www.canuckplace.org

Issue No. 14

Canuck Place CHILDREN'S HOSPICE

Winter Family Newsletter



LETTER FROM THE NEW CEO

I want to take this opportunity to introduce myself and extend a warm and generous hello to all of you. I've been with Canuck Place for over eight years, leading the Development team and I'm thrilled to step into the role of Interim Chief Executive Officer. It is truly an honour and a privilege to be leading this exceptional organization.

As a community, we are still navigating a global pandemic and most recently the floods and mudslides in BC. We understand that this brings greater uncertainty in challenging times. Our hearts are with you, your loved ones, and your communities. We will continue to focus on providing exceptional care for your family, as that has always been the heart of our guiding values here at Canuck Place.

Yours truly, Denise Praill, CFRE | Interim Chief Executive Officer

CANUCK PLACE Care IN THE TIME OF COVID-19

Dear Canuck Place families,

As we move into 2022, we know that the COVID-19 pandemic continues. At Canuck Place, we continue to adapt and update our practices as needed to keep everyone safe and also continue to provide the care you need.

Current safety practices:

1) **Everyone** (children, families, staff, volunteers, visitors) **who enters the hospices** must have a health screen. For children and families, a staff member will call you at home the day before your admission and ask you a series of questions. When your child is staying in hospice, your nurse will check your child every shift for any symptoms, and if you are staying in house, or coming in to

MESSAGE FROM FAC CHAIR

- Angela, FAC Chair Seasons Greetings!

I'm so pleased to represent the Family Advisory Council (FAC) as the chair for this year and I'm thankful to the outgoing chair Alysone Martel for her years of service on the FAC.



Winter 2021

This fall has been full of opportunity for a return to some of our more regular schedules for some. Wherever your family falls on the continuum, I hope you are well.

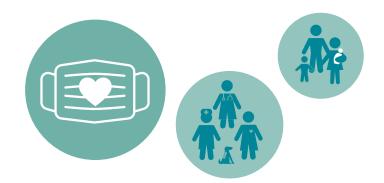
JOIN THE FAC

Becoming a member of the FAC is a great way to take part in this amazing community of parents and Canuck Place staff. If you're interested in joining us, please do send an interest inquiry to emer.kiniry@canuckplace.org

see your child, we will also ask you screening questions every day. We ask everyone with **any cold or flu-like symptoms (even mild ones) not to come to the hospice.** The symptoms we look for are as outlined by Public Health, and described on the BC COVID-19 self-assessment tool (https://bc.thrive.health/)

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2) **Masks are required.** Most everyone must wear a medical mask when in a shared or common area. We will provide the mask upon entry. Young children (under 5 years of age), 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.



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...CANUCK PLACE Care IN THE TIME OF COVID-19





3) Vaccination required for all staff, volunteers and visitors. The intake nurse will also be recording your/your child's COVID-19 vaccination status on their care plan. There is no vaccination requirement for you (parents/guardians) or your child, but knowing this information will help with our safety strategies while you are in-hospice. If you have been unable to access a COVID vaccine site, and/or have questions about the vaccine for yourself or your child please don't hesitate to discuss with a member of the care team.

4) We ask everyone in our hospices to wash their hands frequently.



5) We have reduced the number of people within the hospices: Please book a family suite if parent/caregivers and siblings would like to be present during a stay, or let the intake nurse know your plans for being in-hospice. If you would like for family members outside of your household to come to the hospice for a visit, please check with the charge nurse to arrange. Please note at our Vancouver hospice, we are not using shared rooms for children and are generally using only two of our four family suites.

With these safety practices in place, we continue to be able to provide in-hospice care to children and families with stays for respite, symptom management and end-of-life care. Recreation, music therapy and school programming is all offered on-site. A reminder that to book a stay, please reach out to the intake nurse (604-742-3476 or intake@canuckplace.org)

As well, we know that using technology to reach out to children and families in your homes can be a vital and welcome layer of support. Our 24/7 clinical care line (604-742-3475 or toll free 1- 877-882-2288) is always here for you, and other virtual health supports including counselling, consultation with a nurse, nurse practitioner or physician can be arranged. Our school and recreation therapy programs will continue to offer some online classes and activities

We acknowledge these are challenging times and want you to know we are here for you. Please don't hesitate to connect with us.

