



Message from FAC Chair

Dear Canuck Place Families,

I hope this note finds you and your families as well as can be.

I am looking forward to another year on the council and can't believe it's already been five years since I joined the Family Advisory Council! In the past few months we welcomed three more members, Huamei Kang, Joe Goodings, and most recently, Grace Hobby to our council. It is really exciting to have Grace join as she is our first adult sibling member!

We are sure all our new members will enrich our council and the work we do to help ensure Canuck Place kids receive excellent care. We would also like to thank Shawna-Marie Phillips for her dedication to the council this past six years. Hope everyone has a joyful fall and winter season.

Angela Uncles, FAC Chair

MESSAGE FROM THE BOARD

Hello Canuck Place families.

For those of you that are new to the program, I have been serving as the FAC Liaison to the Board, after having been an FAC member from 2015-2021. On behalf of the board I am very excited to share the announcement of our new Board Chair, Suzanne Steenburgh. Suzanne has spent the last four years on the board, most recently as Vice-Chair and chair of the Quality Committee. Suzanne Steenburgh is a former nurse and health leader with almost 20 years of experience in children's health.

During her career, Suzanne held roles including Director for Quality, Safety and Accreditation, Program Manager, and Nurse Clinician with the Provincial Health Services Authority. As part of these roles, Suzanne led safety programs for multiple child and youth programs and agencies, supported the teams through Accreditation Canada surveys (achieving ongoing Exemplary Status), held oversight of



Suzanne Steenburgh,
Board Chair

several medical/surgical inpatient units and clinics, and led teams through the design process for two of the new inpatient floors at the Teck Acute Care Center. Suzanne holds a Bachelor of Science in Nursing, a Master's in Nursing, and certifications in Lean Leader Methodologies, Change Management, Quality Improvement, and Executive Coaching.

Suzanne lives in Vancouver with her husband and children and currently spends her time supporting a small family business and volunteering to support local charities.

Bob Smart, former Board Chair will remain on the Board. We are grateful for his continued guidance. The Board also welcomes two new board members: Dr. Matthew Chow and Tom Wong.

Being involved in the FAC and the Board to help improve care for children and families continues to be an important way for me to bring meaning to our own family experience.

**Sincerely,
Barbra Mohan, CPCH Board Member and
FAC Liaison**



Barbra Mohan,
FAC Liaison



Canuck Place Children's Hospice acknowledges with gratitude that our work takes place on the traditional and unceded lands of the Coast Salish Peoples, including the territories of the ṣx^wməθk^wəy̓əmaʔl̓ təməx^w (Musqueam), Skwxwú7mesh-ulh Temíxw (Squamish), sə́lilwətaʔl̓ təməx^w (Tsleil-Waututh) Nations, Stó:lō (Stolo) people, the Semá:th (Sumas), and Mathxwí (Matsqui) First Nations. Our program spans the province of BC and occupies the lands and territories of BC's Indigenous peoples. As a health care organization, we recognize that there is systemic racism within and throughout health care, and that we have the responsibility and power at Canuck Place to create culturally safe and appropriate environments of care.

Canuck Place for All

At Canuck Place we understand that uniqueness is powerful. We hold each other accountable for an inclusive environment where employees feel empowered to share their experiences and ideas and know that they belong. We believe diversity drives innovation and the best pediatric palliative care for children and their families, therefore we welcome that every person brings an individual perspective and experience to advance our mission.

At Canuck Place, we have more work to do to advance diversity and inclusion and we are building a culture where difference is valued. We have a commitment to inclusion across gender identity or expression, sexual orientation, religion, ethnicity, age, neurodiversity and disability status, to ensure our team members are empowered to bring their full, authentic selves to work.



Dear Families,

I am thrilled to welcome you to our fall 2023 family newsletter. You and your children inspire the clinical care and experiences we share at Canuck Place. Our staff feel privileged to support each of your unique journeys.

In 2023, families attended amazing events including, Remembering Our Children, our Summer BBQ, and Summer in the City adventures. Our team has launched the Research Initiative, Family Engagement Coalition, and received ChildKind International Certification, making Canuck Place the only pediatric hospice in the world to receive this designation. As an organization we continue to keep our focus on Quality and Safety of Care, working with provincial health partners on the pediatric Advanced Care Planning strategy, building the infrastructure for an Electronic Health Record system at Canuck Place, and preparing for our Accreditation Canada survey in June 2024.

In 2022, we undertook a robust strategic planning process to identify the future direction of Canuck Place. We consulted with staff and volunteer teams, Board, a small group of Canuck Place family members and healthcare leaders/partners in BC, across Canada and in the US. We asked for their insights into Canuck Place's strengths, the challenges that face us, and the opportunities they believe are available to us, given our operating environment. We channeled the information gathered identifying priorities, desired outputs, outcomes, and impacts we will focus on achieving over the next three years. Below is a synopsis of the work ahead.

