CHILDREN'S
HEART NETWORK
of BC Society

FALL 2025

HEART MATTERS

Gwen's Story

By Gwen Joinson

When I was born, they found I had many congenital heart defects: Transposition of the Great Arteries, an atrial septal defect, and a ventricular septal defect. Before I was even one, I had two open-heart surgeries at BC Children's Hospital. Those surgeries gave me the chance to grow up, go to school, and do the things I love.

In the years after, I had a lot of heart catheterizations, tests, and scans. I still had pulmonary stenosis, which was slowly getting worse and making my heart work harder and harder. I couldn't do gym class the same way as other kids, and running just wasn't an option for me, I would get tired. But I was able to ride horses, and I found that during those hard days, I felt like I could do anything when I was with them.

This past fall, when I was 13, I had my third open-heart surgery with Dr. Magic at BC Children's. He was amazing, not only did he patch my pulmonary artery, but he also told me that he believed I could do anything I set my mind to. Hearing that from him made me want to prove him right. I also had incredible encouragement from my cardiologist, Dr. Sinclair, who has been there for me since I was a baby, through so many of my appointments and tests.

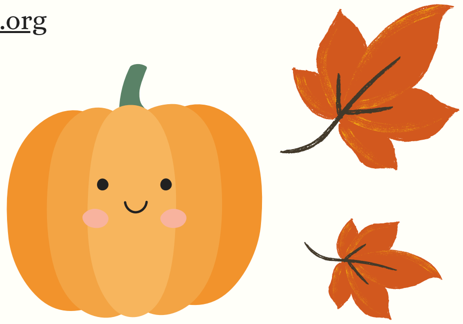
continued on page 5

IN THIS ISSUE

WHAT'S HAPPENING

CPR Workshop

Saturday, Nov. 1st at St. John Ambulance in Surrey
To register email saitken@childrensheartnetwork.org



Pumpkin Patch Events

Lower Mainland - Oct. 4th at 1:30pm – Hazelmere Pumpkin Patch in Surrey
Victoria – Oct. 26th at 2-:00pm – Galey Farms
Nanaimo – Oct. 19th at 2:00pm – Superior Farms
Kelowna – Oct. 5th at 1:00pm– McMillan Farms in Kelowna
To RSVP please email Samantha at saitken@childrensheartnetwork.org

CHN Holiday Parties – Save the Date! Watch for more information and email invitation

Lower Mainland Breakfast with Santa – Saturday, Nov. 29th at 9:30am at the Grand Villa Hotel in Burnaby
Island Butchart Carousel and Lights – Saturday, Dec. 6th at 3:00pm – Butchart Gardens Carousel Room
Okanagan Breakfast with Santa – Saturday, Dec. 6th at 9:30am at the Coast Capri Hotel

CHN's 22nd Annual Gala Dinner

Save the Date! Our annual Gala returns on Friday, May 8th at the Arras Ballroom in Vancouver. For 22 years, this celebration has brought together our community to raise over $1 million for children with congenital heart disease and their families. Thanks to your generosity, we support more than 600 families each year with vital programs, connections, and cherished memories. **Tickets go on sale in January—don't miss it!**

BOARD & STAFF

ABOUT

Heart Matters is the newsletter of the Children's Heart Network, which works to educate, support, and enhance the lives of children, youth, and families living with congenital heart disease.

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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Hearts of Gold Corner

A summer of connection, fun, and social events.

This summer was a busy and meaningful one for the Hearts of Gold youth group, CHN's program for teens (ages 13–18) living with heart disease. Each month, members were invited to take part in fun, pre-planned activities ranging from thrills at Playland to relaxed movie nights at the theatre.

Beyond the activities themselves, the true focus of the program has been on building peer support and lasting social connections. We've welcomed new members over the summer, and it's been inspiring to see how warmly the group embraces new teens—especially since joining a new group can feel intimidating at first. For many, recent heart procedures or medical tests can leave them feeling like outsiders, but Hearts of Gold creates a safe space where they are understood and accepted.

At its core, Hearts of Gold is about connection: connection to a diagnosis, to peers who share similar experiences, and to themselves. Through the program, teens are learning more about their needs, discovering who they want to be, and gaining the skills to advocate for themselves as they prepare for the transition to adult care.

We took on the thrills and chills of Playland, sharing laughter, excitement, and plenty of rollercoaster screams together!

