



## Message from FAC Chair

Happy New Year to my dear Canuck Place families!

I don't know about everyone else but there was a certain melancholy I felt coming into the new year this year. Not all years are met with the same kind of anticipation as others and it really made me think about our community and how we all hold suffering and joy together. I feel really privileged to be part of a community that walks down dark roads together. We light up and lift up one another!

This past season on the Family Advisory Council has felt very full, as we interviewed and welcomed four new members to our council, including Pooja Dixit, Marion Fernandez, and Chris and Hollie Hall! You may recall Chris and Hollie from this year's Light a Life campaign. We are so happy to fill our council with more parents and are looking forward to another great year supporting Canuck Place and one another.

Please take good care of yourselves,

**Angela Uncles, FAC Chair**

## MESSAGE FROM THE BOARD

## Barbra Mohan Family Representative

Hello families,

For a little over a year now, I have been serving as the Family Advisory Committee (FAC) Liaison to the Board, after having been an FAC member from 2015-2021. Since reconvening in September, the Board has reviewed and given input on Canuck Place's strategic priorities, learned about the new CPCH Research Initiative, and had an opportunity to receive updates on operational priorities like succession planning and moving towards better electronic health records. At each meeting, I also update the Board on the activities and discussions of the FAC. As the liaison, my role is to help keep the experience of families at the forefront of Board

decision making and it's been inspiring to see how committed this group of people is, to the care of children with life-threatening illnesses.

When our son Jasper received end of life care in 2013, I had no idea that the strength and compassion of this organization extends from the front-end staff and volunteers right through to the Board of Directors. 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, FAC Liaison**





Dear Families,

I am thrilled to welcome you to our winter 2023 family newsletter. We are thinking of all our families, and where they are in Canuck Place care.

Your journeys inspire the clinical care at Canuck Place. In 2022, our families attended amazing events including, the Summer BBQ, Winter Family Festival, and Summer in the City, and our annual Light a Life fundraiser featured the Hall family, who shared their bright light, Lily.

Our team has launched the Research Initiative, Family Coalition, prepared for ChildKind Accreditation and we've hired two new staff positions in Patient and Family Engagement Advisors, we're grateful for your perspective as we continue to provide complex care to children and families.

Sincerely,  
Denise Praill, CEO, Canuck Place

**The BMO Vancouver Marathon is on May 7, and Canuck Place child Charlie-Anne Cox is once again rolling 21km in the race with team "Charlie's Angels" to raise funds for Canuck Place alongside her mom, step-dad, Canuck Place parent Aubrey Dalima, 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. She and her family have set out to reach a fundraising goal of 20k and are nearly half way there!

Canuck Place mom, Aubrey Dalima has also joined their team and is challenging 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.