Denise Prail, Chief Executive Officer, Canuck Place Children's Hospice

Canuck Place 2023-2026 Key Strategic Priorities

- **DEFINE THE POPULATION OF KIDS AND FAMILIES WE SERVE** to ensure children and families get the right care.
- **CONFIRM OUR MODEL OF CARE AND CLARIFY OUR SERVICES** so that children and families receive services that meet their PPC needs; children experience less suffering and better quality of life.
- **DEFINE OUR ROLE IN THE HEALTHCARE SYSTEM** so that Canuck Place is treated as an essential part of the healthcare system with a voice at relevant tables and influence on decisions affecting the future of care for the children and families.
- **ADVANCE OUR KNOWLEDGE & RESEARCH INITIATIVES** to increase the competency and capacity of healthcare providers and the healthcare system to care for children with serious illness using a palliative approach.
- **CRYSTALLIZE OUR MISSION, VISION, AND VALUES** so that there is greater clarity with external audiences who understand and support Canuck Place's unique contribution (Mission) and its strategic intent (Vision).
- **ATTRACT & RETAIN THE RIGHT PEOPLE** so that Canuck Place has long-term operational capacity and is able to support our Mission.
- **SECURE/ENSURE FUNDING TO SUPPORT OPERATIONS** to ensure Canuck Place has long-term financial sustainability.

UPDATE ON INFECTION PREVENTION AND CONTROL PRACTICES.

Dear children, youth, and families,

We hope this letter finds you well. As we head into respiratory virus season, and in response to the directions of the Provincial Health Officer, Canuck Place is making sure our infection prevention and control practices are in place to keep us all safe. We will continue to follow the guidance of our public health leaders, Ministry of Health, and health authority partners.

Current safety practices

1. Everyone (children, families, staff, volunteers, visitors) who enters the hospices must have a health screen. For children and families coming for a pre-booked hospice admission, a staff member will call you at home the day before your admission and ask you a series of questions about viral illness symptoms. If you are coming to the hospice for a visit, an appointment or group session, you will complete your screening when you arrive. We ask everyone with any cold or flu-like symptoms (even mild ones) not to come to the hospice. If you have booked a respite stay, we know this can be stressful and disappointing when we need to re-book due to illness; we thank you in advance for your understanding as we navigate keeping everyone safe.
2. Masks are now required. Staff, volunteers, contractors, and visitors must wear a mask when in shared or common areas and we are asking family members to wear one as well. We will provide the mask upon entry. Children under five years of age, those not able to wear a mask, and those children admitted for care do not need to wear a mask. You do not have to mask when in your family suite, your child's room or in the dining room while eating. For family support activities, including counselling, groups and meetings, please follow the direction of the staff member leading the activity or session.
3. We ask everyone in our hospices to clean their hands frequently.
4. We encourage everyone over six months of age to get their flu and COVID vaccines.

Our services continue in both hospices, as do our virtual care offerings and we are here for you and your family. As always, our 24-Hour Clinical Care Line can be reached at 604-742-3475 or toll free at 1- 877-882-2288. To book a stay, please reach out to the intake nurse (604-742-3476 or intake@canuckplace.org).

Please don't hesitate to reach out with any questions, comments, or concerns. We welcome your feedback.

Regards,



Kristina Boyer, RN, MScA
Clinical Program Director



Dr. Hal Siden, MD, MHSc, FRCP
Medical Director



Celebrating our New Volunteers!

We would like to give a big congratulations and warm welcome to our 23 new Family Volunteers! These amazing individuals completed the screening, selection, and four sessions of training (20+ hours) over two weeks. We are so proud of all of them!



The Toews

The journey of parenthood can be filled with joy, excitement, and anticipation. However, sometimes unexpected challenges arise, requiring families to navigate uncertain and difficult paths.

Parents Marie and Wes Toews, received the heartbreaking news of a Trisomy 18 diagnosis during Marie's pregnancy in 2022. Trisomy 18, also known as Edward's syndrome, is a chromosomal disorder caused by having an extra copy of chromosomes in the cells. In their time of need, Canuck Place Children's Hospice emerged as a steadfast support for the Toews, providing compassionate complex care, helping them create cherished memories with their daughter, Sophia.

Canuck Place is the sole provider of pediatric palliative care in BC and the Yukon. They offer a wide range of services, including medical care, pain and symptom management, grief and bereavement counselling, recreation and music therapy, and end-of-life support. Canuck Place care helps improve the quality of life for children and their families, by easing suffering and providing physical, emotional,

and spiritual support during difficult times.

The news of Sophia's diagnosis plunged Marie and Wes into a world of uncertainty. However, their introduction to Canuck Place Nurse Practitioner, Camara van Breemen was life-lifting for them. Camara's calming presence, knowledge, and experience absorbed some of their shock, and helped prepare them for both the possibilities and hopes. Together, they created a unique care plan that accurately reflected Sophia's diagnosis and the family's values in caring for her through end-of-life.

Advanced care planning is a crucial aspect of Canuck Place's support for families facing life-threatening conditions. Canuck Place nurses and physicians recognize the importance of addressing the complex medical decisions that arise throughout the journey of a child's illness. Through advanced care planning, Canuck Place works closely with families, like the Toews, to develop personalized care plans that align with their values, preferences, and goals. These plans encompass not only medical decisions but also emotional, spiritual, and practical considerations. By engaging in open two-way conversations, Canuck Place

helped the Toews feel more empowered to make informed choices about Sophia's care, and guided them to focus on cherishing every precious moment together.