Regards,



Kristina Boyer, RN, MScA Clinical Program Director



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



Sharon, Zach, Cameron (in frame) and Glenn Bulger

NAVIGATING LOSS WITH LOVE AND GRACE

There is no one thing that can prepare a parent for hearing the words, 'your child has cancer.'

In 2019, Sharon and Glenn Bulger were introduced to Canuck Place two years into their son Cameron's cancer journey, after he was terminally diagnosed with a rare brain tumour.

Canuck Place nurses helped the Bulgers create a unique family care plan that evolved as Cameron's illness progressed and the family chose to stay at home for Cameron's end of life care.

Canuck Place nurses cared for the entire Bulger family through in-home clinical care visits, 24hour clinical care line phone calls, and end-of-life support.

Sharon Bulger gave a beautiful speech at the Gift of Time gala, presented by Nicola Wealth, in October, which raised a record \$1.55 million to support complex care at Canuck Place.

"The Canuck Place team walked with us on the hard days and helped make them better. On the worst days, they held us until we could find the strength to stand again," says Sharon. "Losing Cameron was the hardest thing we have ever endured and we are so grateful for donors who see us, who see our pain, and give so selflessly to ensure we are supported and loved."

OCTOBER AT THE HOSPICE: KIDS CAMP AND FIN RETURNS!

In the fall of 2021, the Canuck Place team took Canuck Place kids and siblings back to *Kawkawa Camp* & *Retreat* located on the sunny shores of Kawkawa Lake, in Hope, B.C! The theme this year was Under the Sea Hawaiian Extravaganza. Children enjoyed activities on the water, warmed up by the campfire, practiced archery and riflery, made



Nurses Laura Wallbridge and Jenny Hauk with Tyler

ukuleles, played games and enjoyed indoor activities. Special guests included the Vancouver Aquarium, the Langley Ukelele Ensemble and baking with our very own Guru.



Tyler and his mom

For Halloween, we had a special guest visit. Fin, the Vancouver Canucks mascot, came to the hospice to decorate some spooky cupcakes with the kids and their siblings! This year, Fin dressed up as a disco orca! Fin and the kids decorated cupcakes with candies and toppings, prepared lovingly by our kitchen staff and Canuck Place chef Harry, who came up with the idea for this wonderful activity. Fin also enjoyed the pumpkin carvings at Canuck place, and especially the one of himself! We all had a FINtastic time!



Canucks Mascot Fin visits with children at the hospice.

Every day our recreation therapy team comes to work and helps children and families living with life-threatening illnesses have their best day ever. In fall, they packed in a ton of moments and created more memories than ever thought possible!

MEET THE SUIS, A CANUCK PLACE FAMILY A ONE IN A MILLION

In August 2016, Jessica and Chris Sui were expecting their second child their one in a million. At the routine 20-week ultrasound, they discovered their daughter, Charlotte, had several abnormalities, the most severe being a heart defect — a gene defect so rare that only one other family in the world was medically documented.

The end was already known, but Charlotte's journey had yet to be written.

"We were given the option many times to terminate the pregnancy," Jessica notes. "But we chose to carry her and savour her life until her time was complete."

The Sui family was intrduced to Canuck Place Children's Hospice during Jessica's pregnancy. Canuck Place is B.C. &



Clinical Nurse Specialist, Nadine Lusney, Chris and Jessica Sui

Yukon's only pediatric palliative care provider, supporting children with life-threatening illnesses and their families as they navigate complex care, grief and loss, all while creating lasting memories.

"The magic of Canuck Place is that we see and recognize the unpredictable and uncertainty," says Dr. Hal Siden, Canuck Place's medical director. "Canuck Place's specialized clinical team leads with a gentle therapeutic approach to complex diseases and conditions that respects the uniqueness of every family's situation and their child's diagnosis."

