

Fall Family Newsletter

Hello families!

My journey with Canuck Place started in September of 2018 after the birth of my second daughter, Faith. Faith was born with a severe brain injury, and after spending a week in the NICU, we knew that we wanted to give her the best quality of life possible. Enter Canuck Place. It was here that we were welcomed with compassion, guidance, and never-ending support. We knew that Faith's days here on Earth with us would be limited, but Canuck Place allowed each one to be spent with family, building memories. We only got 40 days with Faith before she said goodbye, but they are 40 days I will forever treasure. I continue living each day looking for ways to honour and



MESSAGE FROM FAC CHAIR

connect with Faith, one of the reasons I joined the FAC.

I joined the FAC in the Spring of 2020, knowing that I wanted to give back to an organization that has given my family and I so much. I didn't know that with this, I would find another home within Canuck Place and a connection with others, that a bereaved parent yearns for. Through the FAC, we have an opportunity to provide guidance, feedback and have a direct impact on care for children and families. It is with great honour and appreciation that I was nominated as Chair this Fall.

On behalf of your Family Advisory Council I would like to wish you and your families a gentle holiday season.

Sincerely, Meagan Colenutt, FAC Chair

FAC COUNCIL MEMBERS

Meagan Colenutt (Chair) | Marion Fernandez (Vice Chair) | Barbra Mohan (BoD Representative)
Pooja Dixit | Joe Goodings | Chris Hall | Hollie Hall | Grace Hobby | Huamei Kang
Riki Lawson | Kerena Letcher | Angela Uncles

Message from the Board



I wanted to share with families that the Canuck Place Board of Directors has some updates. Robert Coard has been named Board Chair, and three new Board Directors, Linda Cheung, Tom Shepansky, and Dr. Randeep Gill, have joined the Canuck Place Board. Heartfelt thanks to Suzanne Steenburgh, former Board Chair, who will continue serving as Director and Past Chair, and to John DeLucchi, for his dedicated service during his final term. Barry Macdonald, will begin serving as Vice Chair & Secretary, and Jill Donaldson, will serve as Vice Chair. Continuing in their roles, Tom Webster, Teresa Budd, Barbra Mohan, Bob Smart, Markus T. Delves, and Tom C Wong, bring invaluable experience and commitment to our board. Special thanks to our committee advisory members—Elaine Sanders, Jaxson Creasey, Craig Thompson, and Allison Muniak—for their ongoing support. Of special note to families, Jaxson is a former patient at Canuck Place who graduated and is now completing his law degree at the University of Victoria. Together, we are supporting advancement in pediatric palliative care and creating meaningful memories for Canuck Place families.

Sincerely, Barbra Mohan, CPCH Board Member and FAC Liaison,
Canuck Place mom

Message from Clinical Program Director



I would like to take this opportunity to thank FAC member Kerena Letcher and her husband Jordan for their keynote presentation at the BC Centre for Palliative Care "All Together Symposium" and sharing their story of Heston with the palliative care community in British Columbia. They spoke so eloquently about their journey with Heston and the impact of pediatric palliative care on their experience. Canuck Place clinicians also presented at the International Palliative Care Congress in Montreal this fall sharing some of what we have learned about caring for children and families through our clinical experience and knowledge and innovation work. As we move into December, I know this time of year can be challenging for many and I want to extend the heartfelt support and warmth of the season from all of us at Canuck Place to you and your families.

Sincerely, Kristina Boyer, Clinical Program Director



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 ṣxʷməθkʷəy̓əmaʔl təməxʷ (Musqueam), Skwxwú7mesh-ulh Temíxw (Squamish), səlilwətaʔl təməxʷ (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.



Camara van Breemen, Canuck Place Nurse Practitioner, Marysa Ho, Spencer Ho, and Lukas Domingo, Canuck Place Siblings.

Making time to create beautiful memories

Canuck Place was honoured to hear from siblings Spencer and Marysa Ho and Lukas Domingo at the 2024 Gift of Time Gala.

They shared the poignant story of their siblings, Mitchell Ho and Kristian Domingo, who both received end-of-life care at Canuck Place. Mitchell and Kristian were childhood best friends, and the Ho and Domingo families are longtime family friends. Mitchell passed away at 11 years old after a cardiac event, while Kristian succumbed to cancer nine years later at the age of 20. Both families found the support they needed, thanks to the dedicated care provided by Canuck Place physicians, nurses, and counsellors.