Camara and the Canuck Place clinical team provided the Toews with information and education about Sophia's condition as well as available resources on how to take care of her medical needs. Counsellors and support staff offered emotional and psychosocial support to help them navigate their feelings, fears, and hopes, while grieving the loss of their sweet Sophia. Canuck Place nurses and physicians also worked closely with the Toews to assist in finding the necessary medical support in their hometown on Vancouver Island. Canuck Place's community-based care approach and advanced care planning ensured that the Toews family could receive the support they needed at home, in the hospital, and even virtually, without any financial burden.

"We visited Canuck Place for medical respite care while they taught us how to care for Sophia," explains Marie. "This skill building allowed us to help Sophia thrive more at home, which was very important to us, and the Canuck Place team continued to support us in our



Marie and Wes Toews, Canuck Place Parents, remembering their daughter Sophia

home for the rest of Sophia's life."

Dealing with a life-altering diagnosis can be an overwhelming and isolating experience. The Canuck Place counselling team recognizes the importance of emotional support for Canuck Place families like the Toews, offering guidance and solace throughout their grief journey.

Sophia's life may have been short, but her impact was profound. Canuck Place recognizes the importance of creating meaningful moments and memories for families on program, ensuring a child's life would forever be cherished. Canuck Place recreation therapists took special care to capture precious moments through making foot molds and a pendant with Sophia's footprint, allowing the Toews family to cherish and hold onto these memories for a lifetime.

Canuck Place guides families through the darkest of times, and helps them find solace, strength, and joy along the way. Through their comprehensive care, emotional support, and commitment to creating precious memories, Canuck Place care has a profound impact on families like the Toews, facing unimaginable challenges.

"When we first got Sophia's diagnosis, the weight of responsibility to navigate that on our own, was a lot," Wes explains. "What we quickly came to experience is that the support of Canuck Place allowed us to be present during our experience and care for ourselves and our daughter as her parents, rather than feeling the enormity of her care or decision making alone."

The story of the Toews family is just one among many that illustrate the transformative

impact Canuck Place has on families facing similar circumstances. Canuck Place continues to be a lifeline for families who find themselves in the midst of medical complexities, providing comprehensive care and support from diagnosis and beyond. By offering compassionate care tailored to the unique needs of each family, Canuck Place ensures that no family walks this challenging journey alone.

The services provided by Canuck Place are made possible through the generosity of donors and supporters.

Canuck Place would like to thank the Toews family, for sharing their inspiring story as family speakers at the Gift of Time Gala presented by Nicola Wealth in September.

The Angels



Federico and Cristina Angel, Canuck Place Grandparents

“Canuck Place helped each one of us grieve in our own way. Just the care and love with which they approached our family was incredible,” says Cristina, Canuck Place Grandparent.

Grandparents Federico and Cristina Angel were devastated when they learned their first grandchild, Alejo, was diagnosed with a rare terminal cancer. Their son Federico, daughter-in-law Erin, and Alejo, received in-home care through Canuck Place’s Enhanced Community Care Program, and after his passing, the family, including the grandparents, received grief and bereavement support from the incredible counselling team at Canuck Place.

Counsellors at Canuck Place support the mental well-being of all family members, and help build the capacity of families to navigate the long-term pain of loss.

“We care for the whole family,” explains Canuck Place counsellor Deborah Davison. “We offer care that requires participation and partnership

with family and encompasses the whole family holistically.”

Canuck Place recognizes that grandparent grief is unique, they hold individual counselling sessions as well as grandparent bereavement groups. The entire Angel family received counselling support, including Federico and Cristina.

“Grandparents are not only grieving a much-loved grandchild, they are also witnessing their beloved child suffer,” Deborah explains. “Supporting and helping grandparents process their own losses distinctly from parent grief takes any pressure off either of them in the broader family relational dynamic.”

Federico explains that while the pain of losing their grandson did not go away, the expert care, love, and support Alejo and their entire family received from Canuck Place nurses and counsellors lessened the pain.

“Canuck Place helped each one of us grieve in our own way. Just the care and love with which they approached our family was incredible,” says Cristina.



Jamey and Nick Fraser, Canuck Place Parents with Rachel, Canuck Place Nurse Practitioner

Family Advisory Council Needs You!

The Canuck Place Family Advisory Council needs more parents (or caregivers) to join the council—this is your chance to provide the family perspective to the senior leadership, Board of Directors, clinical and communications/fundraising teams.

We are looking for representatives from across the province, and members can call in via Zoom and do not need to join in person physically. Anyone is welcome—whether you have a child active on the program, are bereaved, have been associated with the program for many years or only for a

short time. We have nine meetings each year. Our meetings begin at 6 p.m. and occur on the second Thursday of every month.

If you have a couple hours to join virtually, or when we return to in person meetings at the hospice, we'd love to hear from you!

If you're interested, please contact fac@canuckplace.org

Even if you can't join the group, we are open to receiving input from any family member.