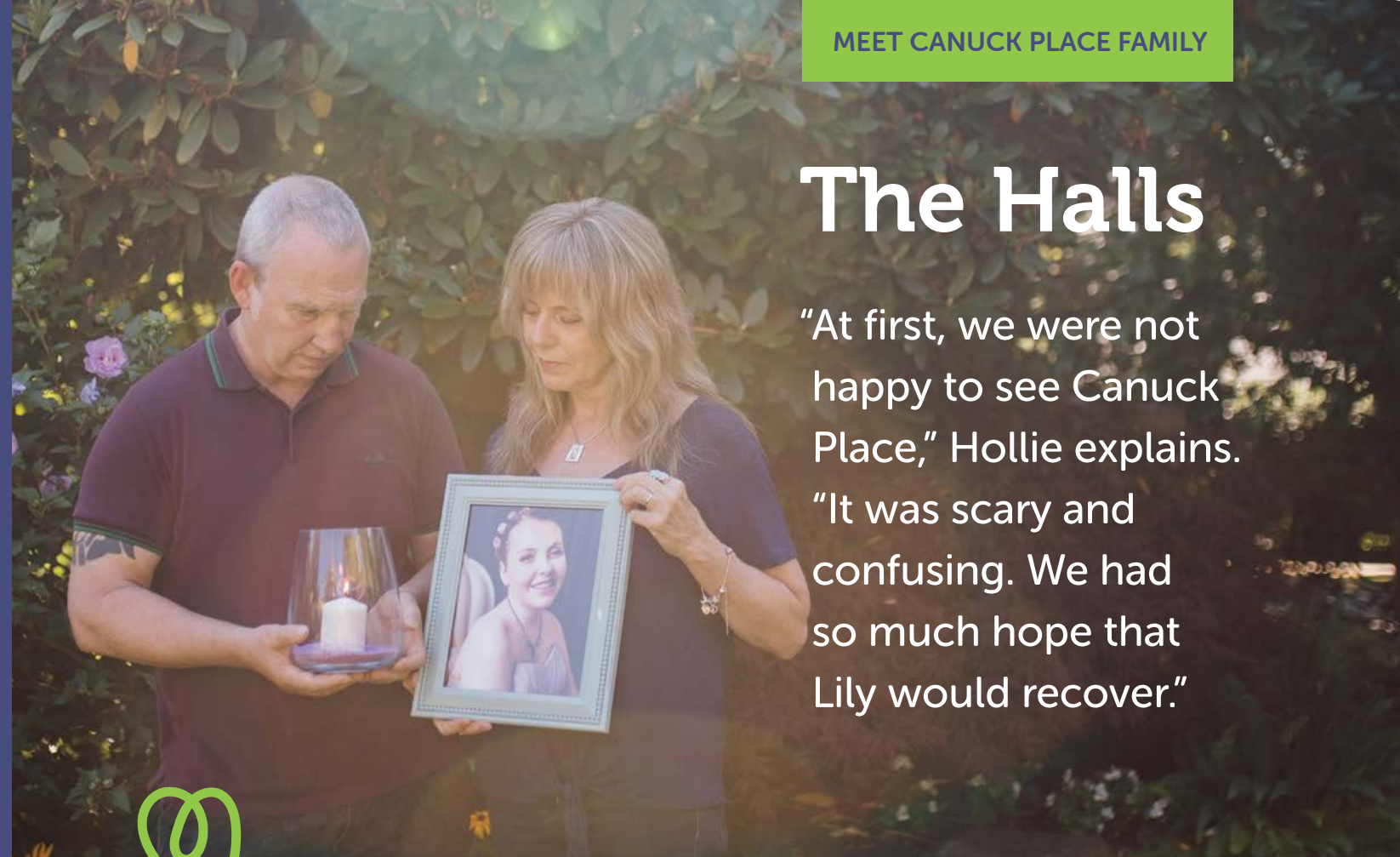
**If you'd like to get involved and join their team, scan or [click here!](#)**



Aubrey, Lauren (in frame), Charlie-Anne, Izzy the wonder dog, Cherie, and Drew planning for the big race!

# The Halls

**"At first, we were not happy to see Canuck Place," Hollie explains. "It was scary and confusing. We had so much hope that Lily would recover."**



Canuck Place parents, Chris and Hollie Hall, holding a framed photo of their daughter, Lily

**When the Hall family reflects back on their journey with Canuck Place, they remember how they were nurtured at a time when they needed it most.**

Chris and Hollie Hall's youngest daughter Lily was diagnosed with a rare, malignant brain tumour when she was 13 years old. After many years of treatment, the Hall family found their way into Canuck Place care in 2017, when Lily was 16 years old.

"At first, we were not happy to see Canuck Place," Hollie explains. "It was scary and confusing. We had so much hope that Lily would recover."

Canuck Place clinicians walked alongside the Hall family from the start of Lily's diagnosis while they utilized many of Canuck Place's family support services, including medical respite care, giving them much-needed rest and renewal.

Canuck Place continues to play a big role in the Hall's life. They meet with Canuck Place counsellor Andrea for grief counselling, attend bereavement group, sit on the Canuck Place Family Advisory Council, and remember Lily with love and compassion.

"Lily was exceptionally kind and caring," Chris reflects. "She was a beautiful girl, interested in people's stories and was never afraid to compliment people she saw on the street, in the elevator, or anywhere she went."

To this day, Canuck Place staff remember Lily fondly, reflecting on her energy, her smile, and her genuine interest in their lives.

Hollie describes Canuck Place as a sanctuary that nurtures the entire family, and continues to do so years after Lily's passing.



# The Angels

**In our modern day world, time is a luxury, and Canuck Place families, like the Angels, understand the value of precious moments.**

Alejandro Angel, lovingly known as Alejo, had a full head of dark, thick hair. His parents, Erin and Federico, described him as an old soul in a little body. Alejo was the first grandchild on both sides of the family, and he was deeply loved and cherished. At just two weeks old, Alejo was diagnosed with a rare cancer presenting as a soft tissue malignant tumour.

