

HEART MATTERS



With Heartfelt Thanks to Triple Crown for Heart

The Children's Heart Network (CHN) extends our sincere thanks to the Triple Crown for Heart organizing committee, riders, volunteers, and donors for their continued commitment to heart families across British Columbia.

Triple Crown for Heart is an annual charity cycling event that challenges participants to climb one, two, or all three North Shore mountains — Seymour, Grouse, and Cypress — in a single day. The ride brings together cyclists of all levels in support of heart families across BC. This year's ride will take place on July 18, 2026, more information is available at triplecrownforheart.ca.

The Triple Crown for Heart donates the money raised to both the Children's Heart Network and BC Children's Hospital Foundation. In 2024 the TC4H donated \$20,000 and in 2025 it was an incredible \$31,500 for the Children's Heart Network. These funds will help support our children's, teen, and family camps, where families affected by congenital heart defects can connect, share experiences, and build lasting relationships. These programs create spaces where children and teens feel understood, and where families are reminded they are not alone.

The success of Triple Crown for Heart is the result of months of thoughtful planning and dedication by the organizing committee. Their hard work behind the scenes ensures the ride is not only well run and safe, but also welcoming and meaningful for everyone involved.

We are deeply grateful for the time, care, and energy they give year after year in support of our community.

Volunteers play a vital role in bringing this event to life, from supporting riders along the route to cheering them on at the finish line. We warmly encourage members of the CHN and the congenital heart community to consider volunteering and being part of this inspiring day.

To everyone involved — thank you. Your generosity and dedication continue to strengthen our heart family community across BC and make these vital programs possible.

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CHN's Valentine Chocolate Sale

Thursday, February 12th at BCCH from 9:00am to 3:00pm

Purchase some top-quality Daniel's Belgian Chocolate for Family and Friends and support The Children's Heart Network.

CHN's 22nd Annual Gala Dinner - Don't Miss the Event of the Year!

We are thrilled to announce that our annual gala, "An Evening for Every Heart" will be hosted at a brand new venue - **The Arras Ballroom** just off Granville and West 7 in Vancouver. Join us for an unforgettable evening - a three course dinner with expertly selected wine pairings, the infamous silent and live auctions, and some surprises to be announced soon!

Sponsorships are still available. Please email serenamawani@gmail.com for more information.

Date: Friday, May 8th at 6:00pm

Location: The Arras Ballroom, 1464 West 7th Ave, Vancouver

Tickets: Early Bird Tickets \$275 until March 30th, then \$300. A tax receipt for \$150 will be issued for each ticket.



Gather your friends, organize a table, and join us in supporting the Children's Heart Network. Together, we can make a difference!

Hearts of Gold – Lower Mainland and Victoria

Hearts of Gold is a community for teens aged 13–18 who have congenital heart conditions. The group meets monthly for fun and engaging activities, including hockey games, ceramic painting, dinner and a movie, skating, bowling, Playland visits, and an annual trip to Camp Zajac.

If you are a heart teen or a parent of one and would like more information about joining a Hearts of Gold group, please contact the appropriate coordinator:

- Lower Mainland: Emily Deimling – chnheartsofgold@gmail.com
- Victoria/Island: Shae Mellors – viheartsofgold@gmail.com

Our CHN Spring Event for Heart Families will be held on March 29th from 2-4:30pm at Bonsor Recreation Complex in Burnaby. Mark your calendar. We will have Easter crafts, a magician, pizza and more! Watch for the invitation in early February.

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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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WHAT'S HAPPENING

Are you ready for CAMP?

Hearts of Gold Youth Camp for teens 13-18 years old will be held at Camp Zajac in Mission over the May long weekend, May 15-18th. If you are a heart teen and you want to have tons of fun while connecting with other youth living with CHD then sign up for camp!

If you live on the Island or outside the lower mainland we will be able to help cover transportation costs. Please email saitken@childrensheartnetwork.org
CHN will cover all cost other than a \$75 registration fee.

To register for HOG camp click HERE and when you get to the payment section choose the option to have CHN cover the cost.