We put our detective skills to the test in an escape room! While we may not have cracked all the codes, we strengthened our teamwork and had plenty of laughs along the way.

I'm looking forward to even more adventures, monthly activities, and peer support opportunities as we head into the school year. I encourage any teens involved with the Children's Heart Network to join us for upcoming events—whether it's one or all of them! Hearts of Gold is a place to make lifelong friends, share experiences, and enjoy unique activities together.

Sincerely,
-Emily Deimling; MSc, CCLS
Hearts of Gold Youth Coordinator

Any questions or comments can be sent to my email at chnheartsofgold@gmail.com

Hearts of Gold Vancouver Island | CHN also runs a Hearts of Gold Youth Group in the Victoria area.
Upcoming events for heart teens:
October 19th - Escape Room
November 16th - Laser Tag
December 12th - Limo Ride to see the Christmas lights and dinner!

For more information email Shae Mellors at viheartsofgold@gmail.com

Have you heard of Kids Up Front?

Kids Up Front recently celebrated an incredible milestone — 20 years of making memories! Since 2019, in BC they've distributed over 87,800 tickets to children and families across Canada. This one-of-a-kind organization partners with hundreds of agencies and generous donors to provide unforgettable experiences that enrich lives and bring families together.

Our Children's Heart Network families have been fortunate to benefit for many years. This summer, Nate and his family cheered on the BC Lions, while Rocco and his family were thrilled to attend the very first WNBA game in Vancouver, featuring the Seattle Storm versus the Atlanta Dream!

If you have tickets to an event that you can't use (even last minute) you can email them to Kids Up Front and they will make sure they get used and appreciated. **Email vancouver@kidsupfront.com**

Meet Dawn McKellar
Our new CHN Education Coordinator

About Me

I live on Vancouver Island with my husband and two teenagers. I love to ski in the winter and paddle board in the summer

My name is Dawn, and I am excited to be rejoining the Children's Heart Network team. Previously I worked as the Hearts of Gold Youth Coordinator and also served as a board member. Over the past 18 years, I have had the privilege of working as a Child Life Specialist at BC Children's Hospital, where I have supported children and families through complex medical journeys. I am currently based in the Multi-Organ Transplant Program and the Renal Dialysis Unit, where I remain deeply committed to providing compassionate, family-centered care. I look forward to contributing to the important work of the Children's Heart Network.

If there is something you or your family would like to learn about as it relates to your child's heart condition, or supports you would like to see, please feel free to connect with Dawn at: dawn@childrensheartnetwork.org

Gwen’s Story (cont’d from page one)

The heart community has cheered me on every step of the way, and knowing they believed in me gave me extra motivation to keep going. After six weeks I was back on my horse and nine months later, I could now run 8 km without stopping, and I had made Team Canada for youth dressage something I never imagined would be possible so soon after surgery.

I started riding when I was five, but when I was 11, I found dressage, and I knew right away that this was my sport. I love how it's all about the connection with your horse, almost like having your own secret language. That's exactly how it is with my horse, Bentley. He's not just my competition partner he's my best friend. He helped me through my recovery, I would FaceTime him every day, and he always knows how to make me smile.

Bentley and I train in Victoria, BC. We have a pretty busy schedule, balancing school and riding, but it's worth it. Bentley is so smart and always tries his hardest for me. I've learned to trust him completely, and every ride teaches me something new.

In 2025, something amazing happened, I got to represent Canada at the North American Youth Championships (NAYC) in Michigan. Think of the Olympics but for kids. It was such a dream come true, especially so soon after surgery. Bentley and I competed in the FEI Children's division and got some of our best scores ever: a 2nd place, a 3rd place, and a 6th place in our division out of 22 riders from Canada, the United States, and Mexico. I was also chosen to speak for Team Canada at the Parade of Nations, which was such an honour. Meeting riders from all over North America and taking part in media training was so cool, it made me even more excited for the future.

One of the biggest things I learned at NAYC is that it's not just about the results. It's about the friends you make, the things you learn, and enjoying every moment. I worked really hard to get there, and having the support of my heart community, my doctors, and my equestrian community meant so much to me.

Now, I'm starting Grade 9 this fall, and Bentley and I are already working toward our next goals. I want to keep getting better, compete in more shows, and hopefully represent Canada again. When I think about how far I've come from being a baby in the hospital needing heart surgery, to riding Bentley in international competitions it makes me so proud. Dr. Magic's words still stick with me, and every time I ride or run, I remember that I really can do anything I set my mind to.