The trajectory of Alejo's cancer was rapid. His life expectancy went from one year to a couple of weeks with one devastating X-ray result. This was when Erin and Federico were introduced to Canuck Place.

"Canuck Place nurse practitioner Rachel was present at BC Children's Hospital when we were given the diagnosis that our son had an incurable cancer that was in every cell of his body," Erin says. "We didn't know at that point how important Canuck Place was going to be to us."

At this stage in Alejo's diagnosis,

Erin and Federico were given the option to move into the Vancouver hospice, providing an opportunity for rest, for renewal and to spend precious time together. The COVID-19 pandemic was in full swing, and Erin and Federico knew visits from extended family would be challenging. They decided to stay home with Alejo, where they could be surrounded by friends and family.

Canuck Place was there with loving care, meeting the Angels when and where they needed it. They were able to make precious memories together at home, while caring for Alejo, thanks to the Enhanced Community Care Program.

Canuck Place nurse practitioner Rachel and clinical nurse specialist Nadine ensured the Angels were well cared for at home by providing equipment and medications to keep Alejo comfortable, and the guidance they needed to navigate the final weeks of his life. But most of all, Canuck Place allowed the Angels to feel supported and validated with every decision they made.

We were tossed into the darkest place possible, and Canuck Place surrounded us like a

warm blanket that lifted us up and helped guide us through the storm," says Federico.

"We chose to be at home so we could maximize Alejo's life through what we felt was important — full access to our family and the opportunity to go on outings."

The Angel family also utilized the 24-Hour Clinical Care Line. "The call line gave us peace of mind that we had a lifeline. Someone to reach out to with any question or concern — without feeling bothersome," explains Federico.

The final time the Angel family called the 24-Hour-Clinical Care Line was the day Alejo passed away, just five short weeks after he came into the world. Alejo was wrapped in his parent's arms and surrounded by love. His grandparents, aunts, uncles and godparents came to be by their side. This was possible because of their in-home care.

The Angel family are also supported by Canuck Place through grief and bereavement counselling services. Canuck Place counsellor Mary Coleman is an integral part of Erin and Federico's healing journey, providing a space for them to



Quinn and Angel families

heal as well as their family.

"We were blessed to be paired with our counsellor Mary after Alejo's passing," Erin says. "We were lost in a storm, and she taught us how to navigate the waves."

A child's care plan is completely individualized at Canuck Place, and incorporates the family's wishes and goals. For the Angel family, being at home allowed them to be in a place where they felt comfortable, and a familiar place where they could surround Alejo with love and affection.

"Unlike hospitals, Canuck Place isn't about your child's diagnosis or illness," Erin explains.

"It's about giving you the ability to be present with your child and family. Canuck Place floats

in and makes the impossible seem effortless and removes certain stressors so you can be a family and focus on building memories together."

Erin and Federico lovingly share that Alejo gave them the greatest gift. He made them parents. Bringing depth and richness into their lives. His short life is remembered fondly, and is memorialized through memory making mementos with the recreation therapy team. The small silver pendants that have Alejo's tiny footprint are adoringly worn by each of his grandmothers.

For families whose time is short, Canuck Place allows them to focus on the quality of the time, rather than the quantity.

Erin and Federico gracefully



Alejo's grandmothers wearing silver pendants with Alejo's footprints on them

shared their story at the Gift of Time gala, presented by Nicola Wealth, which raised over \$1.7M to support complex care at Canuck Place.





Jamey and Nick Fraser, Canuck Place family 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 all 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 6:00 pm 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 Emer Kiniry, [emer.kiniry@canuckplace.org](mailto:emer.kiniry@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.

The Family Advisory Council (FAC) is a conduit for communication between families and the staff, administration and the Board of Directors of Canuck Place Children's Hospice. 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**

# Canuck Place Families Sharing Stories Across Canada

FAC member Kerena Letcher and Barbra Mohan Canuck Place board member joined a national panel for National Children's Pediatric Palliative Care Day

The national panel was hosted by the Canadian Hospice Palliative Care Association and the Canadian Network Of Palliative Care For Children. Panelists and Canuck Place mothers, Barbra Mohan and Kerena Letcher highlighted the care both families receive(d) from Canuck Place. If you were unable to tune in live, please see the recorded version should you wish to watch it.