Marysa emphasized the profound impact Canuck Place has had on her life, serving as a source of comfort and stability during times of loss and beyond. "I was eight years old when we were introduced to Canuck Place and Mitchell passed,"

she said. "I was 16 when Kristian passed, and I started volunteering at the hospice. At 24, I began working at Canuck Place as a Care Aide while studying to become an RN. Amidst all the ups and downs that come with growing up, Canuck Place has been a constant for me throughout all that change. The consistency of their services, team, and mission provides a lot of support for me."

Lukas spoke about the importance of family bonds and finding strength in hope. "It was with strength and hope that my parents made the choice to have Kristian be kept in the exceptional care of Canuck Place," he explained. "I was frustrated and felt hopeless, but the clinical care team made Kristian's last few moments special."

The siblings highlighted the impact of community and how Canuck Place offered support and guidance during the most challenging times. "Will, one of the Care Aides at the house, began to come out and chat with me," Spencer shared. "He asked me about basketball, girls, and school. Really, he just made me feel like a normal kid again."

The story of Mitchell and Kristian, and the enduring bond between their families, underscores the vital role Canuck Place plays in providing compassionate care and support. The hospice not only helps families navigate the difficult journey of end-of-life care but also offers a sense of community and continuity that extends beyond the immediate crisis. The siblings experience highlights the lasting impact of Canuck Place's mission and the importance of such support systems in helping families cope with loss and find solace in shared memories.



Coastal City Ballet perform a beautiful dance at the Gift of Time gala, a collaboration and Capstone project by Canuck Place sibling, Jillian Funnell.

Canuck Place sibling celebrates brother through dance

Canuck Place sibling Jillian Funnell lost her brother Ian in December of 2021 when the family was in-hospice at Canuck Place Vancouver. Through her experience with Canuck Place she has been a strong advocate for the need for sibling support and recognizing the unique experiences of siblings during illness, end-of-life and bereavement.

From the first time Canuck Place meets a family, clinicians ask about the siblings and get an understanding of their brother or sister's illness and we learn from the family what they need to guide and coach them. This includes providing education about children's understanding of death and through development, how to make connection with their seriously-ill sibling and how to create memories and legacy - regardless of their age - that needs to last a lifetime. It also means, remembering together the unique love that the sibling holds with their brother or sister.

For Jillian, creating legacy and meaning was important. As part of her BC high school Capstone project, she identified that having her dance company perform at Canuck Place's Gift of Time gala was important to her. Jillian has done ballet with Pacific Dance Arts since 2011. Attached to the school is also a pre-

professional ballet company called Coastal City Ballet. Jillian selected the performance collaborating with the production and dance company. The beautiful performance by Coastal City Ballet started the gala and guests were captivated by her capstone project.

Additionally, Jillian volunteered at the event and helped coordinate the silent auction area. "Incorporating Jillian's beautiful performance really augmented the Gift of Time gala presentation," said Courtenay Cardinal, Director of Events & Sponsorship for Canuck Place. "I am so grateful for her sharing her sibling experience in her own way with our guests."



Gift of Time gala audience captivated by the stunning performance.

Finding healing in grief



As a parent, you have hopes and dreams for your child—that they'll be happy, healthy, and celebrate life's milestones. You don't plan for your child to receive a cancer diagnosis before their second birthday.

At just 14 months old, Tristan Rempel was diagnosed with ependymoma brain cancer after his brain tumor erupted. While he made a miraculous recovery, his cancer came back when he was three years old, and his parents, Jenn and Matt, received the agonizing news that their son's cancer was terminal.

It was at this time that the Rempel family was introduced to Canuck Place.

After their initial meeting with Canuck Place clinicians, the Rempels immediately felt a sense of relief in identifying their care goals for Tristan and how they could work with Canuck Place to achieve them.

"Canuck Place nurses supported our desire to stay at home, outside

of William's Lake, for as long as possible and the team was available to us by phone, email, and video chat whenever we needed them," says Jenn. Canuck Place nurses also arranged to have in-home care nurses visit the Rempel family several times a week, to manage Tristan's medical appointments, organize his medications and show Jenn how to administer them.

