



Carlee's Story

BY CHARLES VASQUEZ

I remember as if it happened yesterday. Not even two months into the pregnancy, we got referred to BC Women's Hospital for a series of tests and found out our baby had a congenital defect that she would have to endure her whole life. Back then, we were so young, we could not comprehend the gravity of the diagnosis. At one point, we were given the option to terminate the pregnancy. But, upholding our faith and values, we did not even entertain the thought and made a quick decision to choose life.

On December 17, 2012, a tiny star was born. We named her Carlee Nina Vasquez. She arrived a month ahead of schedule at 36 weeks, and oh, she was so small at just 3 kg. She was only 45 cm long and could fit between the tips of my fingers and my elbow. At birth, she was as pale as paper, and severely anemic. She needed a blood transfusion, and multiple other ones followed. Carlee had inherited a bone marrow failure syndrome called

Diamond Blackfan Anemia (DBA). It's a rare disease that occurs in 10 children born out of a million, according to the DBA Foundation.

Carlee spent the first few months of her life, including her first Christmas, at BC Children's Hospital's neonatal intensive care unit (NICU). There, they monitored her for oxygen desaturation and provided nasogastric intubation, or NG tube feeding. She needed to stabilize and grow so she could have a heart-stenting procedure.

At six weeks, the doctors could not wait any longer. Carlee was desaturating very often and had to be rushed for an emergency stent procedure, even though she was underweight for the operation. She managed to pull through it, with much thanks to her cardiologist and interventionist, Dr. Kevin Harris.

Our family was then introduced to Dr. Tammie Dewan, Dr. Elizabeth Grant, and a complex care team who became Carlee's greatest medical care

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VOLUNTEERS NEEDED

Our families enjoy the spring, summer, fall, and winter gatherings that CHN sponsors. We are always looking for volunteers, so if you have some time, talent, and expertise that you are willing to share, please contact Sam Aitken at saitken@childrensheartnetwork.org.

The views expressed in this newsletter are those of the authors, and not necessarily those of the board of the Children's Heart Network. The best sources of medical information are your child's physician and the health care professionals who provide care for your child.

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COFFEE GROUPS NEAR YOU

These groups meet monthly; come and meet other heart parents while enjoying treats on CHN.

For more information please contact:

ABBOTSFORD – Rupe Brah

rupe3395@gmail.com

CHILLIWACK – Melissa Martz

mellymartz@outlook.com

KAMLOOPS – Miranda Brown

cmazn2003@yahoo.ca

KELOWNA – Karla Allan

kdvk@hotmail.com

LANGLEY – Tecia Beulens

tbeulens@telus.net

COQUITLAM/PITT MEADOWS –

Amylou Watkins and Gabby Torrens

amylouwatkens@hotmail.com

gabby@torrens.ca

NANAIMO – Andrea Van Rossum

andrea.vanrossum@gmail.com

PRINCE GEORGE – Veronica Vandermeulen

veronicav0603@gmail.com

RICHMOND – Kate Walker

kwalker@childrensheartnetwork.org

VANCOUVER – Samantha Aitken

saitken@childrensheartnetwork.org

VICTORIA – Teri Godin

terigodin@gmail.com

SIGN UP TO GET CONNECTED

If you have a child growing up with heart disease please email us at chn@childrensheartnetwork.org so that we can add you to our mailing list to receive invitations to all our fun events!

THANK YOU

CHN would like to thank the Province of BC for its continued support of CHN through its Community Gaming Grants program.



CHN would like to thank the CKNW Kids' Fund for their generous support of our Heart Beats and Hearts of Gold camp programs.



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advocates. They gave us much-needed support and attention as Carlee transitioned from the NICU to the recovery ward and, finally, in February 2014, our home.

Our second bedroom turned into a hospital room full of medical equipment. I remember my wife and I learned in a short amount of time to do so many tasks related to Carlee's medical needs. At one point, we practiced putting the NG tube on each other so we could safely apply it to Carlee.