Heart Beats Camp for children ages 8-13 years old will be held at Camp Zajac in Mission from July 20-24th. Parents will drop off their children at camp on Monday morning and then pick them up on Friday morning. Have a great time while connecting with other heart kids your age. Swimming, Ropes Course, Arts & Crafts, Games, Horseback Riding, Campfires and more!

If you live on the Island or outside the lower mainland we will be able to help cover transportation costs. Please email saitken@childrensheartnetwork.org
CHN will cover all cost other than a \$75 registration fee.

To register for Heart Beats camp click HERE and choose the Mixed Medical camp July 20th. When you get to the payment section choose the option to have CHN cover the cost.

Family Camp:

This year we will host one Family Camp at Camp Kawkawa near Hope, BC on the weekend of June 19-21st. Watch for the email invitation in February!

If you live on the Island or outside the lower mainland there may be some support to help cover transportation costs. Priority will be given to those families that have not yet attended a Family Camp. We hope that you can join us!



What is Marfan Syndrome?

By Leslie Raffin RN BScN Cardiology Nurse Clinician

Not all the children we see in the heart center have heart defects they were born with.

Some have connective tissue diseases such as Marfan syndrome, Loeys Dietz syndrome, FTAAD and several others that affect the aorta, mitral valve, pulmonary valve and other blood vessels in the body. The heart center follows approximately 200 children with genetic diseases that affect the aorta.

About 1 in 5,000 people have Marfan syndrome, including men and women of all races and ethnic groups. About 3 out of 4 people with Marfan syndrome inherit it, meaning they get the genetic mutation from a parent who has it. But some people with Marfan syndrome are the first in their family to have it; when this happens, it is called a spontaneous mutation. There is a 50 percent chance that a person with Marfan syndrome will pass along the genetic mutation each time they have a child

- (Marfan Foundation@Marfan.org)

Connective tissue is found in every single part of the body except the hard lens in the eye. So, patients with Marfan syndrome can also affect the tissues that hold the eye lens in place, the lungs, spine, feet, spinal cord sac and skin.

Children are usually diagnosed when physical features start appearing, such as scoliosis, turned in ankles, eye lens slipping or when there is another family member known to have Marfan syndrome.

Very rarely, a child is diagnosed when they are infants, and this is usually a more severe case.

We prescribe medications to slow down the rate that their aorta grows as well as try to prevent aneurysms and dissection.

Children with Marfan syndrome are often followed by cardiology, orthopedics, respirology, genetics, ophthalmology and sometimes we add physiotherapy and pain specialists.

These children may require surgery on their spine, feet or heart and may have complications from pneumothorax (lung) or spinal dural ectasia.

They require lifelong monitoring and family planning counselling along with expert care. At graduation from the heart center, we give extensive teaching on medications, lifestyle, testing and monitoring.

2026 is an excellent time in history to be living with Marfan syndrome as new treatments improve and extend lifespan.



SAVE THE DATE

The 3rd Heritable Aortic Disorders Symposium
will be held in Vancouver May 22+23
heritableaorticdisorders.com



Our Family's Journey With Neonatal Marfan Syndrome

By Kris & Ashley Armstrong



February 13, 2020, our family's life changed, the day Brooks entered the world. Along with the joy of welcoming him, we were introduced to a diagnosis most people have never heard of: Neonatal Marfan Syndrome. It is rare, complex, and relentless—and it affects every part of Brooks' body, and every part of our lives.

Twice a year, we travel to BC Children's Hospital, where Brooks is followed by a dedicated team of specialists. These visits are essential. His care requires coordination between multiple experts, each monitoring a different piece of a very complicated puzzle. While those trips bring reassurance, they are also a reminder of how fragile and serious his condition is.

A significant part of that weight comes from Brooks' heart. Knowing that multiple heart surgeries are not a question of if, but when, is a constant source of stress and fear for our family. Each cardiology appointment—often twice a year—brings heightened anxiety as we wait to hear if things are stable or if the next major step is approaching. Those visits linger long after they're over, carrying emotional strain that's hard to put into words.

What most people don't see is that Brooks lives in constant pain. Pain is his baseline. It's there when he wakes up, when he plays, when he rests, and when he goes to sleep. As his parents, it is heartbreaking to watch your child push through discomfort just to do things other kids take for granted. There is no off switch. No break.