In addition to care coordination for Tristan, the Rempels also received Canuck Place counselling support, helping them navigate their complex feelings of grief. Like many families, their grief began from the moment Tristan was diagnosed—anxious about what the future held.

"For me, the question became how do I process my grief while Tristan is still alive without letting that steal what I have with him in the present," says Jenn.

Matt and Jenn found an unexpected beauty in their grief. It allowed them to be intentional with the time they had left. "Knowing

that time is something you will never get back, presented us with the opportunity to spend quality time together as a family," Jenn explains. "Together, we poured a lifetime of memories into two years and made the most of every minute that we had with Tristan."

The entire Rempel family would travel from their small town near Williams Lake to Canuck Place for medical respite care, giving Matt and Jenn some much needed rest and renewal, while their other children could enjoy various activities together with the recreation therapy team. Counselling support while they were at the hospice allowed each member of the Rempel family to navigate the complex journey of grief.

At Canuck Place, hope and heartbreak are intertwined. And if you love deeply, you grieve deeply.

"I did a lot of grieving before Tristan died," Jenn shares. "And when he did die, I saw that as a continuation of what was already happening. I was able to find healing in grief and learned that grief goes hand-in-hand with heartache, but there is also a lot of peace in it as well."

Tristan, and all the children at Canuck Place, leave a legacy behind—one of love, light, and hope.

Strength in Hope Golf Tournament

It was an amazing day on the course for the players, volunteers and generous sponsors who supported the Strength in Hope Golf Tournament. They smashed their goals, raising a record amount – over \$115,000!

And the best part? A portion of these funds support care at Canuck Place Children's Hospice.



Teresa Domingo, Canuck Place Mom, with golf tournament participant.

Canuck Place child, Wesley, gives a "big cheque" to Canuck Place for his birthday



Wesley Hodson and his family with the big cheque!

Canuck Place has been a home away from home for Wesley and his family. This year he celebrated his 11th birthday in a truly special way, by running a fundraiser for Canuck Place! Wesley's family was introduced to Canuck Place when he was diagnosed with a rare genetic disorder called Smith McGinnis Syndrome, which affects a child's behaviour, emotions, and learning processes.

Wesley loves the TV show, The Office, so he was excited to have his own "Michael Scott Cheque Moment" when he and his family proudly presented a cheque for over \$2,400 to the Canuck Place team that loves and cares for them.

"Wesley absolutely loves Canuck Place. He loves hanging out with the nurses and going on the bus for outings with Recreation Therapy," says his mom, Karyn.

Friends and family honour Canuck Place teen

The Markus Schouten Memorial Roller Hockey Fundraiser continues to honour his legacy in a meaningful way, raising an impressive \$107,694 for Canuck Place over the past two years. Markus passed away at Canuck Place in 2022 and every summer since, his friends and family come together to celebrate his life and his love for Hockey. Special thanks to Mike and Jennifer, and the entire Schouten family, for their unwavering support in organizing this event.

Special thanks to Markus' buddies, Carson, Marcus, Eric, Levi, James and Lincoln who are guided by their



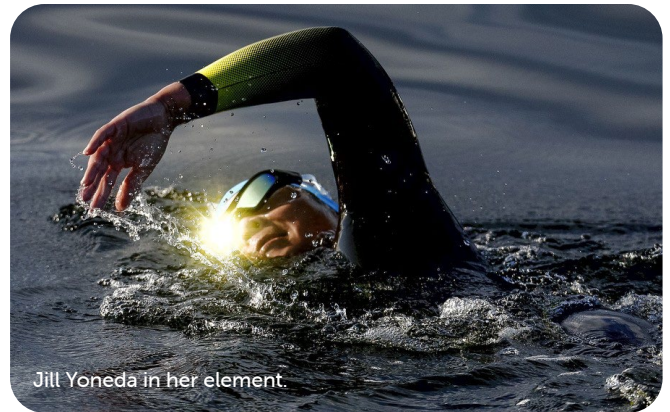
Markus Schouten's friends and family celebrate his life and love for hockey.

friend's sage words: "Go get a new set of roller blades to play hockey on, so you have something to do in the summer other than watch your screens." Through their energy, they celebrate Markus' passion for hockey and community spirit.