The introduction to Canuck Place is never easy — and the Suis were resistant. "No parent wants to believe and accept that their child will die," says Jessica. "But Canuck Place kindly supported our resistance, already walking us through uncertainty during those early days."

Caring for a newborn is difficult, and because of Charlotte's condition, her care required even more attention. Her cleft lip and palate required a special feeding bottle and her oxygen would desaturate. She was a feisty and spirited baby who would cry with the exuberance and defiance of a healthy baby, which was not good for her oxygen levels.

Canuck Place nurses and physicians helped the Suis with Charlotte's complex care needs. They counselled on how to lessen her discomforts, administered medication and provided oxygen equipment and made regular clinical visits to the Suis' home. One of the misconceptions about pediatric palliative care is that the child must stay in the hospice. In fact, Canuck Place nurse practitioners increased home visits by 31% during the pandemic through Canuck Place's Nancy Chan Enhanced Community Care Program. This program provides choices for families to receive inhome care.

"Canuck Place nurse practitioner, Camara, oversaw Charlotte's medical needs and was a breath of fresh air every time she came to visit us," recalls Jessica. "Often, she would bring fresh-baked cookies from the hospice, much to our oldest daughter Bethany's delight. Her willingness to just sit with us and listen to our fears, our sorrow, and our hopes allowed us to build a meaningful relationship during those days. The complexity of Charlotte's care resulted in us as parents neglecting our wellbeing as we poured our focus and energy into caring for our ill child."

In addition to at-home care, the Suis also visited the hospice for respite care.

During their stay in the family suites at the hospice, Jessica and Chris received much-needed care through home-cooked meals, strolls through the garden and massage treatments —



offering a slight return to normalcy.

Charlotte died peacefully at home in November of 2016. While her days were short, they were filled with love and comfort. Because of Canuck Place, the Suis could cherish the time they had with Charlotte.

Charlotte's light shines on, even after her passing. Part of Canuck Place's program includes ongoing bereavement and grief counselling and memory-making to honour a life lived.

"We have a beautifully framed mold of Charlotte's tiny feet as well as necklaces of Charlotte's fingerprint mold. We often take these items out in times of remembrance such as Charlotte's birthday and the day that she passed away," says Jessica.

"When families experience the death of a child, it is important they receive the support and care necessary to aid them as they process such a great loss," says Canuck Place counsellor, Deborah Davison. "We are committed to presence and companionship, holding space to validate their experience, helping them find their way. Their child matters, their family matters, their love matters."

Every life is precious, no matter how long it shines, and with support from Canuck Place, Charlotte's light shines on.

"Part of the pain in losing a child is the loneliness of holding such an experience by ourselves," says Jessica.

"Canuck Place reminded us that we were not alone, that others walk similar journeys, and that our hurt, doubts, questions and even guilt were validated."

Chris, Bethany (8), Charlotte (in frame), Willow (3), and Jessica Sui



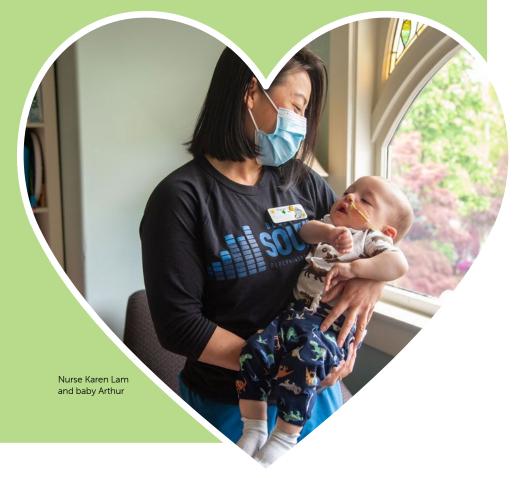
Counsellor Deborah Davison and the Suis

For 26 years, Canuck Place has provided exceptional complex medical care, while helping families create lasting memories. But not without donor support. You can light a life this holiday season for Canuck Place children like Charlotte.