Listening to Our Families and their Voices

Canuck Place has a Family Advisory Council (FAC). This volunteer Council is integral to supporting the organization in delivering the best care to children and families across BC and the Yukon.

The FAC is a conduit for communication between families and the staff, administration, and the Board of Directors of Canuck Place. FAC members offer the perspective of families towards improving the quality and safety of existing Canuck Place services, the development of new policies and services, and having a dialogue about issues of mutual concern.

The FAC works to enhance the experiences of all families at Canuck Place and in all locations of care.



Upcoming Meeting Dates

Second Thursday Monthly for 9 months of the year



Location
Virtual (Zoom)



Who
Canuck Place family members

24 years of compassionate care

Canuck Place nurses are highly-trained, specialized professionals who walk alongside children with life-threatening illnesses and their families.

Nursing Manager, Brenda Dewar has dedicated 24 years to this important work. Her compassionate care during times of high vulnerability, helps create a healing environment where families are accepted, empowered, and treated with dignity and respect.

When asked to describe her nursing team in one word—dedication, emerges clearly. “Everyone works so hard to make a difference in the lives of children and families on the Canuck Place program,” explains Brenda.



Brenda Dewar, Former
Canuck Place Nurse Manager



Brenda Dewar, Former Canuck Place Nurse
Manager, and Elan Epp, Canuck Place Teen

Caring for children with complex medical needs can be challenging and unpredictable. Canuck Place nurses like Brenda embrace this uncertainty and lead with a gentle, therapeutic approach that respects the uniqueness of every family’s situation.

Brenda retired this year. Her nurturing presence at the hospice will certainly be missed. The compassionate, intuitive, and devoted care that Brenda has provided in her 24 years of exceptional care, has made a world of difference for children and families who need it the most. We know we join all of our families in celebrating Brenda’s care.





Michaela Wallis, Canuck Place Music Therapist, with Armaan, Canuck Place Teen

A big welcome to our new music therapist!

We are so thrilled to welcome Music therapist, Michaela Wallis to our team!

“I feel so blessed to work as a music therapist. On any given day, I’m able to create a session on the spot, tailored to what each child needs at that particular moment. I love that each child and family is unique, which means each day and session is totally new and exciting!”



Sam Ray, Canuck Place Registered Nurse

Introducing our new Registered Nurse Sam Ray

Please join us in welcoming our new Registered Nurse, Sam Ray! Sam’s first day was September 11, primarily based out of Canuck Place Vancouver - Glen Brae Manor. Sam has previously worked at the Abbotsford Regional Hospital on the pediatric unit for just over a year following her graduation from nursing school. Since then, she has worked at BC Children’s Hospital in the emergency department and has been there for almost three years. Sam enjoys biking, knitting, travelling, and hanging out with friends! She also enjoys canning different fruits and vegetables such as peaches, beets, and pickles. Sam’s favourite food is spaghetti and meatballs!

The Frasers



Nick Fraser, Canuck Place Dad, with Blakely, Canuck Place Sibling

Canuck Place dads find strength in tender places

Canuck Place is here to support dads like Nick Fraser through the difficulty of losing their child.

Nick and his family were introduced to Canuck Place when their son Kolbi became seriously ill with brain cancer. Nick recalls when Canuck Place Nurse Practitioner Rachel first came to his home to meet his son Kolbi.

“When Rachel arrived, we knew we were in the best possible hands.”

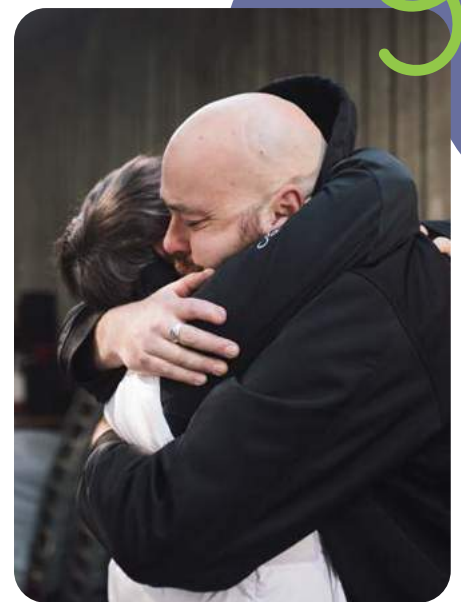
As Kolbi’s condition worsened, it became apparent that the Fraser family wanted to be at home as much as possible for Kolbi’s end-of-life care.

When a child is diagnosed with a progressive, life-threatening condition, Canuck Place nurses provide specialized

end-of-life care through the Enhanced Community Care Program. This includes extensive care coordination in-home, in-hospital, and working with healthcare professionals in the community to ensure families receive the right care at the right time. Families and clinicians can also call the 24-Hour Clinical Care Line, where they can speak with our clinical team and ask questions ranging from everyday care to complex issues surrounding medications, pain and symptom management, and end-of-life support.

Canuck Place helped the Frasers to feel more empowered. During the summer of 2020, they embarked on a cross-Canada road trip, and without Canuck Place, this beautiful family memory would have been much more difficult.

