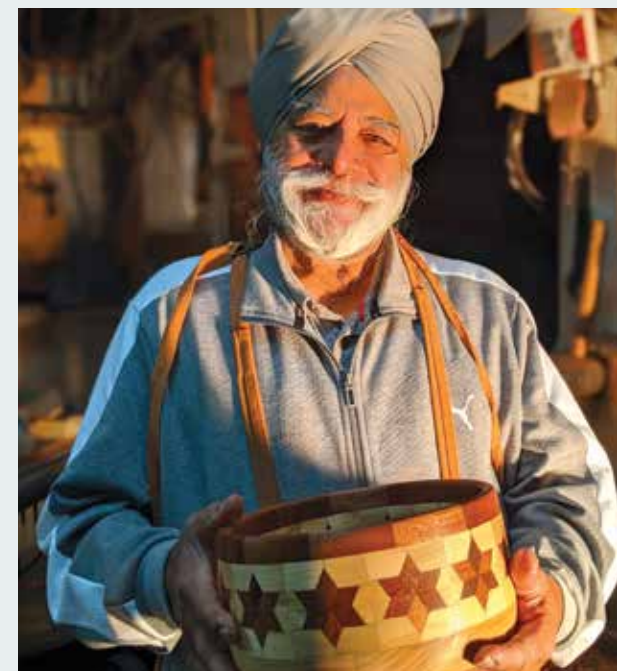
Nirmal Singh Bhogal, an 80-year-old grandfather, is a devout Sikh dedicated to the act of Seva (“selfless service”) and has volunteered with health-related causes for years.

When the pandemic halted these activities, Nirmal decided to raise funds for charity. He put his well-seasoned carpentry skills to use in crafting and selling beautiful wooden bowls, and Baba’s BooBoo Bowls was born.

The name comes from the “boo-boos” Nirmal hopes to help cure in child cancer patients, as well as the imperfections in the scrap wood he uses to create the bowls.

With his grandson Mehar and daughter-in-law Ranjit, Nirmal has been donating the proceeds to the oncology department at BC Children’s Hospital. They’ve raised \$62,000 so far, with a target of \$75,000.

Having known people who have suffered from cancer, Nirmal feels a personal connection to the cause. “I feel happy to do something for somebody,” he said.



When a good cause gets personal

It all started with a simple fitness challenge and ended with a huge gift, inspired by a brave child’s battle with cancer, that represented a step forward in creating hope for cancer patients.

Dan Jordan is a senior vice president at Colliers, a multi-national real estate company that was founded in BC. He set up a 30-day fitness challenge for BC employees with the goal of raising \$5,000 for BC Children’s Hospital Foundation.

It wasn’t long before the employees discovered this charitable cause was hitting closer to home than they’d initially realized. Nicholas, the young son of a fellow Colliers employee, was undergoing treatment at BC Children’s to fight cancer, and with this as their rallying cry the other employees took their fundraising to another level.

During the 30-day workout challenge, Colliers employees raised an amazing \$155,746, over 30 times the original goal.

These hard-earned funds were donated to BC Children’s Hospital to support oncology research, mental health and social work.

Nicholas and his family are deeply grateful to all the supportive employees at Colliers, as well as the medical staff at BC Children’s who have provided such great care.



Celebrating 40 years of smiles

"If we can help put a smile on a child's face," said Maria Giles, "that's the whole world. They're our future."

Maria is someone who knows a lot about smiles. In April 2021 she was recognized for 40 years of delighting customers as a team member of Save-On-Foods, an organization she loves to work for.

As a valuable team member at the Willingdon Save-On-Foods store in Burnaby, Maria has been injecting fun and creativity into fundraising events to support BC Children's Hospital.

This includes dressing up in a full cowboy outfit during Round Up charity drives, where customers can round up their bill to the nearest dollar and donate the difference, and Hawaiian days,

in which all team members wear colourful Hawaiian outfits to encourage donations. She even convinced two male store managers to wear grass skirts to support the cause.