Because Marfan Syndrome is so poorly understood, especially the neonatal form, much of our journey has been spent fighting—fighting for answers, for care, for understanding, and for accommodations.

We often find ourselves explaining Brooks' condition to teachers, caregivers, and even medical professionals who have never encountered it before. Advocacy isn't optional for our family; it's survival.

And yet, in the middle of all of this, Brooks is a fighter. He doesn't see himself as different. He wants to be just like every other kid. He pushes himself daily to keep up, to stay involved, to make sure he isn't left behind. Whether it's playing, learning, or simply being part of the action, Brooks gives everything he has—even when his body tells him to slow down.

One of his greatest joys is playing with his brother. Their bond is pure and powerful, filled with laughter, imagination, and moments that remind us why we keep fighting so hard. Brooks is also wonderfully quirky, endlessly curious, and absolutely full of life. His smile can light up a room. His determination humbles us. His spirit inspires everyone who truly gets to know him.

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Neonatal Marfan Syndrome may shape Brooks' life, but it does not define who he is. He is more than his diagnosis. He is brave, resilient, loving, and strong in ways most adults will never need to be.

Our family didn't choose this journey—but we will continue to walk it beside Brooks, advocating fiercely, loving deeply, and believing in him always. Because if Brooks has taught us anything, it's that strength doesn't always look loud or obvious. Sometimes, it looks like a little boy who keeps going—no matter what.



Smooth Sailing: Let's Talk Transition

Join us for a virtual workshop to learn more about navigating the transition to **adult healthcare**. The workshop speakers include young people who have already transitioned to adult care, who will share what they learned from their experiences, and provide valuable tips and advice to help you sail smoothly through any changes that come your way. Don't miss out on this opportunity to connect with others and gain the tools you need to thrive during this time. See you there!

Workshop content includes:

- What is transition and why is it important?
- Let's talk change: Differences between pediatric and adult care
- Taking charge of your health and gaining independence
- Travel, attending post secondary, and moving away from home
- Your safety plan toolkit: How to prepare for a health emergency

Who should attend: Any young person (16 – 25 years) who is transitioning to adult care services. Parents or guardians are also encouraged to attend.



Workshop Dates:

- **Monday, February 2nd from 6:30 – 7:30 pm**
- **Thursday, May 14th from 6:30 – 7:30 pm**
- **Wednesday, September 9th from 6:30 – 7:30 pm**
- **Tuesday, November 24th from 6:30 – 7:30 pm**

For more information and to get the Zoom link sent to you to access the workshop, please contact: Emma Iacoeatemma.iacoe@phc.ca – Leader of the Scotiabank Youth Transition Program at St.Paul's Hospital in Vancouver.



CHN Celebrates the Holidays!

WINTER 2026

Vancouver Island

We had our Annual Holiday party at Butchart Gardens on Dec. 6th and it was a huge success! Our Island CHN families met in the Carousel Room for a party that started with rides on the famous menagerie carousel comprised of 30 hand-carved wooden animals. Families enjoyed arts & crafts, hot chocolate and treats while connecting with others on similar heart journeys with their children. After the party all families were able to enjoy the incredible holiday lights all over the gardens!

Okanagan

We were thrilled to host the 4th Annual Pancake Breakfast in Kelowna with the largest group attending ever! Long time heart mom, Deb Dachwitz, her adult heart son Joey, our friend Leo Rutledge (Santa) and heart moms Jessica Hamilton and Leanna Drummond made all the magic happen. We had a wonderful Breakfast with Santa on Dec. 6th at the Coast Capri Hotel. Families came from far and wide to join in the fun and some took advantage of the "Take the Elevator Home" special room rate offered by the hotel and made a weekend out of it. After a plentiful buffet breakfast, some crafts and cookie decorating, a very special guest arrived! Heart parents made new connections and children made new friends leading the way to many more fun Okanagan CHN events. If you live in the Okanagan and have an idea for a spring or summer CHN event, please email us at saitken@childrensheartnetwork.org



Lower Mainland

This year's event was such a fun, festive day! We had over 250 heart family members join us at the Delta Grand Villa Hotel in Burnaby to celebrate the holidays. Again, every child got to pick out a stuffy to take home thanks to an amazing donation from Starlight Children's Foundation. Families were dressed up, enjoyed a fabulous brunch, and then took part in face painting, balloon animals, Christmas crafts, assessing the dozens of raffle prizes, and cookie decorating. The highlight for the little ones was undoubtedly the arrival of Mr. and Mrs. Claus, who spent time chatting with all the children, everyone providing big smiles for our amazing guest photographer.