Scan here or click here:



Barbra Mohan



Kerena Letcher



The Letcher family

# Tribute to CFKF

For over 28 years, our committed friends at the Vancouver Canucks and Canucks for Kids Fund (CFKF) have provided vital grants and shared their incredible name, "Canuck". Annually, over 4% of Canuck Place funding is granted by the CFKF. In addition to the incredible magical moments made possible for children and families by Vancouver Canucks staff, ownership, players, mascot Fin and treasured alumni, we are inspired by their heart, commitment and generosity. Always in our hearts — Go Canucks Go!



## Canuck Place Serious Illness Conversation Guide – Pediatrics®

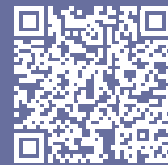
At Canuck Place, we provide a patient and family-centred approach to care to understand a family's goals, wishes and values. Canuck Place has adapted the Serious Illness Conversation Guide - Pediatrics® (SICG-Peds®), which provides a systematic approach to having conversations about children with serious illnesses, adapted from Ariadne Labs. This guide supports pediatric clinicians in having sensitive and challenging discussions with families throughout their healthcare encounters. Additionally, Canuck Place clinical staff have championed education and training workshops to guide other pediatric clinicians to improve communication skills and base decision-making on patient and family experiences.

Last year, a family engagement component to the SICG-Peds® training was initiated with the addition of the Family Partner Faculty role participating in the role-play training sessions. This role has provided an opportunity to deepen the learning experience and knowledge for pediatric clinicians and support a participatory approach to offer families meaningful engagement and share their experiences to inform and bring new insights through their perspectives.

The family faculty participants have shared how important this opportunity and work has been for them and expressed feeling empowered. "I felt very valued, which enhanced the experience. I was struck with how it's such a unique opportunity to provide feedback for learners when they assume the role of a parent or clinician and make assumptions or have revelations while doing the training. I felt keenly aware... of how my presence was impacting the learners." Family Partner Faculty SICG-Peds® Evaluation.



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



## New Look New Website Family Pages

From December 2021 to September 2022, Canuck Place executed an overhaul of the canuckplace.org website to better serve the our key's audiences (families, donors, clinicians), to address risk and security issues of an aging site, to streamline the user journey and improve user experience; and to update the look and feel.

We worked collaboratively with the clinical team and family partners to evaluate and address organizational goals. A few key goals identified in the process, was to have a clearly identified, dedicated section on the site to find information on family services, a resource area with family teaching documents to support caring for children at home, and a family engagement area detailing our commitment to collaboration and feedback as well as 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 Lisa Pratt, Associate Director, Marketing & Communications: [lisa.pratt@canuckplace.org](mailto:lisa.pratt@canuckplace.org).**



## MEET CANUCK PLACE FAMILY

# The Ngs



The Ngs remembering Matthew during Lunar New Year.

Lunar New Year is a time of joyful celebration – a time that brings luck and prosperity. And for families like the Ngs, it's a time to make precious memories.

Canuck Place parents Maggie and Stewart were first introduced to Canuck Place in January 2020, when their son Matthew was diagnosed with Trisomy 18, an incurable genetic disorder.

Matthew stayed in the hospice for medical respite, where his parents and four sisters could spend quality time together.

During their stay, the Ng family spent time in one of Canuck Place's family suites, cuddling Matthew and making lasting memories. To support the Ng family journey, the recreation therapy team created tangible items of a life lived – foot molds and necklace

pendants with Matthew's fingerprint.

"Canuck Place was a heaven-sent sanctuary where my family and I felt supported and safe to express our love for Matthew," said Maggie.

This past Lunar New Year,

the Ngs celebrated family union with delicious treats and meals, decorations, treasured traditions such as watching the lion dance, collecting red envelopes, and honouring Matthew with a birthday celebration.



Stella, Jessica, Andrea, and Emma Ng, Canuck Place siblings



# 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 care for children with complex, serious illnesses and palliative care. We are excited to share that the Canuck Place Board of Directors and Senior Leadership have supported dedicated funding for research to continue to grow and improve the experience and care approaches for children with serious illness and their families.

Dr. Hal Siden leads the CPCH Research Initiative as research chair, and funding supports the work of a research manager, coordinator, patient and family liaison, librarian, data analyst, and others who collaborate with Canuck Place to engage in local, national and international studies. 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.

Based on a comprehensive logic model, the work and research conducted with the research initiative funding have short and long-term goals. Canuck Place aims to elevate the organization's profile and reputation as a leader in pediatric palliative care; continue to demonstrate commitment and integrity to improve care to the public and children and families; provide leadership in the international network of pediatric palliative care research and care providers; attract healthcare clinical expertise; and increase philanthropic donations to support the care provided.