National Children's Hospice Day

On October 8, Canuck Place recognized Canada's second annual National Children's Hospice Palliative Care Day. The goal is to raise awareness about the importance of pediatric palliative care (PPC) and improve the quality of living and dying for children with life-threatening conditions.

Canuck Place is dedicated to ongoing research, led by medical director Dr. Hal Siden. Nurse Practictioner, Camara van Breemen developed the Serious Illness Conversation Guide for pediatrics, while our staff have also collaborated with other specialized programs in the country to develop national PPC nursing competencies that can be applied in any setting where children with life-threatening conditions and their families receive care. As a result of Canuck Place sharing ongoing research globally with specialists and local health care facilities, children world-wide have access to the best practices in pediatric palliative care.





TRIBUTE TO CFKF

For over 26 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 CPCH 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!

CPCH NEW BOARD CHAIR AND BOARD MEMBERS

Canuck Place Children's Hospice held its Annual General Meeting electing Bob Smart as Board Chair, and four new board members to the Canuck Place Children's Hospice Society Board of Directors. Suzanne Steenburgh will continue her role as Vice Chair, Michael Cinnamond will remain Treasurer and Teresa Budd begin serving as Vice Chair & Secretary.

Joining Canuck Place Children's Hospice Board of Directors for the first time are Jill Donaldson, Jennifer Baumbusch, Barry Macdonald, and Canuck Place mother, Barbra Mohan, who will represent the families on Canuck Place's program at the board level. They join continuing board members John DeLucchi, Markus T. Delves, Dr. Douglas Cochrane, Dr. Carolyn Steinberg, Tom Webster and Robert Coard.



Bob Smart, ICD.D

As President and CEO of Primex Manufacturing Ltd., a B.C.-based plastic injection molder, Bob led the company from a regional supplier to become the market leader in engineered plastic panels to the Telecommunications Industry in North America. Bob recently retired from Primex and now focuses his energy and expertise as a strategic advisor to businesses and organizations.



Jennifer Baumbusch, PhD, RN is an Associate Professor and CIHR Chair in Sex ϑ Gender Science (2020 – 2024) at the School of Nursing at the University of British Columbia (UBC). Dr. Baumbusch directs a research program on health care delivery and nursing practices with older adults. Her focus is long-term residential nursing care, family contributions to care delivery, well-being of individuals with disabilities and their families, and knowledge translation.



Jill Donaldson, JD, ICD.D is a Principal at IWJ Law, Business + Investment Counsel. As a senior corporate and securities lawyer for over 20 years, Jill has extensive experience working with senior executives and their boards in the areas of strategic planning and implementation, governance and stakeholder capitalism, mergers and acquisitions, and compliance and risk management.



Barry Macdonald, FCPA, FCA, ICD.D is Chairman and CEO of Truvera Trust & Mortgage Group. Barry's extensive experience includes a 34-year career as a tax partner with PricewaterhouseCoopers, serving as Chair of the Board of Chartered Professional Accountants of BC (CPA BC) and service as a director and strategic advisor on many corporate boards, including the SFU Community Real Estate Trust (UniverCity), EasyPark, and Frontfundr.



Barbra Mohan became part of the Canuck Place family when her fifteen-year-old son Jasper received end-of-life care at Canuck Place 2013. Following Jasper's passing, Barbra served a six-year term on the Canuck Place Family Advisory Committee (FAC). Currently, Barbra is the Manager of Human Resources for the Cowichan Valley Regional District.

CANUCK PLACE IS WHERE CARE & WONDER THRIVE

At Canuck Place, we support children who transition into adult care at age 19 with a detailed plan for resources and a special Canuck Place graduation ceremony.

The Canuck Place recreation therapy team also organizes an outing of choice for teens who transition off our program. Canuck Place recreation therapists and volunteers took Canuck Place teen Vincent (19) to Lighthouse Park for a hiking trail adventure.

Even though he lives in West Vancouver, Vincent has never been able to access the park because he uses a wheelchair for mobility. Lighthouse Park has no paved pathways and is not normally wheelchair accessible—but our team found

a way to make sure that Vincent was able to enjoy a day in the park and the views of the sea.