A huge heart-felt thank you goes out to Bonnie Wu, her parents and her heart son Eddy, they donated a plethora of fantastic toys to the raffle so it was the most successful one we have had yet! We would also like to thank Dr. Potts, his assistant Bryan Chow, our team of volunteers and the following sponsors, without whom this event would not be possible: Dakota Best and family for the fabulous ceramics the children got to paint, The Delta Marriott Hotel, Fratelli Bakery, Daniel Chocolates and all the families and businesses that donated to the raffle.

Thank you RBC!

RBC's Employee Volunteer Grant Program offers financial support to charities where their employees and retirees actively volunteer at events, providing grants for logged volunteer hours, with specific programs like the Communities Together Fund for team projects. This unique, employee-driven initiative combines funding and volunteerism to make a tangible difference in our communities. This year, the CHN was supported by a team of RBC employees at three of our events. They volunteered at our Annual Gala dinner, our Pumpkin Patch event for heart families in October and more recently at our Breakfast with Santa in Burnaby. We are so grateful for the support of team leader Kitty Leung, her group of volunteers and to RBC for their hard work and donation in support of our BC heart families!



FREE IN-PERSON CONFERENCE!

From Pediatric to Adult Care: Empowering Your Journey.

Supporting Young People with Congenital Heart Disease (CHD) in their Transition to Adult Care.

Hosted by: The Virani Provincial Adult Congenital Heart (VPACH) Program at St. Paul's Hospital in collaboration with BC Children's Division of Cardiology

What to Expect:

- Education & information sessions about CHD and transition with Congenital Cardiologists, Cardiac Surgery, Nursing and more!
- Interactive Q&A with experts and patients with lived experience.
- Tour of the St. Paul's Hospital Cardiac Clinic and testing areas.
- Peer engagement opportunities for young people with CHD.

Who Should Attend:

Young people (ages 16–25) with CHD and their parents or guardians.

- No registration fee.
- Limited spots – first come, first served.

(Maximum 3 people per family; all must register).

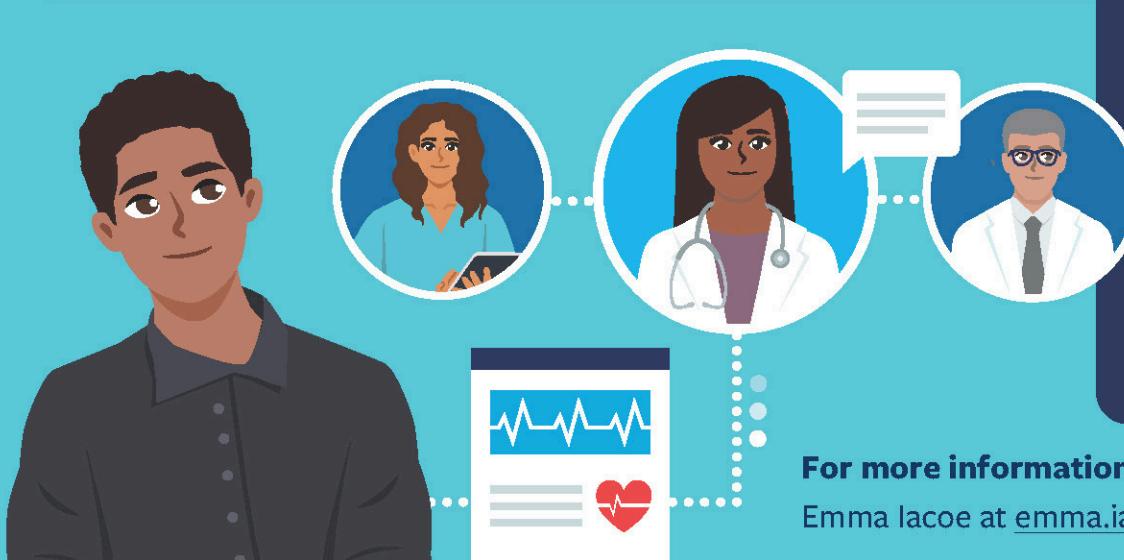


When: Saturday, March 7, 2025

Where: St. Paul's Hospital – Cullen Family Theatre (Level 1, Providence Building)

- Registration: 8:30 AM
- Opening Remarks: 9:00 AM
- Conference ends: 2:45 PM

Lunch and refreshments included!