Jill Yoneda made waves of impact for Canuck Place

This summer competitive swimmer, Jill Yoneda, made waves for Canuck Place with her extraordinary swim across the Georgia Strait. Jill started out in Victoria, braving 15 hours in the water on a route that had never been attempted before and swimming an incredible 40km non-stop. She inspired over 400 donors to raise \$66,032, which was generously matched by the Canucks For Kids Fund for a total of \$132,064.

This was Jill's 3rd swim for Canuck Place, and a tribute to her late cousin, Joshua, who passed away after he was diagnosed with cancer of the spinal cord. We are incredibly grateful to Jill, her crew, her supporters and the Canuck Place community. Her legacy of courage continues to inspire us all!



Jill Yoneda in her element.



Jill Yoneda (in Canucks jersey) celebrates at Canuck Place - Vancouver with supporters and the Canucks for Kids Fund.

18th Annual Ride for the Kids raises over \$17,000

For the past 18 years, Canucks alumni Jeff Bandura and his cycling team have channelled their passion into making a difference for children and families, raising over \$800,000 for Canuck Place care. Their Ride for Kids fundraiser is always a highlight of our summer! With flashing lights from police escorts, their most recent ride arrived at Dave Lede House with Jeff, his team and our favourite mascot, Fin

bringing smiles to children, staff, and families. Ride for Kids is a testament to the incredible strength of the Canuck Place community and the impact of individuals who give so selflessly. This year alone they raised over \$17,000 for Canuck Place care. Thank you to Jeff Bandura, his cycling team, and the generous sponsors for your unwavering compassion and ongoing support for Canuck Place families.



Canucks Alumni and Ride for Kids founder, Jeff Bandura, with his cycling support team on their stop at Canuck Place Abbotsford - Dave Lede House.



Mireille Larosa, Canuck Place Mom and Canuck Place Connectors lead, training for her cycling tour in Switzerland.



Tour de Canuck Place

Canuck Place mom and Canuck Place Connectors Lead, Mireille Larosa, will be cycling across BC in September 2025 to raise funds for Canuck Place.

Mireille's son baby Charles was diagnosed at seven months old with Alpers Syndrome, a rare and incurable mitochondrial disorder. The family received medical respite and end-of-life care in the Vancouver hospice, and in-home care in North Vancouver.

"The terminal diagnosis of our sweet baby Charles shattered me to my core. Canuck Place counsellors helped me navigate my new reality, guide me, ground me, and by extension my family, as our world fell apart," says Mireille.

Mireille took up cycling just one year ago, spending a bit of time in the Swiss Alps last summer training for her Tour de Canuck Place. September 2025 is when she is kicking off her cycling tour of BC to raise funds and showcase the province-wide exceptional care Canuck Place provides.

She would also like to visit Canuck Place families along the route!

If you are interested in meeting Mireille – please reach out to our family engagement advisors Dana Warburton and Sarah Rodrigues at familyexperience@canuckplace.org and let us know!

If you are concerned about your town being on the route, please also connect with us. Mireille is committed to finalizing a cycling route that is both supportive and inclusive for Canuck Place families.

Here is the list of BC cities she's visiting!

Abbotsford
 Agassiz Armstrong Balfour
 Barrowtown Blind Bay Burnaby Burns Lake
 Castlegar Cedarvale Central Saanich
 Chase Chilliwack Cold Stream Comox
 Coquitlam Courtenay Cranbrook
 Creston Delta Dewdney Duncan
 Enderby Fort Fraser Fraser Lake
 Ganges Gibsons Grand Forks
 Greendale Greenwood Halfmoon Bay
 Harrison Mills Hazelton Kamloops
 Kelowna Kimberley Kitwanga Ladysmith
 Lake Country Lang Bay Langford Langley
 Maple Ridge Merritt Midway Mission
 Nanaimo Nanoose Bay Nelson
 New Westminster North Cowichan
 North Vancouver Okanagan Falls
 Oliver Osoyoos Parksville Peachland
 Penticton Pitt Meadows Port Coquitlam
 Port Moody Powell River Prince George
 Prince Rupert Pritchard Qualicum Beach
 Roberts Creek Rock Creek Saanich Salmo
 Salmon Arm Saltair Sechelt Shawnigan Lake
 Sidney Smithers Summerland Surrey Terrace
 Topley Trail Tsawwassen Vancouver Vanderhoof
 Vernon Victoria West Kelowna
 West Vancouver White Rock Witset

Abbotsford Canucks Bring Halloween Magic to Canuck Place with Pumpkin Carving

In the lead-up to Halloween festivities, the Abbotsford Canucks came by Canuck Place Abbotsford – Dave Lede House for a fun afternoon of pumpkin carving. They shared their time with children and families in the hospice and brought smiles and laughter!