On September 11, 2014, nine months after she was born, Carlee had her open-heart surgery. It was her mother's birthday. We waited for hours in anticipation. A bit of relief came after we saw Carlee's cardiac surgeon, Dr. Campbell, looking relaxed after the operation and standing in line to get a cup of coffee. Not long after that, we were able to see Carlee. It had already been quite a journey. I thought that we were on our way to better days, but I was wrong.

Over the next few months, Carlee suffered multiple lung infections and had to battle through chronic lung disease. She was hospitalized a number of times for long periods.

At one point, a supervirus compromised her immune system and her lungs. It was a Code Blue situation, and I'll never forget it. She was in very bad shape and required critical medical care. We almost lost her. My late wife broke down seeing Carlee in the pediatric intensive care unit (PICU) for the first time after that episode. "When I walked in the room and saw her in bed with all those attachments, it broke my heart," she said.

In the end, Carlee's medical team in the PICU at Complex Care and Respiriology took very good care of her, and she made a phenomenal recovery. Since then, Carlee's medical condition has stabilized. She still regularly visits multiple departments at BC Children's Hospital. She has had a number of surgeries, including a gastronomy tube procedure and two cleft palate repairs. Last year, she suffered a serious neck injury, breaking her C2 vertebra, and had to wear a halo brace for a few months.

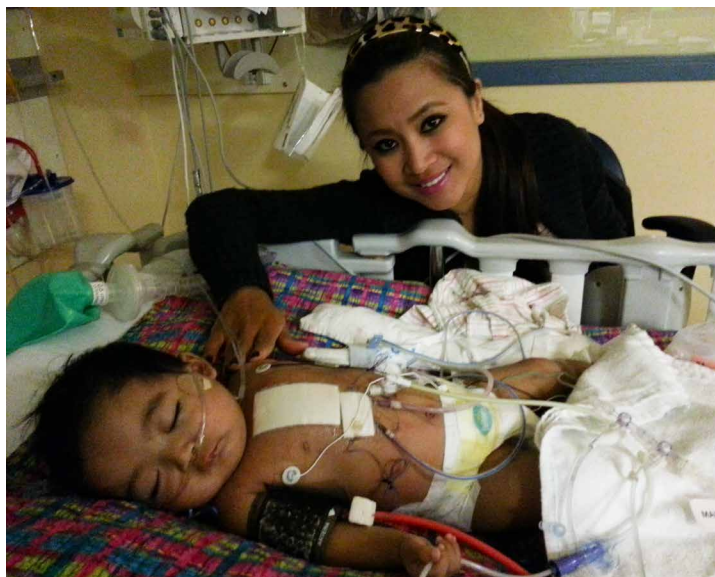
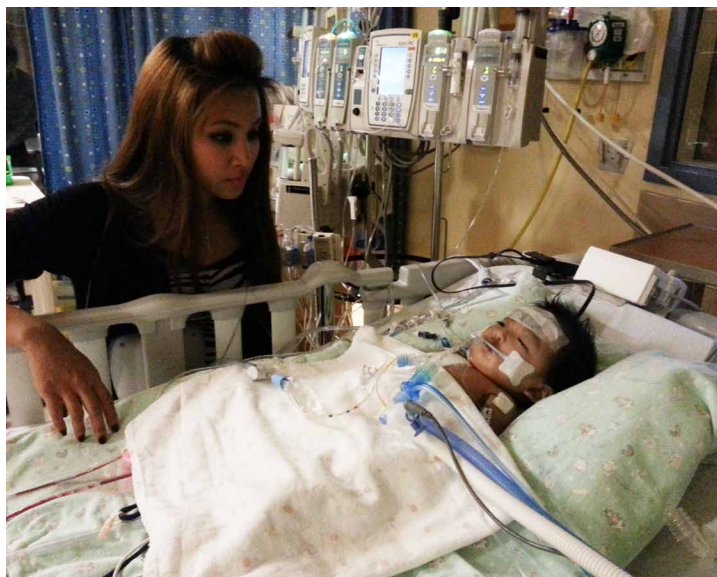
In early 2017, we lost my wife and Carlee's mother to lung cancer. Having to endure so much already in her early life, Carlee is still too young to understand the devastating loss of her very loving mom. Last month, Carlee turned seven. Despite many challenges, she is a very happy child. She is a little stronger now and is very active. She is blessed with a very loving and supportive older sister and grandparents.