PEDIATRIC CARDIOLOGY TRAVEL OUTREACH 2025-26 SCHEDULE

*Tues-Thurs clinic Clinic dates and locations are subject to change

Date	**Location**
January 7, 8, 9	Penticton
January 28, 29, 30	Whitehorse
February 4, 5, 6	Kamloops
February 18, 19, 20	Kelowna
February 25, 26, 27	Prince George
March 4, 5, 6	Trail
March 18, 19, 20	Vernon
March 24, 25, 26	Terrace
April 8, 9, 10	Williams Lake
April 22, 23, 24	Kamloops
May 6, 7, 8	Pentiction
May 20, 21, 22	Kelowna
June 3, 4, 5	Prince George
June 17, 18, 19	Vernon
June 24, 25, 26	Whitehorse
July 7, 8, 9	Terrace
July 22, 23, 24	Cranbrook
July 29, 30, 31	Kamloops
August 12, 13, 14	Kelowna
August 24, 25, 26	Fort St John
September 2, 3, 4	Vernon
September 16, 17, 18	Trail
September 23, 24, 25	Penticton
October 7, 8, 9	Prince George
October 21, 22, 23	Kamloops
November 4, 5, 6	Kelowna
November 17, 18, 19	Terrace
December 1, 2, 3	Vernon

Mental Health Check-In for Heart Kids

Living with CHD can sometimes bring extra stress, especially during busy school months. Here are a few ways to keep your child's (and family's) emotional well-being in check:

Notice changes in mood or energy

Is your child more withdrawn, anxious, or unusually tired? These can be signs they need extra support.

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Create space to talk

A simple "How are you feeling today?" can open the door to meaningful conversations.

Offer stress outlets

Drawing, journaling, listening to music, or gentle physical activity can help kids process big feelings.

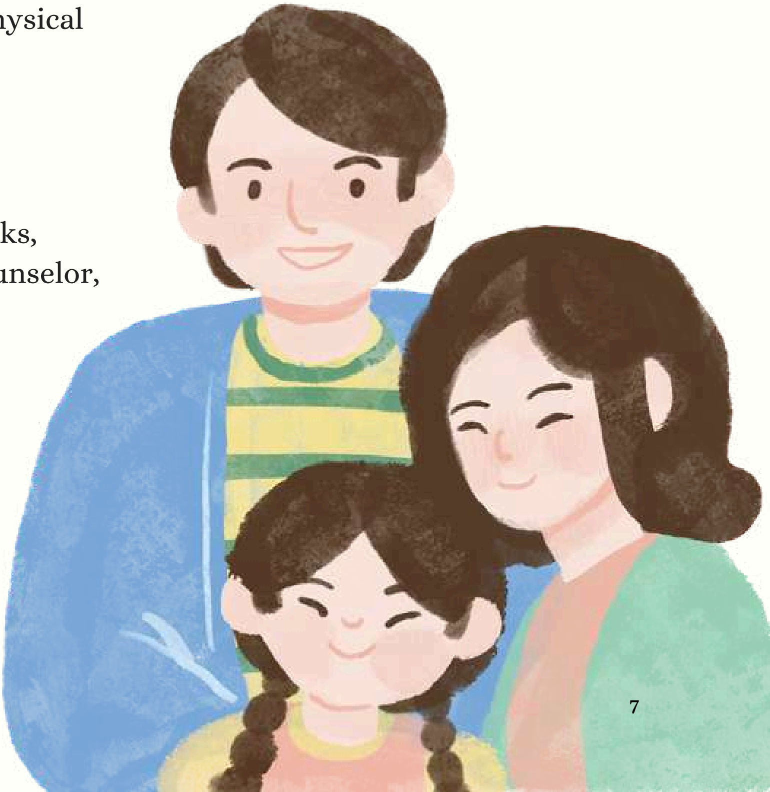
Know when to reach out

If worries or sadness last more than a couple of weeks, consider talking with your child's doctor, school counselor, or a pediatric psychologist.

Don't forget parents & siblings

Caring for a heart hero affects the whole family. Check in with yourself and your other kids, too.

