



Izaiah's Story

BY STEFANIE SCHILLING

Looking at this smiling, 11-year-old boy, with his swept-to-the-side long hair, you would never guess the turbulent start he had in this world and what it has meant for us to be connected to the Children's Heart Network during this time. Izaiah Sergioneo Schilling-Regala was born on November 30, 2007, at BC Women's Hospital in Vancouver. There were no complications during the pregnancy or during his birth, but our doctor, Dr. Ferguson, did detect a heart murmur.

It was still present a day later and Dr. Ferguson explained that one in 100 newborns have heart murmurs, but only one in 10 of these need heart surgeries.

Izaiah fell in that one in 10. The murmur hadn't been diagnosed in utero because it was only noticeable once Izaiah started breathing on his own. At less than a week old, he was diagnosed with a ventricular septal defect, an atrial septal defect, and a

coarctation of the aorta. Izaiah was admitted to the cardiac ward and a week later, he underwent open-heart surgery. My wife Stefanie and I stayed with him round-the-clock the whole week until they sent us home after his operation.

I remember it was not long after we left the hospital when we got one of the worst phone calls a parent can get. To this day, seeing a call display showing the number of the hospital traumatizes me. We will never forget the nurse's voice. It was grave and monotone and she said we had to return immediately.

Hours after his surgery, Izaiah wasn't doing well. Our cardiac surgeon, Dr. Campbell, got back to the hospital just as Izaiah's heart stopped. Dr. Campbell physically pumped Izaiah's heart with his hands for 15 minutes and then put him on ECMO (extracorporeal membrane oxygenation). ECMO involves a pump

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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.

-  @ChildrensHeartNetwork
-  @Childrens_Heart
-  @childrensheartnetwork

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 – **Rachel Gammon**
footballmama02@hotmail.com

CHILLIWACK – **Melissa Martz**
mellymartz@outlook.com

KAMLOOPS – **Miranda Brown**
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kwalker@childrensheartnetwork.org

VANCOUVER – **Samantha Aitken**
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VICTORIA – **Teri Godin**
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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 Orphans' Fund for their generous support of our Heartbeats and Hearts of Gold camp programs.



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that circulates blood through an artificial lung and then back into the bloodstream, essentially “heart-lung bypass” outside the baby’s body.

Two weeks later, Izaiah was stronger and was taken off ECMO. The next five months were like a roller coaster ride for us as Izaiah moved between the ICU and the cardiac ward to address various respiratory distresses. BC Children’s Hospital became our home. The caregivers were like our family. This is also when we first connected with the Children’s Heart Network (CHN). Eventually, through CHN’s Coffee Groups, Stefanie connected with many parents of children with various heart conditions. She would go on to attend CHN Coffee Groups in Richmond and later, she started a group in Vancouver and became a resource parent.

In September 2009, Izaiah had his second heart surgery to widen his aorta. They were able to do this one without opening up his chest. His aorta was so weak he had to be put into a medically induced coma for a week to keep his blood pressure low in order for scar tissue to build and strengthen it.

In January 2014, he had another open heart surgery to repair an obstruction in his lower ventricle outflow tract and to widen an area near his aortic valve. Shortly after this, the doctors performed another surgery to adjust and correct the outcome of the initial one.

Perhaps because Izaiah had been bedridden, with very little physical activity for a long time, his feet and ankles didn’t develop properly. This meant that he walked on his tippy toes, his heels not hitting the ground. In February 2016, after trying other surgery with little success, Izaiah underwent a massive reconstruction of both his feet and ankles. His doctor, Dr. Alvarez, extended his foot tendons by transplanting his upper leg tendons. Izaiah spent six months in recovery. He couldn’t walk for almost three of those and was confined to a wheelchair. I am forever

empathetic to people who use wheelchairs long term and am thankful that Izaiah’s time in one was only a brief stint. In the end, it was more than worth it because Izaiah loves to play basketball, and after the extension, he was able to fully plant his foot on the ground and shuffle with balance.

In January 2018, Izaiah was diagnosed with five non-cancerous tumours on his right hand. All I could think of when they were testing them was that memory from his first days as a baby when the doctor told us that only one in 10 babies with a murmur will need heart surgery. Thankfully, they ended up being benign and Izaiah spent about six months recovering from their removal.