Thank you to all the real miracle workers—the doctors, nurses, and medical staff at BCCH—and to all the community support workers who helped Carlee and our family through all the hardships of the last few years. We haven't had a chance to appropriately recognize and appreciate them, but we are very thankful and forever grateful to have had them come into our lives.

These days, Carlee enjoys swimming, ice skating, and playing the piano. She now selects her own interests and activities. Recently, she has shown interest in playing the guitar, and she is now enjoying learning with her sister. Carlee is healthy enough to travel and see the world. In the last two years, we have visited places all over North America.

We have also been able to enjoy many wonderful activities organized by the Children's Heart Network, including coffee groups, holiday parties, and camps. Through this community, we have met and connected with many families who are going through similar challenges. The friendships and a strong support group fostered by CHN reminds families like ours that we are never alone.

When I look at Carlee today and recall everything she's been through, it gives me pure inspiration, courage, and strength to persevere. Even now, I always catch myself looking at her and having the same thought: *You are the most precious thing I have ever seen in this life.* She still has a long journey ahead, but I am confident she has the heart and strength for it. ♥



CHN Celebrates the Holidays!

Vancouver Island

On December 7, families from Vancouver Island's Heart Beats group enjoyed a festive pancake breakfast (with bacon and all sorts of yummy treats) at The Westin Bear Mountain Golf Resort & Spa in Victoria. We had 22 families who filled a banquet room and enjoyed the buffet, crafts, cookie decorating, a magic show, and best of all, a special visit with Santa. There were many great moments. Children played. There was gorgeous crafting, laughs with the magician, and plenty of smiles and excitement with Santa. Heart moms and dads were able to connect over coffee.

Many thanks to all the volunteers that helped to make it so special! Our Victoria cardiology staff joined in too, greeting everyone and supporting the craft and cookie tables. In addition, a huge thank you goes out to Leeann, who took fabulous Santa photos for all of our families. Local magician Donald Dunphy captured the kids' attention. There were many giggles, from both parents and children! The highlight came when Santa arrived with a sack full of chocolate!

The families on Vancouver Island look forward to connecting again in the spring. Hopefully, there will be an Easter egg hunt in early April.



Lower Mainland

This year's event was such a fun, festive day! We had over 250 heart family members join us at the Grand Villa Casino Hotel & Conference Centre in Burnaby to celebrate the holidays. The decorations were gorgeous, and The Great Gordini put on a very entertaining magic show. Families got dressed up, enjoyed a fabulous brunch, and then took part in face painting, making balloon animals, Christmas crafts, and cookie decorating. They also had fun checking out the dozens of raffle prizes. The little

ones were thrilled with the arrival of Mr. and Mrs. Claus. There were many big smiles for our photographer, Liz. We would like to thank the following sponsors, without whom this event would not have been possible:

- Fratelli Bakery
- Daniel Le Chocolat Belge
- Liz Ciulla Photography
- All the families and businesses that donated to the raffle ♥