The reason behind Maria's staunch support of BC Children's is close to her heart. Her daughter Vanessa was born with developmental issues, and thanks to the staff and experts at BC Children's Vanessa is now living a full and happy life.

Even after 40 years at Save-On-Foods, Maria is still going strong, both in her love of serving customers and helping BC Children's. "I won't change my passion for raising money for BC Children's Hospital," said Maria. "It's a passion, it's a drive that I won't change until the day I retire, and I won't even change after that."



A warm welcome to our new Board chair



"Ultimately, I am here for the children, and for the opportunity to make a real difference in their healthcare. They are our entire future—and what we do for them today will not only shape their individual lives, but the success of our province."

DARRELL JONES
CHAIR, BOARD OF DIRECTORS,
BC CHILDREN'S
HOSPITAL FOUNDATION
PRESIDENT, SAVE-ON-FOODS

BC Children's Hospital Foundation is delighted to share that Darrell Jones, President of Save-On-Foods, is the new chair of its Board of Directors.

During his past five years as Board member and vice-chair, Darrell has been a passionate advocate of child health. As a community and corporate leader embedded in the fabric of our province, Darrell is well-poised to continue leading the Foundation upwards in its ambitious quest to conquer childhood illness.

We extend a warm welcome to Darrell in his new role.

Rewriting the story for children of the future

Alfons Welcher loved to tell stories to a captive audience of family and friends. His gentle nature and sense of humour charmed those who he spoke to. Alfons' 89 years of life were filled with unique experiences and stories of his own. His love of travel and adventure took him everywhere from Europe, to the warm Arizona desert, to cities throughout Canada.

Alfons was born in Germany in 1929, the youngest of 12 siblings. In 1954, the 24-year-old emigrated to Canada, unexpectedly ending up as a passenger on one of the first-ever transatlantic flights. Alfons lived and worked in Saskatchewan and Powell River until a farm in the Fraser Valley became his home.

Trained as a horticulturist in Germany, Alfons' deep understanding of growing and harvesting plants, vegetables and fruit led to a satisfying 30 years of farming. Alfons was described by family as being ahead of his time in his approach to healthy living.

He kept active, ate fresh foods and truly understood the meaning of farm to table.

While Alfons didn't have a family of his own, he cared deeply for the welfare of children. His forward-thinking mindset inspired him to meet with an advisor to discuss how he could make a difference for children with his assets. A regular donor to BC Children's Hospital Foundation, Alfons received advice around tax planning and charitable giving, cementing his decision to leave his estate, and designate his segregated mutual funds to the Foundation when he passed away in 2018.

Alfons lived a simple life but, with the support of his family and advisor, was deeply satisfied in being able to leave a meaningful legacy for the children of BC. His gift will help to rewrite the story for kids battling childhood illness, so they too can share their words with others for years to come.

Legacy Giving: Many ways to change lives

There are many ways you can help change lives through a legacy gift—a planned future gift where your generosity benefits generations to come. Like Alfons, when you work with an advisor you are able to choose the best approach for your life and the impact you wish to make.

Official beneficiary forms need to be completed for registered financial accounts held by your financial institution. Insurance policies may also be designated on the insurer's beneficiary form. **Some benefits include:**

- > **Fewer delays:** Your gift to your charity would typically be distributed more quickly by the financial institution, and get to work sooner.
- > **Lower probate fees:** Your designated asset would not form part of your estate for purposes of calculating this fee.
- > **Your decision remains:** Designating your registered financial asset, or your life insurance policy, ensures your charitable choice is unhindered by family members who may not challenge your gift.
- > **Lower taxes on other income:** While certain registered assets, like an RRSP or RRIF must be reported as income, the charitable tax receipts provide a donation credit that may offset other income taxes.

Learn more at bcchf.ca/legacy



What if kids didn't get sick?

BC Children's Hospital provides care to 100,000 kids every year, many of them battling devastating diseases and chronic conditions. Your donation will fund groundbreaking research and advances in care that are needed to conquer childhood illnesses.

What if you helped?