“Rachel made our road trip possible by organizing medication,



Rachel Neufeld, Canuck Place Nurse Practitioner and Nick Fraser, Canuck Place Dad

paperwork, and even showed us how to replace that pesky catheter. She made us feel supported and able to care for Kolbi,” says Nick. “Everyone going through losing a child needs care like we received at Canuck Place.”

Canuck Place collaborating for improved care



Canuck Place is collaborating with provincial partners on an initiative on pediatric advance care planning (pACP). Canuck Place along with Child Health BC, Children's and Women's Indigenous Health, Perinatal Services BC and BC Children's Hospital are working together for a provincial approach to pACP.

This is a two-year Ministry of Health priority project. The goal of the project is to improve the delivery of pACP services for child/youth/young adult with serious illness and their families throughout British Columbia.

We are currently hosting engagement sessions with health care partners, families, youth, and indigenous partners across the province to understand current state, gaps in care, and opportunities for improvement. We are grateful for the participation, sharing, and perspectives of our partners in this work. There will be more engagement opportunities to come over the course of the initiative. Stay tuned!

Canuck Place Website

Family Services and Engagement Pages

Last year, our team worked collaboratively with the clinical team and family partners to evaluate and address organizational goals for the website. A few key goals were identified in the process.

1. A dedicated section on the site to find information on family services
2. A resource area with family teaching documents to support caring for children at home
3. A family engagement area detailing our commitment to collaboration and feedback
4. Engagement opportunities for families to get involved in care, share their story to support fundraising campaigns, or join the FAC.



If you have feedback about our website, please reach out to Avery Nicholson, Manager, Marketing and Communications: avery.nicholson@canuckplace.org



CPCH RESEARCH INITIATIVE

Dr. Hal Siden, Canuck Place Medical Director, Scientific Director, CPCH Research Initiative

Healthcare research provides a process to advance knowledge for society's good, improve health, and find better ways to treat and prevent disease/illness. Canuck Place has aspired and envisioned to promote research activities in pediatric palliative care and serious illness since the hospice opened in 1995.

Over the past 28 years, Canuck Place has grown and evolved. As a result, our program has become internationally recognized for providing palliative care to children with complex, serious illnesses. We are excited to share that the Canuck Place Board of Directors and Senior Leadership support dedicated funding for research to continue to grow and improve the experience and care approaches for children with serious illness and their families.

Patient-oriented research is a priority, which engages patients, their caregivers, and families as partners in the research process. This engagement helps to ensure that studies focus on patient-identified needs and experiences, which ultimately leads to better patient outcomes. We hope to cultivate a culture of inquiry and work together to

develop an environment conducive to research that benefits and represents the families Canuck Place serves.

The CPCH Research Initiative is developing the highest standard of care and model of best practices and will educate others in the medical profession to ultimately benefit children throughout BC and the Yukon and around the world.

In 2022-23, Canuck Place clinicians accomplished the following:

- 48 pediatric palliative care presentations by CPCH clinical staff to provincial, national and global audiences fulfilling CPCH mandate to share knowledge for the benefit of seriously ill children everywhere
- 10 research publications
- 25 research projects improving the quality of care for children and families
- 44 Clinical Trainees, including: medical residents, fellows, student nurses, and Research Initiative trainees



Canuck Place becomes first pediatric hospice to receive ChildKind International Certification

Canuck Place has made an organizational commitment to pain prevention, assessment, and treatment. The culture and philosophy Canuck Place has upheld through the years focuses on comfort and compassion in the care provided and puts children and families at the centre of our program.

Canuck Place applied for ChildKind International certification (childkindinternational.org) as an organization. Accreditors from ChildKind visited Canuck Place on January 31. In March, Canuck Place received certification—we are the first pediatric hospice in the world to receive this certification.

ChildKind is a global non-profit composed of internationally recognized experts that fosters institutional commitment to pediatric pain care. ChildKind accomplishes its mission through encouraging excellence in pain care by recognizing and supporting healthcare institutions that have developed best practices. To date, 12 pediatric hospitals in the USA, three hospitals in Canada, and one hospital in Singapore are ChildKind certified, and now Canuck Place.

“The ChildKind site visit team was extremely impressed with the passionate and compassionate care provided by all staff and volunteers at Canuck Place Children’s Hospice,” says Allen Finley, ChildKind International Certification Member. “Pain and comfort care are integrated into a holistic approach to treating the patient and entire family, and the institutional commitment is very strong.”

“As a ChildKind certified pediatric hospice, Canuck Place is committed as an organization and as healthcare providers to the treatment of pain, and promotion of children’s comfort and ease of suffering,” says Denise Prail, Canuck Place Chief Executive Officer. “This certification is a testament to the work of our exceptional team to ensure that comfort and compassion are embedded in Canuck Place care. We will continue to deliver the best pain care possible to children and families on our program.”