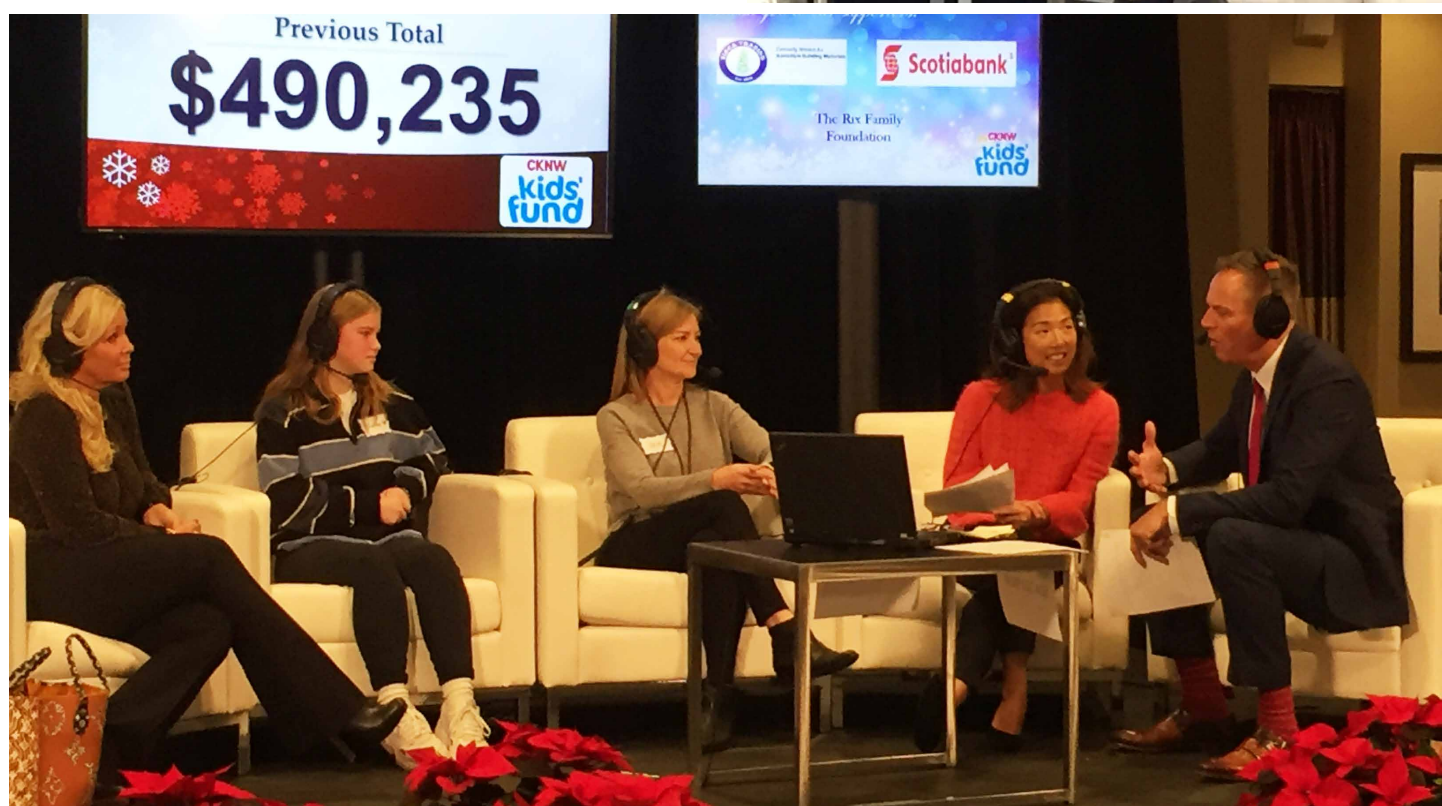


CKNW Kids' Fund 42nd Annual Pledge Day

For 75 years, the CKNW Kids' Fund has granted millions of dollars to support hundreds of thousands of children with a variety of challenges. Through the generosity of organizations, communities, and other donors, the CKNW Kids' Fund helps BC families by providing grants for essential specialized medical equipment, therapies, and programs and camps for vulnerable children. For over 10 years, the CKNW Kids' Fund has awarded the Children's Heart Network a camp grant, which has allowed us to send many children and teens to a summer camp, where they can have fun and connect with other heart kids.

On December 3, Samantha Aitken (CHN provincial coordinator) and Hailey Wispinski (one of our Hearts of Gold teens) attended the CKNW Kids' Fund 42nd Annual Pledge Day at the Fairmont Hotel Vancouver. They were interviewed on air by Global News co-anchors Chris Gailus and Sophie Lui. Hailey shared some of the fun experiences she has had at camp over the years, as well as how camp has helped her build friendships with other heart kids: "No one understands quite as well what you are going through as a heart kid, as someone who has had a similar journey. The friends I have made at camp really get it." Hailey did a fantastic job!

The on-air total this year was a whopping \$2,656,230! A huge thank you to everyone that supported the CKNW Kids' Fund this year; your donations also support the Children's Heart Network! ♥





Sharing News About Your Child's Illness with Others—Helpful Hints

BY CAMARA VAN BREEMEN, MN

As parents of a child with heart disease, you are familiar with answering questions from family and friends: “What is wrong?” “What is the diagnosis?” “Will she get better?” “What can we do to help?” Questions like these can come as a welcome support or as a burden, depending on who asks, the certainty with which you can answer, and your particular energy level and mood at the time. You may struggle to balance your families’ and friends’ need for information with the anxiety that sharing your worries and hopes may bring.