Mental health is just as important as heart health. You don't have to manage it alone.
Mental Health Resources (via BCCH): QR CODE



Staying Healthy This Cold & Flu Season
Practical Tips for CHD Families

As the weather cools and kids head back to school, colds, flu, and other respiratory bugs tend to spread quickly. For children living with congenital heart disease (CHD), even a simple cold can sometimes lead to complications. Here are some ways to keep your family as healthy as possible this season:

Vaccinations matter.
Talk to your cardiologist or family doctor about flu and COVID-19 vaccines for your child, siblings, and caregivers. Vaccination helps protect your heart hero and the whole family.

Handwashing is key.
Encourage kids to wash their hands often: before meals, after recess, and as soon as they get home. Hand sanitizer is a good backup when soap and water aren't available.

Keep distance when needed.
If your child is recovering from surgery or has a higher risk of infection, consider asking teachers to seat them near the front of the class, away from kids who are coughing or sneezing.

Rest & hydration.
Fatigue can make kids more vulnerable to illness. Build in time for rest after school and encourage plenty of fluids.

Have a plan.
Ask your cardiology team what steps to take if your child gets sick — when to call your doctor, when to go to the ER, and what warning signs to watch for.

Bonus Tip: Share your child's specific health needs with their teacher and school nurse so everyone is prepared to support them during cold/flu season.
Check out our school resources here (QR CODE).

What to Do (and Not Do) When Children Are Anxious

How to respect feelings without empowering fears

By Clark Goldstein, PhD

When children are chronically anxious, even the most well-meaning parents can fall into a negative cycle and, not wanting a child to suffer, actually exacerbate the youngster's anxiety. It happens when parents, anticipating a child's fears, try to protect her from them. Here are pointers for helping children escape the cycle of anxiety.

1. The goal isn't to eliminate anxiety, but to help a child manage it. None of us wants to see a child unhappy, but the best way to help kids overcome anxiety isn't to try to remove stressors that trigger it. It's to help them learn to tolerate their anxiety and function as well as they can, even when they're anxious. And as a byproduct of that, the anxiety will decrease or fall away over time.

2. Don't avoid things just because they make a child anxious. Helping children avoid the things they are afraid of will make them feel better in the short term, but it reinforces the anxiety over the long run. If a child in an uncomfortable situation gets upset, starts to cry—not to be manipulative, but just because that's how she feels—and her parents whisk her out of there, or remove the thing she's afraid of, she's learned that coping mechanism, and that cycle has the potential to repeat itself.

3. Express positive—but realistic— expectations. You can't promise a child that her fears are unrealistic—that she won't fail a test, that she'll have fun ice skating, or that another child won't laugh at her during show & tell.

But you can express confidence that she's going to be okay, she will be able to manage it, and that, as she faces her fears, the anxiety level will drop over time. This gives her confidence that your expectations are realistic, and that you're not going to ask her to do something she can't handle.

4. Respect her feelings, but don't empower them. It's important to understand that validation doesn't always mean agreement. So if a child is terrified about going to the doctor because she's due for a shot, you don't want to belittle her fears, but you also don't want to amplify them. You want to listen and be empathetic, help her understand what she's anxious about, and encourage her to feel that she can face her fears. The message you want to send is, "I know you're scared, and that's okay, and I'm here, and I'm going to help you get through this."

7. Encourage the child to tolerate her anxiety. Let your child know that you appreciate the work it takes to tolerate anxiety in order to do what she wants or needs to do. It's really encouraging her to engage in life and to let the anxiety take its natural curve. We call it the "habituation curve"—it will drop over time as she continues to have contact with the stressor. It might not drop to zero, it might not drop as quickly as you would like, but that's how we get over our fears.

8. Try to keep the anticipatory period short. When we're afraid of something, the hardest time is really before we do it. So another rule of thumb for parents is to really try to eliminate or reduce the anticipatory period. If a child is nervous about going to a doctor's appointment, you don't want to launch into a discussion about it two hours before you go; that's likely to get your child more keyed up. So just try to shorten that period to a minimum.

9. Think things through with the child. Sometimes it helps to talk through what would happen if a child's fear came true—how would she handle it? A child who's anxious about separating from her parents might worry about what would happen if they didn't come to pick her up. So we talk about that. If your mom doesn't come at the end of soccer practice, what would you do? "Well I would tell the coach my mom's not here." And what do you think the coach would do? "Well he would call my mom. Or he would wait with me." A child who's afraid that a stranger might be sent to pick her up can have a code word from her parents that anyone they sent would know. For some kids, having a plan can reduce the uncertainty in a healthy, effective way.