The ChildKind International certification is based on five principles that organizations whose mission is to improve the quality of pediatric pain care must demonstrate their institution exhibits:

OUR FOUR TRANSFORMATIVE CANUCK PLACE COMFORT CARE GOALS

1. Make Pain Matter We need to improve equity, eliminate stigma, and make pain matter to everyone—health professionals, policy makers, funders, researchers, clinicians, and society at large.

2. Make Pain Understood All Health Care Providers’ need to improve their knowledge of all types of pain across the life course through investment in research and quality improvement. Our understanding must integrate biological, psychological, and social elements.

3. Make Pain Visual The goal is to consistently and routinely use standardized, reliable pain tools that are developmentally appropriate, that is properly documented, and followed-up with reassessment. Pain status should be determined in every child and treatment decision, and driven by a person-centred approach.

4. Make Pain Better If possible, we need to avoid unnecessary pain and prevent the transition from acute to chronic pain. We must strive for universal access to effective pain treatments for all children and adolescents.

Your Canuck Place Family Engagement Advisors

Canuck Place has hired two Patient and Family Engagement Advisors, Dana Warburton and Sara Rodrigues. This new care team role at Canuck Place provides patients and families with a peer-to-peer relationship as they navigate the healthcare system, and a way to partner with families to improve Canuck Place services through their experiences with service delivery.



Dana Warburton

Patient and Family Engagement Advisors support:

- patients and families to feel heard, understood, and empowered
- the family's relationship with staff and the care team
- the commitment of caring and valuing the family's lived experiences
- the improvement of patient care outcomes through family perspectives and developing solutions together
- families to navigate the healthcare system through their lived experiences as a parent with a child with complex care needs

Remember you can connect with Sara or Dana regardless of location, services, or programs you engage with at Canuck Place.

Families and staff can now call or text Sara and Dana as needed or continue to use their shared email: familyexperience@canuckplace.org

By phone: Sara (DLH) 778-792-5570 | Dana (GB) 778-791-1880

In person: Abbotsford location Dave Lede House (Tuesday and Thursday) | Vancouver Location Glen Brae (Tuesday, Wednesday and Friday)

We are always looking for family feedback (feedback about what you love about Canuck Place too!), if you have anyone who would like to connect with us send them our way. We use this information to gather themes that affect our children, youth, families, and caregivers to bring forth quality improvement initiatives.



Sara Rodrigues

Rights and Responsibilities

As a child and family on the Canuck Place program, you will have our respect. We honour your rights as a person and a family. We acknowledge our responsibilities in providing services—and yours in receiving them.

A right is a choice to decide on your own opinion, thoughts, feelings, expression, and entitlement to things.

A responsibility is a duty or obligation—something an individual should do to respect others and follow laws and rules.

Children and Families at Canuck Place have:

- **the Right to information**
- **the Right to choose**
- **the Right to privacy**
- **the Right to be included**
- **the Right to make decisions**
- **the Right to be safe**
- **the Right to be heard**
- **the Right to be themselves**
- **the Right to have their needs met: Physically, Spiritually, Emotionally, Educationally, Developmentally, and Socially**

Canuck Place families have a direct impact on the services we deliver. We welcome and encourage feedback. If you have questions, concerns, or comments about Canuck Place care, you are always welcome to fill out our online feedback form in the Family Engagement section on canuckplace.org.



Canuck Place family, the Bulgers

Opportunity For Family Partners to Participate In Signature Event, Fundraising & Awareness Campaign

April–June 2024

The Communication & Marketing team supports the organization with ongoing education and awareness of the Canuck Place program and to support fundraising for clinical care.

The team regularly develops and promotes family experiences and stories through visual communications, like the website, newspapers, digital advertising, social media, and videos.

For this particular engagement, the team is hoping to select a family living in Vancouver or

the Lower Mainland area, who accesses many aspects of the Canuck Place program including respite, recreation therapy, counselling, and more.

For more detailed information about this opportunity visit canuckplace.org.



The deadline to submit your interest is Dec 4.

The communications team is committed to creating content that truly reflects the diverse communities that our organization serves. We aim to elevate diverse voices and lead positive change through thoughtful and respectful content.

Making Memories all over BC

The Canuck Place recreation therapy team made their way to many BC communities this summer for Summer in the City (SITC) activities. Exciting adventures supporting Canuck Place children and families were held in Kelowna, Victoria, the Lower Mainland, and new this year—Prince George! The recreation therapy team worked hard to organize fun and engaging adaptive experiences for kids of all abilities and ensure that families created lasting memories together.

As part of the outreach SITC program, future planning is underway to continue to host one camp day each summer in more remote communities across BC, in addition to events hosted in the Lower Mainland, Vancouver Island, and in the Okanagan.