Here are a few hints for navigating the info-sharing terrain:

1. Evaluate who is asking and who needs to know.

If you first examine your relationship with those in your wider circle, it can guide you in how much you may want to share. Do you trust this person? Are they someone who can help with the day-to-day or who needs the information to keep others informed? Remember, the story of a seriously ill child

is provocative, and people are naturally interested to learn more and help if they can. However, it’s OK to provide a few short statements about how your child is currently doing rather than a detailed account of past, present, and future plans.

2. Find out what they understand about your child and their condition. Though this may seem a bit tedious (time-consuming?), you may save yourself frustration if you hear a bit about their perspective. It may be that they recently spoke to someone who updated them accurately, or instead they may want to tell you about a miraculous treatment they read about on the internet. Either way, you can then decide whether you agree with their stance or you need to clarify, add information, or share sources of information that will better help their understanding.
3. If you want to share, tailor it to the level of that person’s support, understanding of the disease, and involvement in your life.

The degree or depth of sharing is related to how much emotional or practical support that person offers. For example, if an aunt or grandparent provides care to your child, it is obviously important for that person to understand medications, physical symptoms to respond to, and upcoming appointments and interventions. For a neighbour or a parent from your child's school, you might include a brief statement about your child's function ("She is still in hospital after her surgery") and a little bit about your hopes or worries ("We think it may be a few weeks longer before she is discharged"). If this person is able and willing to be a support, be direct and clear in asking for what you need. These often include practical aspects such as household tasks, support for siblings, or meal preparation. However, it could also be emotional support, which usually entails having someone listen and not offer unsolicited advice or platitudes (it's OK to be direct about this too).

4. To post or not to post? Many families find using a blog or Facebook an efficient and direct way to share information to update many concerned family members and friends. If doing this, consider your audience. Remember to create privacy settings that meet your goals. You may want to outline the purpose of the blog or sharing so that readers know your intention. For example, if you are a family that would love messages of love, prayers, and practical or financial support, outline this. If the blog is a one-way communication portal, say this. "We will not be responding to messages through his forum but are using this so our family and friends have daily updates." Or, "We would love people to post questions, good wishes, and photos to help keep us going." Sites such as CaringBridge offer a specific platform for sharing such information. Additionally, you may want to assign one of your family members to monitor and post information.
5. Construct some useful set phrases. Parents often experience feeling burdened by repeating their child's story or being put on the spot to share information when they do not have the time or energy. Having a few phrases that fit for you and your circumstances can be helpful in settings where in-depth conversation isn't fitting. "Thanks for asking. I am pretty worried about her but don't want to get into it too much right now." Or, "I would love to talk more, but perhaps we can arrange a time to talk on the phone or have a cup of tea."
6. Keep the focus on the child, not the illness. Amid the diagnosis, treatment, and ongoing management of the disease, health care professionals and family members may get sidetracked and prioritize the medical care. Moreover, the child with the serious illness may

overhear countless discussions about their health, but not about their general well-being, accomplishments, and individual attributes. Share these qualities too, and help your child respond to questions and inquiries in a way that empowers them and helps others see that they are more than their illness.

7. Ask for assistance from your health care team. If you are receiving particularly complicated or difficult information, consider taking a trusted support person to attend the meeting with you. Not only can they help remember what was shared, they can also be another source of information for others. Your child's specialists are often also able to connect by telephone or video link if a person integral to the information and decision-making cannot attend the meeting. Or, ask for the meeting notes to be shared so you can review and share with others as needed. If the news you have to share with family members is particularly difficult—the treatment isn't working, or your child is getting sicker despite the interventions—ask for help from a trusted nurse or social worker from your team. Talking over the circumstances, integrating the feelings, and then working through what you would like to share with family and friends can be made easier. In sharing, you may first want to start with the hopes you have for your child ("I really hope that she will get out of ICU..."), but it is also OK to share your worries ("...but I worry that given all she has been through, she may get sicker."). Sometimes speaking the worries out loud can be scary, but doing this isn't negating hope. It is actually creating an opportunity to share the emotional burden and create space to receive the support you may need.