There were messy hands, creative pumpkin designs, and a special spooky song from Michaela Wallis, Canuck Place music therapist. The team spirit and joy created by Canuck Place Recreation Therapy and these young athletes was a special fall magic affair. Thanks to the Abbotsford Canucks for creating special memories with kids and families.



Abbotsford Canucks players carving pumpkins with Canuck Place kids.



Statistics Canada Project: Survey

Canuck Place, in support of Statistics Canada's Living with a Life-Limiting Illness – Access to Care and Related Experiences (LLLI-ACRE) project, would like to invite families to share their thoughts!

We encourage you to participate in Statistics Canada's latest survey, which focuses on the experiences of individuals living with a life-limiting illness and the caregivers who support them.

Statistics Canada recognizes the importance of collaboration between patients, clients, and their caregivers in reaching those who may not otherwise be aware of this study on palliative care. By sharing this study, we hope to encourage family participation, ensuring the information is as accurate and comprehensive as possible.

The data you provide will help healthcare organizations and providers improve the development, planning, and delivery of high-quality care for those living with a life-limiting illness and their unpaid caregivers in Canada.

The goals of this study are to:

- Understand the lived experiences of those living with life-limiting illnesses as well as their caregivers, including access to care and support services.
- Providing insights into the care experiences of Canadians living with life-limiting illnesses, helping to shape better care practices.
- Identify barriers to receiving palliative care and highlight any gaps that need to be addressed to improve services.
- Help healthcare organizations and providers understand how well our healthcare systems are meeting, or are not, meeting, the unique physical, psychological, social and spiritual needs of Canadians with serious illnesses.

All information collected by Statistics Canada as part of the LLLI-ACRE will be protected under the Statistics Act.



Atticus Braun, Canuck Place child with Tara McCarthy, Canuck Place Nurse.



Share your thoughts!



Wesley, Canuck Place Child

Canada's Pediatric Palliative Care Alliance: Survey

Here's your chance to have your say! Canada's Pediatric Palliative Care Alliance is a Health Canada funded project aimed at improving equitable access to high quality pediatric palliative care for all Canadian children and families in their locations of choice.

They are gathering insights on the current state, needs, and strengths of pediatric palliative care in Canada through a Provider Survey, and a People with Lived Experience Survey. There are two surveys:



Service Provider Survey



People with Lived Experience Survey



Merry Melodies Holiday Zoom Party

We are excited to extend a warm invitation to you and your loved ones to join Canuck Place Music Therapist, Michaela Wallis, for an afternoon of holiday music and cheer! Our goal for this session is to provide a space where you can connect with other Canuck Place families and make holiday memories.

We encourage families to bring their own instruments and share your favourite holiday songs with Michaela ahead of the session. Festive attire welcome!

Sign up here!



Details

Date: December 20

Time: 3–3:45 p.m.

Location: Zoom

Summer in the City

Our Recreation therapy team focuses on enhancing quality of life through leisure activities and hobbies to create moments of joy, connection, and fun for the whole family. Canuck Place recreation therapy programs are designed to include and support every family member, creating moments of joy and connection for everyone.

Summer in the City was created by Canuck Place Recreation Therapy team as a way for children and families to be tourists in their own backyards. This summer, our kids and families joined hundreds of fans to cheer on the Vancouver Canadians baseball team, set sail on a swashbuckling pirate adventure and experienced the wonder of being pirates with Pirate Adventures Vancouver, and joined the Vernon Firefighters for a fun dinner and a fire hall experience.



Mary Coleman, Canuck Place counsellor with Soskay, Canuck Place Child.



Canucks Alumni, Stan Smyl, bringing the fun to pumpkin carving!