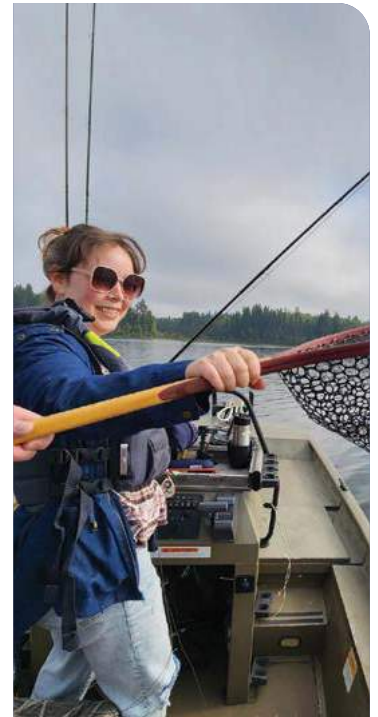
The recreation therapy team had tremendous support from two summer students. The team was joined by Elizabeth Boland-Janke and Kat Bender, who shared their love and support for Canuck Place kids, families, staff, and volunteers.



Li Family on Bowen Island



Ketlo Family in Prince George



Lacey caught a big one in Prince George



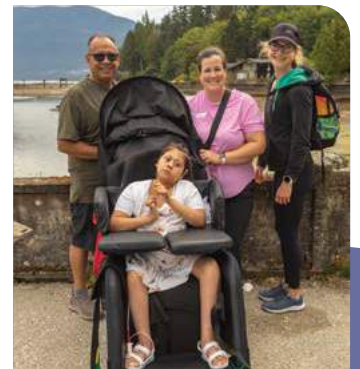
Darvish Family on Bowen Island



Cunningham Family on Bowen Island



Batra Family on Bowen Island



Sidhu Family on Bowen Island



Gasquez / Somers Family at the Superdogs



Fishing on Vivian Lake in Prince George



Braun Family on Bowen Island



Rempel Family on Bowen Island



Willms Family at the PNE



Bostik Family at Whistler Adaptive



Hernandez Family Whistler Adaptive



MacPhee / Fraser Family at Britannia Mines



Hendren Family at Oyama Ziplines



Teresa Domingo, FAC member and Canuck Place Mom, remembering her son, Kristian

Remembering Kristian Domingo

The Kristian Domingo Foundation was started by the Domingo Family in memory of Kristian who passed away at Canuck Place in August 2016. The Foundation honors Kristian's memory by providing financial assistance to young individuals who have faced adversity or are facing challenges as Kristian did in his short life. The Foundation also strives to help the institutions that were instrumental in Kristian's care throughout his cancer journey.

The Foundation was established in 2017 and, as part of its fundraising efforts, organized a golf tournament in August 2018 at Kristian's favourite golf course, Richmond Country Club. The inaugural event was so successful that it has become the Foundation's signature annual event, the Strength in Hope Golf Tournament, to recognize their donors and supporters, to raise awareness for the needs of adolescents and young adults (AYAs) facing adversity in their lives, and to raise funds for their #11 Forever Awards and for other institutions such as Canuck Place for the care and compassion they generously provide to the children and families they look after.



Volunteers supporting the Strength in Hope Golf Tournament

Canuck Place was instrumental in Kristian's care, particularly in the final days of his life. They also provided much needed support to Kristian's parents and brothers, as they navigated through their grief and a life without Kristian. This year's Strength in Hope Golf Tournament was another sold out success allowing the Foundation to continue and expand its #11 Forever Awards at secondary and post-secondary schools, support AYA programs with the BC Cancer Foundation and continue their support of the children and families at Canuck Place.



Aubrey Delima and Cherie Ehlert, Canuck Place Moms, Charlie-Anne, Canuck Place Teen, and Izzy the Wonder Dog

Rolling and Running for Canuck Place Kids

In the spring, Canuck Place child Charlie-Anne Cox rolled 21km in the Vancouver BMO Marathon with team “Charlie’s Angels Joy Runners” to raise funds for Canuck Place alongside her mom, Cherie, and step-dad Drew, and dad Matt and friends!

Charlie-Anne wasn’t supposed to see her first birthday. She is 13 years old and has Spinal Muscular Atrophy (SMA) type 1. SMA is a genetic condition that causes muscle weakness and atrophy and affects a child’s ability to crawl, walk, sit up, and control their own head movements. It also causes severe damage to the muscles used for breathing and swallowing. Charlie-Anne has been on the Canuck Place program since she was 9 months old.

Canuck Place mom, Aubrey Delima joined their team and challenged herself to run the full marathon for her daughters Lauren and Jenna. Lauren passed away on the Canuck Place program in 2010, and Aubrey has accomplished many fundraising events in honour of her daughter over the last decade.

The team rolled by a Canuck Place water station in Stanley Park to loud cheers. Team Charlie’s Angels Joy Runners raised over \$90,000 for Canuck Place!

Where hope blooms

Canuck Place mom Stephanie Hill-Davie helps hope bloom at Canuck Place.

Stephanie and her family were introduced to Canuck Place when her son Owen was six years old after being diagnosed with a single gene defect affecting multiple organs.

“It felt like the room was filled with support that was ready, willing, and able, to lift some of the weight we carried,” Stephanie explains.

Every year Stephanie organizes a sunflower fundraiser, selling seeds and fresh flowers on her farm, Central Canal Farms. This past year, the Hill-Davie family and their army of volunteers raised \$22,000 in honour of their son.