The journey of caring for a child with a serious illness can be difficult and isolating. Try to identify those around you who are willing and capable of providing support. Express your family's needs specifically, but don't feel pressured to communicate anything more than general information about your child's status to those for whom it is unnecessary.

The Courageous Parents Network is maintained by families who have similar challenges as yours, and its website can be a useful resource: <https://courageousparents.network.org/>. ♥

Camara van Breemen, MN, is a nurse practitioner and child therapist who has been working with seriously ill children and their families for over 25 years. She has a strong interest in communication practices between clinicians, children, and families. She can be reached at cvanbreemen@canuckplace.org.

Hints to Help Kids Get Enough Sleep

BY MARGARITA TARTAKOVSKY, MS

Setting healthy sleep¹ habits when your child is young is key for their well-being. Here, Stephanie Silberman, PhD, clinical psychologist, sleep specialist, and author of *The Insomnia Workbook: A Comprehensive Guide to Getting the Sleep You Need*,² shares her insight on helping kids get a good night's rest.

Sleep Problems in Children

"There are many sleep problems that are typical in children," Dr. Silberman said, such as sleep talking or sleep-walking, confusional arousal (where a child is confused and disoriented), and sleep terrors (characterized by a blood-curdling scream and terrifying images).

The most important actions you can take are to "keep the bedroom very safe and free of sharp or harmful objects [and to] lock the windows and doors to the outside." Also helpful is playing soft music or putting in a nightlight, because this makes your child more aware of their surroundings. Sleep deprivation³ increases the risk of these problems, so make sure your child is getting enough sleep each night. This helps to decrease or prevent such problems. To help with sleep terrors, in addition to ensuring your child isn't sleep deprived, "calmly bring them into their room."

Signs Your Child Is Sleep Deprived

"Parents have to be very conscious of the cues that kids are giving them," Dr. Silberman said, since they're unable to verbalize that they're sleepy.

Interestingly, the signs that kids are sleep deprived are completely different from those in adults. Adults get sleepy, but kids "tend to be more hyper, inattentive, irritated, and annoyed." In fact, Dr. Silberman said that a lot has been written about sleep deprivation being mistaken for ADHD.⁴

Also, pay attention to changes in your child. Are your kids participating in school and other activities as usual? Are they dragging?

If your child is showing these symptoms, consider what's possibly causing it. For instance, "does it happen on the weekend when they stay up late with you watching a movie?" Dr. Silberman said. Also, if these symptoms occur in combination with sleep apnea, see a specialist. The same goes for snoring, since kids shouldn't snore.

Sleep-Promoting Suggestions for Children

1. Create a bedtime routine.

As with adults, setting up a bedtime routine helps get kids into sleep mode, Dr. Silberman said. This includes eliminating arousing activities from the routine and adopting relaxing ones. Make sure kids don't participate in physical activities too close to bedtime or eat sugary foods. Calming activities include reading, taking a bath, drinking milk, and giving hugs and kisses. "Our bodies need those types of signals [when] winding down." If your child is old enough, ask them what sleep-promoting activities they prefer.

As much as possible, try to keep the same activities as part of your routine every night, since again, this lets your little one know that it's time for bed. Going to dinner or on vacation? Dr. Silberman emphasized that there's no need for parents to stress about this. If you can, try to work around outings. For instance, if you're at someone's house for dinner, bring your child's pjs with you and put them on there. Once they get home, they know it's close to bedtime.

2. Keep a consistent sleep schedule.

For good sleep hygiene, a consistent sleep and wake cycle is important. As parents know, kids thrive on routines. (Adults do too.) For instance, going to see a movie together? If you have the option, see an earlier showing.

3. Stick with it.

Kids tend to stall before bedtime. They want you to read them just one more book, give them one more hug and kiss, and get them another glass of water, Dr. Silberman said. They'll try to press to get their way.