Register Now

by visiting:
tinyurl.com/bdd3hs25

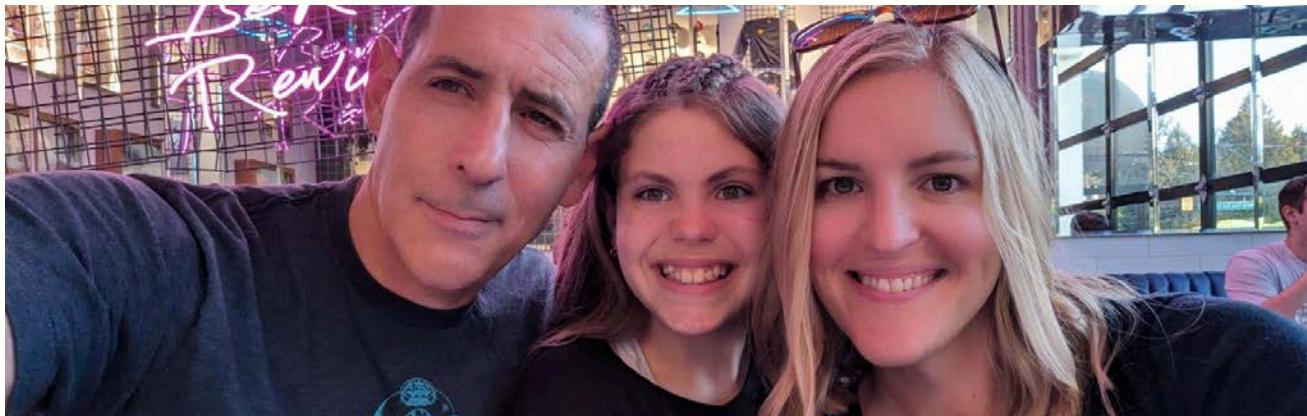
Or scan this QR code:



For more information about this event contact:
Emma Iacoe at emma.iacoe@phc.ca

New Board Members:

Meet Juli Halliwell-Ferrero



Juli has worked in municipal government for 20 years and is currently with the City of Burnaby. She completed her Master of Arts in Leadership (Executive Specialization) in 2023 from Royal Roads University and has served on a number of not-for-profit society boards throughout her career. Juli became a Heart Mom when her daughter Hannah was born in 2011. Hannah was born with a pulmonary valve stenosis and atrial septal defect (ASD), along with some development related challenges. Hannah's first heart surgery was at 16 months old to correct both heart defects and it was then it was discovered that she also had an aortic valve stenosis, which was corrected through a second surgery when she was 3. It was early on in Hannah's life that Juli learned about the CHN and she is thrilled to be able to give back to such an important organization as a board member. Juli lives an active lifestyle in Coquitlam with her daughter, husband and two GSDs (German Shepherd Dogs).

Meet Kris Armstrong

Kris joined the Children's Heart Network after his son was diagnosed with congenital heart disease. Their family has navigated multiple stages of care, and the support from CHN and other heart families has been an important part of their journey. Kris and his family live in British Columbia, where they stay active in the heart community and enjoy giving back to the families who supported them early on.

Kris is an advisor with a wealth management company, where he supports individuals and families in achieving their financial goals. He is passionate about advocacy, connection, and ensuring parents feel supported from the moment they begin their heart journey.

"I am incredibly grateful for the encouragement, understanding, and strength we've received through CHN. Knowing that you're not alone in this overwhelming and emotional experience brings a comfort that is hard to describe. I'm honoured to serve on the CHN board and to help other families find community, hope, and confidence as they navigate their own unique paths. Every story is different, but the threads that connect us make us stronger."