Which brings us to today. There is a neonatal follow-up program that tracks children who were put on ECMO (infant life support) and we continue to see the doctors there every four years or so. Recently, we went to see them so they could measure Izaiah’s lung capacity. It turned out to be Dr. Seear who was on duty for our check-up. We hadn’t seen him for so long. He was the doctor, who, almost 10 years ago, told us, in the ICU, that Izaiah might not make it through the night. He was also there for us when Izaiah was able to leave the hospital five months later. It was an emotional moment when Dr. Seear recognized and called out Izaiah’s name and saw him, now a healthy and active 11-year-old boy. We all felt so very blessed and thankful when Dr. Seear reported Izaiah had 70 percent lung capacity, an excellent level, considering his medical history.

Some days I get frustrated with Izaiah because he’s a preteen boy; however, then I remember those times when I just wanted him to make it through the night.

Through all of this, we have found support and camaraderie through the CHN. One of Izaiah’s best friends is a fellow heart kid and he always looks forward to attending events with him. It is a great way to connect with families who have had similar experiences. ♥





Our Heart Journey

BY SHELLEY EIJBENSEN

The day Seth arrived was a happy day. He was a healthy 8 pounds, 11 ounces, and I was finally done with morning sickness. Little did we know what the next year would bring. Seth's older brothers, Zackary, 7, and Josiah, 9, loved holding and watching him. They loved his every finger and toe and welcomed him into our active household.

From the beginning, however, I noticed things were different with Seth. His appetite was minimal. We had to feed him more often because he would simply refuse to eat more than 4 ounces at a time. He spit up a lot, which my older boys did too, but he wasn't gaining weight like they did. I was concerned, but at the monthly checkups, he was still progressing up the weight charts, even though it was slow. He was also noticeably a calmer baby, but with two very active other children, I was completely happy with that since I had no idea why he was so calm.

A few days before his first birthday, Seth got really sick. We took him to Emergency at Langley Memorial Hospital, where they took blood work and x-rays and diagnosed him with pneumonia and respiratory syncytial virus, or RSV. Healthy children can fight RSV, but Seth was having a hard time doing so because he had an undetected heart defect that was forcing his lungs and heart to work overtime.

He was put on antibiotics and kept in a special room. His heart monitor kept beeping because his oxygen level wouldn't hold and he was not improving. After another sleepless night, with nurses and the doctor not sure why his condition wasn't changing, Seth was transferred to BC Children's Hospital.

When we arrived, heart surgeon Dr. Gandhi took one look at Seth's x-ray and identified his heart defect as total anomalous pulmonary venous return (TAPVR). He was surprised Seth was doing so well up until now. We were grateful to be in Dr. Gandhi's care, but it was a hard thing to absorb. When he started talking about open-heart surgery, it felt like we were in a dream. Our healthy boy had a heart problem?

However, all the odd symptoms in his first year now made more sense. We celebrated Seth's first birthday in the hospital as he recovered from RSV. The staff were amazing. There were balloons and a present for Seth. They certainly made things easier for all of us.

Six weeks after we were discharged, Seth was scheduled to have his heart surgery. As a family, we enjoyed every minute of those six weeks with him. It seemed so important to enjoy each one to its fullest. My husband's parents flew in all the way from Belgium to watch Josiah

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Our Heart Journey, continued from page 4

and Zack so we could be at the hospital with Seth.

Again, the staff and surgeon at BC Children's Hospital were amazing and supportive. Four days after Seth's open-heart surgery, he was able to go home. He took a few weeks

to get back to himself, and then I realized I no longer had a calm, little boy on my hands. He hasn't stopped since that day and we are so very thankful for that. ♥



Seth visiting Paris with his family



Seth with his brothers in 2018

Kids Up Front Makes Christmas Very Special!

Dear Children's Heart Network and Kids Up Front,

Thank you so much for the December 23 Nutcracker Goh Ballet tickets you so generously gifted my daughter and me. We had never been to any professional ballet before and were so delighted by the outstanding talent during the performance. My 11-year-old daughter Lauren loved the little sheep the best, and I just loved it all! Lauren has her first open-heart surgery on February 26 at Vancouver Children's Hospital and so this outing was a real treat to take her mind off the upcoming ordeal.

Thank you again!