Canuck Place children and families visit the Vernon Fire Department for Summer in the City.

Vancouver Canucks at Canuck Place

Creating memories and smiles is what it's all about! This Halloween, Canucks alumni Stan Smyl, Kirk McLean, Darcy Rota, Canucks wives, and Canucks mascot Fin, dressed as Finpool visited to carve pumpkins with families in house.

A big thank you to all of our wonderful visitors who brought smiles, laughter, and creativity to the Vancouver hospice for a magical and fun afternoon. We're so grateful for your time, your team spirit, and the joy you shared with all of us!



Canucks Alumni Stan Smyl, Darcy Rota and Kirk McLean join "Finpool" and Canucks wives Lina Laukkanen and Natalie Miller for pumpkin carving.



Kathryn Wozny, Director Family Support Services and the Premias, Canuck Place Family.

Monthly Family Connection Sessions

Are you a family member or caregiver with a child on program at Canuck Place and are seeking support and connection?

Our Patient & Family Engagement Advisors, Sara and Dana, would like to extend an invite to our Monthly Family Connection Zoom Drop-In Sessions! These sessions will provide a safe space where families can come together to support each other, share stories, and find comfort in knowing they are not alone. This space will not provide medical advice nor is this a counselling session, rather a place for Canuck Place families to come together, connect, and provide peer support.

Our Family Connection Zoom Sessions are characterized by compassion, empathy, and solidarity as we navigate the challenges and triumphs together. We recognize that loneliness and isolation are common themes for parents who have children with complex health issues, as is grieving throughout different complexities of life. Our Family Engagement advisors also recognize the importance of creating safe spaces for families with children with medical complexity. They will ensure that these sessions are a confidential space to share for all participants.

Why peer support?

To walk beside patients and their families throughout their Canuck Place journey. Peer support sessions do not help direct anyone's path—but rather provide opportunities for listening,

validating experiences, and sharing parts of our own journeys as a group. During these sessions, peers can share coping strategies, information and resources, offer non-judgmental support.

Session Details:

Date: The last Friday of every month

Time: 11 a.m.–12:30 p.m.

Location: These sessions will take place via Zoom*

* Please note that given these sessions take place virtually, and a computer and internet connection will be required for participation. If you require any accommodations or additional supports, please reach out to our Family Engagement Advisors.

Join us!

If you are interested in receiving more information or joining our next upcoming Family Connection Zoom Drop-In Session email our Family Engagement Advisors, Sara and Dana at:

familyexperience@canuckplace.org



Welcome Recreational Therapy Assistant, Simran Bains!

Our new Recreational Therapy Assistant, Simran Bains, who will be working at both Glen Brae and Dave Lede House.

Preferred name/pronouns: Simran (she/her)

Favourite Food: Carbonara or an Indian dish called Chole Bhatura (chickpeas with fried bread).

Hobbies/what you like to do outside of work: I love baking and cooking, watching movies, reading novels, going on walks with my dog and family, trying new restaurants.

Where you worked previously/a brief overview of your professional experience

and qualifications: I have been working as a child and youth worker for almost 10 years; I completed my child and youth care degree from Douglas College in 2021. I've worked in many settings including a community non-profit in Surrey called Options Community Services, a group home, after-school programs, and most recently in the Surrey and Delta school districts. Most of my experience is working with children and youth who struggle with mental health and behavioural concerns as well as with neurodivergent children and youth. I've always worked in alternative settings such as learning centers and programs working with children and youth with complex needs in the school districts.

Any additional comments/messages you'd like to share with the team: I'm very excited to start in this role of Rec Therapy Assistant at Canuck Place and looking forward to meeting everyone!



Welcome Clinical Communications Officer, Jasmine Huber!

The Communications & Marketing team is excited to introduce our new Clinical Communications Officer, Jasmine Huber.