The heart of advocacy

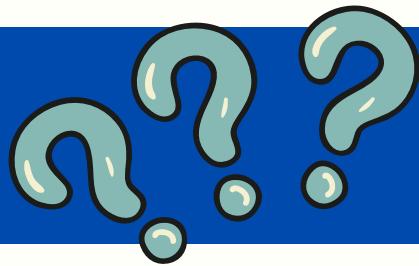
By Dawn Mckellar, BC, CCLS Education Coordinator CHN



When your child was first diagnosed with heart disease, you were likely thrown into a world of unfamiliar terminology, intense emotions, and decisions that may have felt overwhelming. Becoming an advocate may not have been on your mind in those early moments. Yet as a parent of a child with a medical condition, you quickly become aware that your voice has such an impact on the care they receive. You understand your child's needs, their personality, their schedule, and their history better than anyone else, making your perspective invaluable in every healthcare interaction.

This article explores evidence-based, practical strategies to help you navigate the healthcare system with confidence and learn how to advocate effectively for your child. Advocating for your child means giving your child a voice. It means standing up for their best interests, helping ensure they receive the best possible outcomes, and making sure their needs are never overlooked.

Advocacy does not require medical expertise, special training, or unshakable confidence. What it needs is a willingness to engage in honest conversations with your child's healthcare team—sharing your concerns, your observations, and your hopes—and working together to create a plan that supports your child's health and well-being.



You may wonder

**What if I'm overreacting? What if I'm asking too many questions?
What if I'm missing something important?**

These feelings are normal - and they are signs that you care deeply

Below are practical tips to help you partner confidently with your child's healthcare team, ask meaningful questions, and ensure your child receives the thoughtful and comprehensive care they deserve.

1

Acknowledge the emotional weight of the journey

Caring for a child with heart disease can carry an intense emotional weight for parents and caregivers; the experience often brings a complex mix of fear, grief, hope, and exhaustion- emotions that often shift and intertwine from day to day. While every parent's experience is unique, one truth remains constant: these feelings are normal, and acknowledging them is an essential part of navigating the journey.

- **Ask questions—again and again if needed.** Medical information can feel overwhelming, and it's perfectly reasonable not to understand everything right away. Healthcare providers have spent years mastering this knowledge, and they expect parents to seek clarity. Continue asking until you feel confident.
- **Seek emotional support within and beyond the healthcare setting.** Nursing clinicians, social workers, child life specialists, psychologists, and other mental health professionals are often available to help parents process their emotions and learn to advocate effectively for their child. These professionals understand the pressures families face and can provide guidance, reassurance, and coping strategies.
- **Connect with local support groups.** Speaking with other parents who have walked a similar path can offer comfort, perspective, and practical advice. Resource parents and peer networks can help you feel less alone and more empowered.

Research consistently shows that when parents feel emotionally supported, they are better prepared to advocate for their child's needs.



Know your child's condition

Gaining a thorough understanding of your child's heart condition is one of the most empowering steps you can take as a parent or caregiver. When you're well informed, you can participate more confidently in conversations with the healthcare team and play an active role in shaping your child's care plan and ability to advocate for your child.

Try to become familiar with the following key areas:

- **The name of the heart condition and what it means:** Understanding the diagnosis helps you explain it to others and recognize what to expect.
- **Common symptoms and when to seek urgent care:** Knowing warning signs ensures you can act quickly if something feels wrong.
- **Medications your child takes:** Keep an updated list of names, doses, and purposes.
- **Expected course of treatment or surgeries:** Being aware of upcoming procedures helps you prepare both practically and emotionally.
- **How the condition may affect daily life:** This includes growth, feeding, energy levels, school activities, and overall family routines.
- **Communication channels with the care team:** Clarify the best way to reach your child's providers between visits.



Shared decision making

Shared decision making is recognized by heart health organizations as a cornerstone of care for children with congenital heart disease, helping families to stay informed, feel informed, respected and empowered throughout their journey.

When your child's care involves complex choices—such as surgery, interventional procedures, medications, feeding plans, or long-term management—shared decision-making becomes a vital part of the process. As parents, you bring deep knowledge of your child's daily life, your family's routines, your responsibilities, and your values. The health care team brings medical expertise and experience. Working together, you can create a treatment plan that feels informed, balanced, and aligned with what matters most to your family.