Sincerely,
Pam and Lauren Bews

Kids Up Front distributes tickets to arts, culture, and sporting events to deserving kids and their families. CHN is grateful for the joy Kids Up Front brings to our heart families! ♥



News from the Cardiology Partnership Program

BY THE CARDIOLOGY PARTNERSHIP NURSE CLINICIANS

Most families who live outside the Vancouver area are familiar with the Cardiology Partnership Program. It is an incredibly successful program of travelling pediatric cardiology clinics that was envisioned over 20 years ago by Dr. Derek Human, and developed by the pediatric clinical nurse specialists. For the past 18 years, Stella Cockett has been the primary coordinator and nurse clinician for the program, making up to 23 trips per year around the province with one of the cardiologists and echo techs, to see patients who would have otherwise needed to travel to BC Children's Hospital for their appointments. It is with great pride in Stella's commitment to our cardiology families, and in her many accomplishments and contributions to this program, that we announce Stella's upcoming and well-earned retirement. Her commitment to the Children's Heart Network, her involvement in creating a pathway to continuing care from adolescence through adulthood, and her enthusiasm in improving and growing the role of the nurse clinician are surpassed only by her passion for the children and families she has cared for over the years. While Stella would wish to

say goodbye to each family and co-worker in person over scones and tea, we recognize that the size of program and the province makes this impossible, and instead we are taking this opportunity to reach out to her and say goodbye to our exceptional co-worker, friend, and nurse. And of course, tea and scones (and dark chocolate) will always be a welcome reprieve from retirement in the upcoming months.

But this is not the retirement of the partnership program! Over the past three years, nurse clinician Connie Ens has taken on the Northern Health clinics, and for the past five years, Jan Frew has been coordinating the weekly and biweekly clinics in Surrey. In addition to the Northern Health clinics, Connie will be adding a few of the Interior Health clinics and Surrey clinics to her portfolio. Jan will work primarily in the Interior Health clinics and the Surrey clinics and will also be assuming responsibility for the program as a whole. Connie and Jan both look forward to expanding their roles within the Cardiology Partnership Program and meeting the families and health care professionals across the province. ♥



Jan, Stella, and Connie

Community Partnerships in Pediatric Cardiology 2019 Schedule

Date	Location	Cardiologist
January 9, 10, 11	Penticton	Dr. Derek Human
January 23, 24, 25	Prince George	Dr. Walter Duncan
February 6, 7, 8	Kelowna	Dr. Derek Human
February 20, 21, 22	Kamloops	Dr. Shubhayan Sanatani
March 5, 6, 7*	Terrace	Dr. Derek Human
March 20, 21, 22	Vernon	Dr. Martin Hosking
April 3, 4, 5	Williams Lake	Dr. Walter Duncan
April 24, 25, 26	Prince George	Dr. Walter Duncan
May 8, 9, 10	Kamloops	Dr. Kevin Harris
May 22, 23, 24	Penticton	Dr. Derek Human
June 4, 5, 6*	Kelowna	Dr. Shubhayan Sanatani
June, 26, 27, 28	Whitehorse	Dr. Walter Duncan
July 3, 4, 5	Vernon	Dr. Martin Hosking
July 17, 18, 19	Prince George	Dr. Derek Human
July 30, 31, Aug 1*	Terrace	Dr. Shubhayan Sanatani
August 14, 15, 16	Kamloops	Dr. Derek Human
August 28, 29, 30	Trail	Dr. Martin Hosking
August TBA	Hazelton (Telehealth)	Dr. Shubhayan Sanatani
September 11, 12, 13	Fort St. John	Dr. Walter Duncan
September 25, 26, 27	Penticton	Dr. Shubhayan Sanatani
October 9, 10, 11	Kelowna	Dr. Walter Duncan
October 23, 24, 25	Prince George	Dr. Martin Hosking
November 6, 7, 8	Kamloops	Dr. Kevin Harris
November 19, 20, 21*	Terrace	Dr. Walter Duncan
December 4, 5, 6	Vernon	Dr. Martin Hosking

*Tues/Wed/Thur clinic

All other clinics are held Wed/Thur/Fri

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."

5. Don't ask leading questions.

Encourage your child to talk about her feelings, but try not to ask leading questions— "Are you anxious about the big test? Are you worried about the science fair?" To avoid feeding the cycle of anxiety, just ask open-ended questions: "How are you feeling about the science fair?"

6. Don't reinforce the child's fears.

What you don't want to do is be saying, with your tone of voice or body language: "Maybe this is something that you should be afraid of." Let's say a child has had a negative experience with a dog. Next time she's around a dog, you might be anxious about how she will respond, and you might unintentionally send a message that she should, indeed, be worried.