## Canuck Place is applying for **childkind**



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 is now applying independently for ChildKind International certification ([childkindinternational.org](http://childkindinternational.org)) as an organization.

Accreditors from ChildKind visited Canuck Place on January 31.

### 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.

### KEY REASONS FOR CERTIFICATION

- Canuck Place is committed to providing the best pain care possible to children on our program.
- The ChildKind certification process is an opportunity to evaluate current practices, benchmark against similar organizations, and get support in areas where we could improve from recognized experts in the field of pain management.
- Canuck Place will be the first pediatric hospice to apply for Child Kind accreditation
- By becoming a ChildKind Certified Hospice we will demonstrate our commitment as an organization and as healthcare providers to the treatment of pain and promotion of children's comfort and ease of suffering
- ChildKind International is a global initiative that works to reduce the pain and unnecessary suffering of children. Certified hospitals have developed standardized, institution-wide, collaborative approaches to the treatment of children's pain. To date, nine pediatric hospitals in the USA and two hospitals in Canada are ChildKind certified, including SickKids (Toronto) and Alberta Children's Hospital.
- BC Women's Hospital + Health Centre (BCW) Neonatal Intensive Care Unit (NICU) and Canuck Place are partners with BC Children's in the ChildKind certification process



# Welcome Our New Canuck Place Staff Members!

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 services through their experiences with service delivery.

### 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

Sara and Dana look forward to connecting with patients and families on the Canuck Place program, to work collaboratively, ensuring through engagement, their voices and perspectives are included in service planning, delivery, and evaluation.

### Dana Warburton

"I work from a lived experience lens and integrating families' experience into the care of their children is one of my passions. I also work with Foundry Central BC in creating and facilitating Family Peer support training and curriculum. I have lived experience of multiple hospitalizations of my daughter, and this informs my work in a powerful way. Supporting families is such an integral part of supporting the children they love and care for, and I look forward to continuing this work with Canuck Place."



### Sara Rodrigues

"I am a Registered Nurse and most of my background is in ER and ICU over my 13 year career, but my passion is for patient and family-centred care. I live on both sides of the bedside as my daughter was born with a rare disease. It has given me a different perspective on my own practice and my role with Canuck Place."



## Canuck Place Bereavement Care Review

Canuck Place has begun conducting a review of the current state of bereavement services at Canuck Place and across BC and the Yukon. The goal is to understand and determine our role in providing bereavement services to families grieving the death of a child under 19, that aligns with the standards in Pediatric Palliative Care (PPC). Bereavement support is

essential for grieving families, and our counselling team recognizes that the needs of families are changing, and there is a growing knowledge of evidence informed practices in PPC that need to be considered. Project lead and Canuck Place counsellor, Mary Coleman RSW, MSW, attended an FAC meeting last month to begin the process of engaging families for their input on the

project to inform next steps as they consider future services that benefit children and families.



Canuck Place is:

where memories  
are made



Canuck Place family, the Suis

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

July - Oct 2023

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](https://canuckplace.org).

The deadline to submit your interest is April 15.

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.



# Adventures at the Hospice with Canuck Place kids!



Top and bottom left: Soskay; Top right: Joseph; Bottom right: Yannick



Top left: Emiliano; Top right, Kanissa; Middle right: Arav; Bottom left: Tyler; Bottom right: Saihaan



Schools and bakeries across the Lower Mainland and Fraser Valley are fundraising for Milk & Cookies for Canuck Place.

Scan or [click here](#) to see participating locations. →



Now we have you thinking about cookies...you could make our World-Famous Chocolate Chunk Cookies!

## Chocolate Chunk Cookies

*Makes 4 dozen*

1 cup butter  
1 cup sugar  
1 cup brown sugar  
2 eggs  
2.5 cups flour  
1 tsp baking soda  
1 tsp salt  
1 tsp vanilla  
2 cups chocolate chunks or chocolate chips

1. Preheat oven to 375 F.
2. Cream together butter and sugars. Add eggs and beat well.
3. Sift together flour, baking soda, and salt. Add to butter mixture. Add vanilla and mix well. Stir in chocolate chunks or chocolate chips.
4. Drop by the spoonful onto greased cookie sheet. Bake for 10-12 minutes until golden brown. Enjoy!



## 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](http://canuckplace.org).