For working parents, it can be especially hard to enforce bedtime. "They haven't seen their kids during the day and just have a few hours at night [with them]." Many can feel a bit of guilt. But you "shouldn't feel guilty about emphasizing good sleep habits in kids." Children "who sleep better do better in school and have a better mood."

So don't allow stall tactics to become their own routine. Set limits with your kids in a "kind and calming way."

¹ <https://psychcentral.com/sleep/>

² <https://www.amazon.ca/Insomnia-Workbook-Comprehensive-Guide-Getting/dp/1572246359/psychcentral>

³ <https://psychcentral.com/lib/sleep-deprived-nation/>

⁴ <https://psychcentral.com/adhd/>

4. Get everyone involved in the routine.

Have everyone in the house get ready for bed together, especially if you have young children, Dr. Silberman said. You can dim the lights, get into your pjs, and brush your teeth together. One of the reasons kids like to stay up is that they “feel like they’re going to miss something.” “Show them it’s dark outside, there’s nothing to do now,” and everyone is sleeping.

5. Don’t use sleep as a punishment.

Parents never want to create an association between a child’s bad behaviour and bedtime (e.g., “If you don’t do this, you’re going to bed”). Instead, sleep should be viewed as a positive priority.

For instance, Dr. Silberman suggested saying, “Everybody needs sleep; it’s how we grow big and strong. You’ll have a fun day tomorrow because you’ll feel rested; sleep is important for your brain to work.”

6. Don’t get in bed with your child.

Some parents have a tendency to lie down in bed with their kids to help them fall asleep. But this is “teaching your

child that they need you [and] can’t fall asleep without you.” She added, “What happens when you’re not there?”

7. Teach your kids to self-soothe.

It’s important for kids to learn to fall asleep on their own. For instance, parents should put a child to bed when they’re calm and seem “sleepy and happy, instead of waiting until they fall asleep on you. You can sing to them while they’re in their crib, and then gradually leave the room.”

8. Give them a transitional object.

What also helps kids self-soothe is to have a transitional object, such as a stuffed animal or blanket. This can be any object that’s comforting to your child. This way, again, parents don’t have to be there in order for their kids to fall asleep. ♥

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Meet BCCH Pediatric Anesthesiologist Louis Scheepers

Where did you grow up and go to school?

I grew up in South Africa and attended medical school in Johannesburg, a city of about 3 million people. There were lots of interesting and varied medical patients. I moved to Canada in January 1990.

Why did you choose to become a pediatric anesthesiologist?

Children are so trusting and do not hide or modify their personalities. One of the most satisfying and rewarding experiences in medicine is looking after them in ways that do not misplace this trust and providing medical care in a manner that does not worsen their anxiety or increase their fear quotient.

What do you like about working at BCCH?

Providing excellent medical care for children takes a special team that understands their needs and is willing to sacrifice time and energy. I am always amazed at the dedication and commitment provided by the cardiac team, from the operating room nurses, to the perfusionists, to the cath lab nurses, right through to the ICU nurses.

Are there any specialties within anesthesiology?

At BCCH, we have had the pediatric cardiac anesthesia subspecialty for a long time. We have developed and are further developing other subgroups, such as anesthesia for spine surgery, regional blocks, neurosurgery, and complex pain.

Did you have a mentor?

Apart from my mother-in-law, who taught me the subtleties of being married to my wonderful wife, I must also add Clayton Reichert, who always made pediatric cardiac anesthesia interesting and enjoyable. His calm way of dealing with difficult situations and always focusing on the big picture is a testament to his superb clinical skills.



Outside of work, what do you like to do for fun?

My main interests involve family and friends. I like biking, skiing, and hiking, and then relaxing afterward with a nice bottle of red wine and some cheese!

What are you good at, in addition to being an anesthesiologist?

Depends on who you ask, but I am excellent at taking the blame when things go wrong, usually because I am directly responsible for such events. Just ask Dr. Gandhi.

Do you have any pets?

Not to speak of, unless a fish tank full of guppies qualifies. But then, they do not seem to complain too much. ♥

What's Happening?