Owen passed away on the Canuck Place program in 2022. The Hill-Davie family keeps Owen’s spirit alive through beautiful, fresh flowers and fundraising for Canuck Place



Stephanie-Hill Davie, Canuck Place Mom



Dr. Sonia Brar, Canuck Place PPC Fellow, and Dr. Natasha Dato, Canuck Place Physician

Canuck Place Serious Illness Conversation Guide – Pediatrics®

With you, Canuck Place is leading locally, nationally, and globally. Children and our families are our greatest teachers. We share knowledge of what we have learned from kids and families in BC and the Yukon with clinicians in countries where up to 80% of young people with a serious illness will likely die.

This past year, Canuck Place Registered Nurse, Melanie Hameluck, Nurse Practitioner, Camara van Breemen, and Physician, Dr. Natasha Dato travelled to Nepal and India in partnership with Two Worlds Cancer Collaboration. They provided hands-on mentorship, lectures, and teaching sessions to nurses and doctors on comfort care with oncology patients, symptom management, play therapy during procedures, approach to care and pain relief, assessing/treating pain, comfort

holds, non-pharmacological pain relief, and having difficult conversations with children and families using the Canuck Place Serious Illness Conversation Guide - Pediatrics®.



Camara van Breemen, Canuck Place Nurse Practitioner, and Andrea Barbera, Canuck Place Family Partner

You can learn more about our approach to having serious illness conversations [in this YouTube video.](#)



Canuck Place Counselling and Bereavement Review

Canuck Place conducted a review of the current state of bereavement services at Canuck Place, and across BC and the Yukon. We also looked at what other pediatric palliative care programs across Canada offer for bereavement support. Mary Coleman, also a social worker on the Canuck Place counselling team, led this project. What we learned is that bereavement support is essential for grieving families, the needs of families are changing, and there is a growing knowledge of evidence informed practices in PPC that need to be considered. We will use the information gathered to help us determine how our bereavement program can continue to grow and evolve to meet the needs of families grieving the death of a child.

In reviewing how families utilize bereavement services at Canuck Place, it is clear that bereavement care is a team approach and reaches most bereaved families for five years after a death.

A large percentage of bereaved families connect with Canuck Place through services such as recreation therapy events, Remembering Our Children, and other peer connection opportunities (like precious pictures).

- Most families have memory activities and mementos supported by Canuck Place recreation therapy team.
- Through participation in music and recreation therapy, siblings experience continuity of care throughout their journey with Canuck Place. Most families (approximately 65–85%) access some form of formal bereavement counselling, including individual and group support.
- The community care team nurses and nurse practitioners connect with families after the death of a child at home to offer initial bereavement support.

The review also summarized current literature and understanding of child loss, confirming:

- Parents: experience long-lasting distress that impacts all areas of life; with support most adapt and integrate grief, but for some (10-25%) the intensity of acute emotional pain persists and continues to interrupt day to day functioning and relationships.
- Siblings: are often “forgotten grievers” who, like adults benefit from support; most do adapt and integrate the loss with in context of a connected family and community. Supporting parent and caregiver functioning is a critical ingredient to increasing grief resilience in siblings.
- Complex Interplay of Trauma and Grief: Both anticipated natural and sudden injury deaths can often produce traumatic stress responses, highlighting the need for specialized understanding of how trauma intersects with grief and affects adaptation.

Gaps in bereavement care for families who experience the death of a child in BC were found to be in the areas of:

- Family-centred, peer connections
- Specialized counselling for siblings
- Prolonged grief interventions
- Cohesive grief literacy resources
- Specialized bereavement care for neonatal/infant loss
- Formal support for traumatic deaths of a child
- No other comprehensive childhood loss specialist service
- Support for parents in later years of grief (beyond 2 years)

Some recommendations put forward include exploring how we could adjust services to meet varied needs, enhance support for complex grief, and ensure that our family-centred model remains central.

Our next steps in the process are to clearly articulate the scope of the Canuck Place bereavement program and engage with families to understand priorities and needs from their perspective and co-design any future program changes.





Walking the Path of Grief Virtual Sessions for Bereaved Families

Canuck Place counselling team offers virtual sessions for our families as a way to connect with you from the comfort of your own home. These individual sessions are opportunities to connect with other parents and loved ones on our program. These are a combination of information sharing about the topic and conversation about lived experiences.

Grieving During Holidays: The Light of Connection

Thursday December 7, 6:30-8 PM Please RSVP by November 27

Understanding the Nature of Grief

March 7, 6:30-8 pm , RSVP by February 27

Share a Cup of Tea Online Gatherings

February 22 from 6:30 to 8pm, RSVP by November 30

These sessions are offered to families who have previously attended one of the Canuck Place bereavement support groups in the last 7 years. We often hear from families that when the time has come to step away from attending a formal bereavement group, it can be challenging to continue connections with other bereaved families.

Yet, we know that grief has no time line, and parents can long for connections with others in the Canuck Place community for years to come. Make a cup of tea and settle in for an informal virtual gathering facilitated by a Canuck Place Counsellor and a volunteer bereaved parent. We are offering this as a pilot program, so please attend if you think this might be helpful to you.

Please email bereavement@canuckplace.org to RSVP and let us know if you plan to attend.