10. Try to model healthy ways of handling anxiety. There are multiple ways you can help kids handle anxiety by letting them see how you cope with anxiety yourself. Kids are perceptive, and they're going to take it in if you keep complaining on the phone to a friend that you can't handle the stress or the anxiety. I'm not saying to pretend that you don't have stress and anxiety, but let kids hear or see you managing it calmly, tolerating it, feeling good about getting through it.

Read More:
Behavioral Treatment for Kids With Anxiety
https://childmind.org/article/behavioral-treatment-kids -anxiety/

How to Avoid Passing Anxiety on to Your Kids
https://childmind.org/article/how-to-avoid-passing -anxiety-on-to-your-kids/

How to Help Kids Deal With Embarrassment
https://childmind.org/article/help-kids-deal -embarrassment/

Helping Kids Who Are Scared of Going to the Doctor https://childmind.org/article/help-kids-scared-of-going -to-the-doctor/

How to Help Kids Who Are Too Hard on Themselves
https://childmind.org/article/how-to-help-kids-who-are -too-hard-on-themselves/

What Is Separation Anxiety?
https://childmind.org/article/what-is-separation-anxiety/

This article was originally published by the Child Mind Institute and has been reprinted with permission.

Supporting Children with CHDs in School

By Sonia Milbradt

Being a heart parent means learning how to navigate many systems, and the school system can be overwhelming and confusing. Children with Congenital Heart Defects (CHDs) may qualify for extra support in the way of an IEP and school adaptations.

What is a designation and an IEP?

A **designation** is an official identification by the BC Ministry of Education that recognizes a student has a special education need. A designation will open the door to resources and support. For heart kids, the designation will depend upon the need. **Category D** is for a "Physical Disability/Chronic Health Impairment", qualifies the student for additional supports, and receives additional funding provided to the school by the Ministry of Education. **Category Q** is for "Learning Disability", qualifies the student for additional supports, but does not receive additional funding. A designation may also be applied for: autism, giftedness, and mental health challenges.

A designation will lead to a personalized learning plan. An **IEP** (may be referred to as a CB-IEP) is a competency based Individualized Education Plan – a legal document that outlines a student's profile, strengths and stretches, accommodations/supports, and customized goals. The student's **case manager** (a member of the Student Services team who acts as the main point of contact for designated students) will update the IEP yearly. Parents/caregivers are a key part of the IEP process and support team and have a right to participate in this process.

How to Get a Designation

It is important to note that D and Q designations are granted based individually on a student's needs. For a Category D designation, there must be documentation to demonstrate that the "students' functioning and education is significantly affected by their physical disability or chronic health impairment". For a Category Q designation, a learning disability must be diagnosed through a formal cognitive assessment. If you notice your child is struggling in school, speak to your child's classroom teacher and principal.

- Request a psychoeducational assessment

Or

- Submit documentation of an existing diagnosis (done through your family doctor/pediatrician or private provider)
- Ensure your school has access to all medical reports, diagnosis letters, and assessments relevant to your child's needs

Advocating for Supports for Your Child

- Build relationships with your school team – collaborate and communicate clearly and respectfully
- Participate fully in IEP updates
- Be clear and persistent about supports your child needs (extra time, sensory breaks, alternate options to present learning, services like an OT/PT/EA, etc.)
- If you feel like the support is insufficient, request a SBT (School Based Team meeting)
- If concerns persist, you can escalate to your District Principal of Learning Support

Navigating this process can be complex and slow, but it is important you stand up for what your child needs. A meaningful partnership with your child's school team with open communication is essential. Getting a designation and an IEP will open the door to resources and supports for your child to be successful.

Save the Date: The Children's Heart Network Gala returns May 8, 2026!

For over 21 years, our Gala has brought the community together to raise over $1 million in support of children with congenital heart disease and their families. Thanks to your generosity, we're able to provide vital support to over 600 families each year, helping them build cherished memories and find strength in a caring community.

This year marks our 22nd celebration, and we can't wait to welcome you back for an unforgettable night of connection, generosity, and hope.

🎟 Tickets on sale January 2026!
💖 Be part of this milestone year.
📍 Friday, May 8th, Arras Ballroom – Vancouver