CHN Annual General Meeting

WHEN: Thursday, February 20, 7:00 pm

WHERE: BC Women's Hospital Ambulatory Care Centre (lower level), next to BC Children's Hospital

We will have a short meeting and then a presentation on our Hearts of Gold youth program, for heart teens ages 13–18. If your child is approaching this age, come and learn more about our HOG group. A great way for heart teens to have fun, connect, and support each other!

Lower Mainland Heart Beats Family Bowling Event

WHEN: Saturday, April 18, 11:30 am

WHERE: Zone Bowling, 228 Schoolhouse Street, Coquitlam

To RSVP, please email Samantha Aitken at saitken@childrensheartnetwork.org with the number of adults and children in your family and your children's ages, and ensure your CHN membership is up to date.



CHN Summer Camps

Hearts of Gold Camp (for teens ages 13–18)

WHEN: May 15–18

WHERE: Camp Zajac, Mission

For more information, please email Kristi Coldwell at chnheartsofgold@gmail.com.



Vancouver Island Weekend Family Camp

WHEN: June 5–7

WHERE: Camp Thunderbird, Sooke

This camp is for Island heart families who have children ages 4 and up. A fun weekend of archery, rock climbing, crafts, campfires, and more while connecting with other heart families. Spaces are limited; priority will be given to families that haven't attended in the past. For more information, please email Samantha Aitken at saitken@childrensheartnetwork.org.

Heart Beats Summer Camp (for children ages 8–13)

WHEN: July 6–10

WHERE: Camp Zajac, Mission

This camp is for heart children ages 8–13. They will join kids at camp from other medical groups. They will enjoy horseback riding, swimming, canoeing, a ropes course, crafts, campfires, and more while making friends with other heart kids. For more information and the link to register, please email Samantha Aitken at saitken@childrensheartnetwork.org.

Lower Mainland Weekend Family Camp

WHEN: September 25–27

WHERE: Camp Stillwood near Cultus Lake

This camp is for Lower Mainland and Okanagan heart families who have children ages 4 and up. A fun weekend of archery, crafts, rock climbing, campfires, and more while connecting with other heart families. For more information, please email Samantha Aitken at saitken@childrensheartnetwork.org. ♥

Did You Know?

Planning Your Visit to BCCH

Whether you're coming from far away or nearby, planning your visit to the hospital will help ensure a smooth trip.

Major renovations are underway. The BC Children's and BC Women's Redevelopment Project website has the latest construction information: <http://www.phsa.ca/newcw>

Travel Assistance

These programs offer transportation support for families travelling from out of town to medical appointments and hospital stays:

- The Travel Assistance Program (TAP) helps alleviate some of the transportation costs for eligible BC residents who must travel within the province for medical care. Ask your family doctor or your medical team for a form.

https://www.health.gov.bc.ca/tapbc/tap_patient.html

- Health Connections: Each health authority has a unique TAP for residents of their region who need to travel within the province for medical care.

<https://www.health.gov.bc.ca/tapbc/connections.html>

- Other travel help: The TAP has partnered with a number of different transportation companies who provide reduced rates for travel to and from medical appointments. Look for the list of transportation partners.

https://www.health.gov.bc.ca/tapbc/tap_transport.html

- Hope Air arranges free flights to get financially disadvantaged Canadians the health care they need.

<https://hopeair.ca/>

BC Family Residence Program

Families from outside Metro Vancouver with a child who requires care at BC Children's Hospital may be eligible for travel and accommodation assistance during their child's medical stay. To learn more, visit <http://www.bcfamilyresidence.gov.bc.ca/>. ♥



THE 18th ANNUAL Wine Gala & Dinner

Benefitting Children and Youth with Congenital Heart Disease

Butler-served hors d'œuvres
Three-course dinner with wine pairings
Silent and live auctions

Friday, April 24, 2020
6:00 pm – 11:00 pm

TERMINAL CITY CLUB
837 West Hastings Street

Parking can be found below the club or in other
more affordable parking houses downtown

EARLY BIRD \$175 (\$200 AFTER MARCH 15)

A portion of the ticket price will be issued as a tax receipt

To order tickets, visit <https://chnevents.org>.

To become a corporate sponsor or to donate
to the auction, please email Hege Bolthof Hoegler
at hhoegler@childrensheartnetwork.org.