How to Support Shared Decision-Making

- **Communicate your goals, concerns, and priorities:** Let the health care team know what is most important to your family, including fears, cultural values, and practical realities.
- **Take time when possible:** If a decision doesn't need to be made immediately, use the time to process the information, ask questions, and explore options.
- **Ask for clarification:** If any option or recommendation is unclear, ask the team to explain it again.
- **Understand a “watch-and-wait” plan:**
If monitoring is recommended, make sure you clearly know what symptoms or changes should prompt a call or urgent visit.
- **Maintain a positive connection:**
Expressing appreciation helps strengthen communication and trust, especially during stressful moments.



4

Keep an Organized System for Your Child's Heart Condition

Staying organized can support advocacy and be a powerful tool for managing your child's heart condition. Many parents find comfort and confidence in keeping all essential information in one dedicated place. Whether you prefer a physical binder or a digital folder, having a centralized system becomes valuable during clinic visits, emergencies, routine check-ins and can help when transitioning from pediatric to adult cardiology care.

What to Include in Your Binder or Digital Folder

- **Medical history:** Diagnosis, surgeries, procedures, current and past medications, and growth charts. Essential health information: Allergies, baseline vital signs, and emergency instructions.
- **Contact lists:** Phone numbers and emails for your child's cardiologist, pediatrician, specialty teams, and other key providers.
- **Discharge summaries:** Instructions and notes from any hospital stay or procedures.

5

Be Prepared for Clinic Appointments and Hospital Rounds

Clinic visits and hospital rounds can sometimes feel fast-paced, overwhelming, or intimidating—especially when you're trying to absorb information and advocate for your child at the same time. However, these moments are important opportunities to voice concerns, clarify instructions, and ensure that you fully understand your child's care plan. Being prepared can help you feel more confident and help the medical team better support your family.

Tips for Being Prepared

- Write down any symptoms or concerns you have noticed.
- Ask for clear explanations. Encourage the healthcare team to break down the diagnosis, procedures, and treatment plans in plain language. Visual diagrams or explanatory videos can be beneficial for understanding how your child's heart differs from a typical heart.
- Come prepared with questions: Think about your child's unique needs and what you can do at home to support their health and comfort.
- Request educational resources: Ask for diagnosis-specific handouts, trusted websites, and information from children's cardiac foundations. Reliable materials can help you feel more prepared and less overwhelmed.
- Take breaks when needed: These conversations can sometimes be emotionally draining. If you feel overloaded, let the healthcare professional know that you need a moment to pause and regroup.
- Find out who is on your child's healthcare team and their roles, so if you have specific questions, you can direct them to the right person.
- Take notes or ask permission to record instructions, so you don't miss important details.

6

Trust Yourself

As a parent, you are an expert on your child. You notice the subtle changes—the quiet shifts in energy, behaviour, or comfort—that others may easily overlook. Trusting your instincts is not only valid but essential, especially when caring for a child with a heart condition.

If something feels off, speak up, even if you worry it might seem like "overreacting." Many parents of children with heart disease share that listening to their intuition led to earlier medical attention and, ultimately, better outcomes. Your voice matters. Your instincts matter. And when it comes to your child's health, you are one of the most important advocates on the team.

Remember as your child is watching you advocate for them you are in turn teaching them to be self-advocates. This should be a goal you have in mind as your child moves through childhood, adolescence and eventual transition to adult care.

Final Thoughts

Advocating for a child with heart disease is both challenging and deeply meaningful. It requires strength, persistence, and courage—but it also allows you to make a profound difference in your child's health and well-being. By staying informed, asking thoughtful questions, partnering closely with your child's care team, and trusting your own intuition, you help ensure that your child receives the attentive, compassionate, and high-quality care they deserve. Your voice matters, and your advocacy truly makes a difference.

How the CHN can help support you:

Resource Parent Support

Please email chn@childrensheartnetwork.org to get connected to one of our resource parents



Monthly coffee groups

Did you know that the CHN has monthly coffee groups across the province? Contact chn@childrensheartnetwork.org or check out our website childrensheartnetwork.org