Preferred name/pronouns: Jasmine (she/her)

Favourite Food: Cinnamon buns and dim sum

Hobbies/what you like to do outside of work: Hiking, reading, crochet, pottery, yoga, skiing, binge reality tv

Where you worked previously/a brief overview of your professional experience

and qualifications: I have previously worked with international organizations such as the World Health Organization, PATH, Johns Hopkins International Vaccine Access Center, and the UN focused on communications, stakeholder engagement, business development, project management, and advocacy to drive global health projects forward. Outside of my professional life, I've traveled to 65 countries and have lived in 6 different countries beyond my home in Canada. I have my Master's of Science Degree in global health from Trinity College in Dublin and a Bachelors of Arts Degree in health studies from McMaster University, as well as various certifications in strategic communications, digital marketing, project management, and social behavior change.

Any additional comments/messages you'd like to share with the team: I am very excited to contribute to the impactful work of Canuck Place Children's Hospice is doing and to collaborate with all of you!

Working with our Health Care Partners

We continue to work with our provincial partners (BC Children's Hospital, Child Health BC, Perinatal Services BC, and Children's and Women's Indigenous Health), the Ministry of Health as well as children and families towards a provincial approach to Pediatric Advance Care Planning for the province of BC.

In the spring, we updated our pediatric medical orders for scope of treatment (pMOST) form through a provincial working group, engagements with FAC and various other partners across BC. We are currently using the new pMOST form at Canuck Place with the plan for it to become an official provincial Ministry of Health form in late 2025.

Next steps include drafting a provincial guidance

document for clinicians and education to support how we have these important conversations with children and families about what matters most to them across the province. We will be seeking family and youth partners to support development of this guideline and education. If you are interested, check out the engagement opportunity posting in December on canuckplace.org.

To learn more about Pediatric Advance Care Planning, visit our website: canuckplace.org



Family Onboarding Quality Improvement Project

The Family Onboarding Quality Improvement Project is officially live! In October, we piloted our very first Onboarding Family Team Meeting for new families to Canuck Place who are referred from their community providers. This is a time for families to meet with our team after acceptance to Canuck Place, and is a starting point to enhance our initial engagement and ongoing connection with families.



Natasha Zacher, Canuck Place Counsellor, with the Hernandez family.

Based on invaluable feedback and guidance from Canuck Place family partners and the Family Advisory Council, we are aiming to improve information exchange and accessibility of services by understanding family needs.

Canuck Place Website Family Services & Engagement Pages

Visit the canuckplace.org website, where you will find:

- A dedicated section for **family services**
- A **resource area** with family teaching documents to support caring for children at home
- A **family engagement area** detailing our commitment to collaboration and feedback
- **Engagement opportunities** for families to get involved in care share their story to support fundraising campaigns, or join the FAC



Canuck Place Research Initiative: Family Faculty Researchers



Candice Barrens, Parent Partner

Candice is a parent partner with the Siden Lab at the Canuck Place Research Initiative. In this role, she helps produce a monthly publication called Trends in Pediatric Palliative Care Research (TPPCR). This involves gathering and organizing a list of the most important recent studies in pediatric palliative care and working with a community expert to write a commentary that adds personal insights and reflections on the research. .

Candice also plays an important role in our quarterly Parent Journal Club. This is a space for parents of children with complex medical needs to come together and discuss research that is relevant to their experiences in an informal and personal setting. Candice is currently working on a scoping review that looks at how parents and patients are acknowledged for their contribution to health care research.



Laesa Kim, Family Liaison

Patient-oriented research strategies have become an intentional part of all our projects at Canuck Place. Families have always played a vital role in shaping our research – whether by suggesting research ideas, raising questions based on their experiences, or helping us evaluate research designs and tools through parent advisory panels. We also make sure to gather feedback from study participants and use them to improve our research processes.

Taking the lead from CIHR's launch of the initiative Strategy for Patient Oriented Research (SPOR), we have built a more structured approach to patient engagement. One important step has been creating the role of Family Liaison, which is held by Laesa Kim. Laesa engages families across the country in our research and applies the lens of lived experience to all of our projects. Her work has helped us improve recruitment, create more accessible resources, and deepen our understanding of the issues families face. Laesa has also led a now published story on what motivates parents to participate in research and is a co-investigator on our study about pain and irritability of unknown origin (PIUO).

The contributions of family partners are invaluable in making sure our research better reflects the needs and experiences of families. There are many opportunities for you to apply your lived experience to support better care, set research priorities in pediatric palliative care, and design studies to optimize care for families.

If you are interested in learning more, contact Laesa at Laesa.Kim@bcchr.ca