When he reached the lighthouse, Vincent said: "I would never have been able to get here without you guys!"



Vincent and Amrit



Canuck Place accredited facilities dog, Gaia, celebrating her graduation

SOMETHING TO BARK ABOUT!

In February 2021, with support from our partners Pacific Assistance Dogs Society (PADS) and YVR for Kids, we welcomed a new loveable and compassionate Accredited Facilities dog, Gaia.

Gaia supports the care of children with life-threatening illnesses and their families at both our hospices, as well as attending home and hospital visits in the community. Her loving and gentle demeanor, combined with impeccable training, enables her to support our children who require complex care.

On November 28, Gaia officially graduated from the PADS program! We are so grateful to PADS for bringing Gaia into our lives. It's amazing what a simple wag of a tail and a cuddle with a dog can do.

CANUCK PLACE participates in Childkind

We are pleased to announce that we have completed the application process for the upcoming <u>ChildKind</u> <u>International certification</u>.

Over the past year, our Canuck Place ChildKind Committee has been working hard to reduce pain in children by developing the highest standards in pediatric pain care. Canuck Place Children's Hospice has made an institutional commitment to pain prevention, assessment, and treatment and provides ongoing education programs and awareness initiatives to all staff, patients and their caregivers, and volunteers. We would like to acknowledge and thank the members of the Canuck Place ChildKind Committee.

- Adrienne Cocroft
- Angela Aujlay
- Bethany Froese-Canuck Place
 ChildKind Project Lead
- Brenda Dewar
- Christine Fraser
- Deanna Koot
- Emily Watson
- Gail Andrews
- Jenny Hauk

- Joanie Maynard
- Karen Kooyman Gautier
- Kirsten Campbell
- Laura Wallbridge
- Lindsey Underhill
- Marie-Claude Gregoire
- Melanie Hameluck
- Nadine Lusney
- Rachel Neufeld
- Rebecca Woodward

childkind

What's new IN THE CANUCK PLACE SCHOOLROOM!

by Kay Lever, Canuck Place educator

More great changes in the school room!

Since September, the number of children staying in house at our Vancouver location has gradually increased. And it's been so much fun! It was far too quiet for our liking during the height of the pandemic and it's been great to welcome more children back to the school room with COVID safety protocols in place.

Many Canuck Place children have returned to their regular home schools this year too and so we've decreased the number of online classes we are holding. We are still holding two classes a week though, at 10am on Monday and Wednesday mornings. The topics change weekly and are things such as: arctic animals, pigs, kindness and learning about the First Nations communities of BC.

Like last year, we have a core group of children who attend all the classes and really enjoy seeing each other on a regular basis.

We now have the ability to connect the children in-house and the children at home in our online classes. Thanks to our wonderful colleagues here at Canuck Place and our generous donors, we have a large computer screen in the classroom which is attached to the wall and very mobile. This allows all the children in the classroom to see the screen and for them to be seen by the children at home.

This past week we've enjoyed learning how animals survive winter in the arctic. This prompted Diego to coin the phrase 'poop volcano', and we made our own ice-cream together!

If you would like to receive the weekly email outlining the classes for the following week, please contact Kay Lever kay.lever@canuckplace.org







Canuck Place child, Kashton completing an alphabet scavenger hunt around the house

Lighting of the House At glen brae manor





EnChor Choir performance on the front stairs of the hospice



Bethany Sui and Fin



Fin, Bethany Sui, Health Minister Adrian Dix, Jessica, Willow, and Chris Sui



Bethany, Jessica, Willow, and Chris Sui



Neetu Garcha, Fin, Health Minister Adrian Dix, and the Sui family turning on the lights!





Health Minister Adrian Dix, and Denise Praill, Canuck Place Interim CEO

Kashton and family

wishing you a happy holidays



The Bulger family

Want to brighten someone's holidays? Try making our **Canuck Place's World-Famous Chocolate Chunk Cookie** for your loved one!

Chocolate Chunk Cookies

Canuck Place is:

- 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!