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.

Did You Know?

If you work for the provincial government there is a program called the "PECSF – Provincial Employee Community Services Fund." It provides provincial employees the opportunity to make one-time donations or payroll deduction donations to their favourite charities.

PECSF, also called the Community Fund, is the Province of British Columbia's unique, employee-driven workplace giving program. It was started by caring, community-minded public servants in 1965 and since then has raised

over \$45 million for charities throughout the province. The CHN is one of the registered charities you can support!

For more information see:

<https://www2.gov.bc.ca/gov/content/careers-myhr/about-the-bc-public-service/corporate-social-responsibility/pecsf>

CHN Celebrates the Holidays!

Vancouver Island

BY KRISTA MOLIA

On December 1, families from Vancouver Island's Heartbeat group enjoyed a festive pancake breakfast (with bacon and all sorts of yummy treats) at a new venue this year, the Westin Bear Mountain Resort in Victoria. We had 22 families, which added up to a banquet room full of 85 people, who all enjoyed the buffet, crafts, cookie decorating, a magic show, and — best of all — a special visit with Santa. There were many great moments: children playing, gorgeous crafting, laughs with the magician, and plenty of smiles and excitement with Santa and Mrs. Claus.

Many thanks to all the volunteers that helped make it so special! We had so many parents and teens manning

the registration table and supporting the craft and cookie tables. In addition, a huge thank you to the heart moms that made loads of icing and to Aunty Sandra from Knot Just Weddings who demonstrated her photography talent by taking fabulous photos with Santa for all of our families. A local magician, Donald Dunphy, captured the kids' attention, and there were many giggles (from both parents and children!). The highlight of the event was when Santa arrived with a sack full of chocolate!

The families on the Island look forward to connecting again in the spring (hopefully an Easter egg hunt) and with the monthly coffee groups running in Victoria and Nanaimo. ♥



Christmas tree and CHN banner



Santa with the Avis family

Lower Mainland

BY SAMANTHA AITKEN

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. The decorations were gorgeous, and a very entertaining show was put on by "Norden the Magician." Families got 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 children, everyone providing big smiles for the photographer. We would like to thank the following sponsors, without whom this event would not be possible:

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



Santa and Mrs. Claus with the Rogers boys



Santa with Ben



Norden the Magician

FEBRUARY IS
**HEART
MONTH**
GIVE WITH HEART!



Now available at
Amato Gelato:
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Help Us Help Families of Children with
Heart Disease with these Gelato Hearts.
Amato Gelato will donate \$1 of every Heart
sold to the Children's Heart Network.



**CHILDREN'S
Heart Network**

What's Happening?

February is "Heart Month" and February 7-14 is
Congenital Heart Disease Awareness Week.

How you can support the Children's Heart Network:

1. Buy your Mario's Gelati heart-shaped ice cream on a stick for \$3 each or \$30/box of ten starting February 1 at Mario's — 88 East 1st Avenue in Vancouver. Proceeds go to support the CHN! Spoil the kids? Have a birthday party coming up? The best gelati in town!
2. CHN will be having the Annual Valentine's Day chocolate sale at BCCH in the main lobby of the old hospital on February 12 and 13. Come by to pick up top quality Belgian chocolates by Daniel le Chocolat Belge to give to your loved ones on this special day while supporting the CHN!
3. The 17th Annual Children's Heart Network Wine Gala and Dinner will be on Friday, April 26, at the Villa Amato Ballroom. We are thrilled to have Fred Lee (CBC's Man About Town) as our auctioneer again this year. Get your early bird tickets for \$150 per person and you will be attending one of the best galas in town. Enjoy hors d'oeuvres and bubbly, an exquisite three-course dinner with wine pairings, and the best auction in town! To order tickets please go to chnevents.org. To be a corporate sponsor or to donate to the silent auction please email Hege Bolthoff Hoegler at hhoegler@childrensheartnetwork.org. ♥

Benefitting Children And Youth With Congenital Heart Disease

Butler served Hors d'oeuvres and "3 course dinner"
Silent and live auctions

FRIDAY, April 26th, 2019
6:00pm - 11:00pm

VILLA AMATO BALLROOM

88 East 1st Avenue - 3rd floor, Vancouver
Please take advantage of the complimentary valet parking.

TICKET PRICE - \$150 early bird rate until March 15
A portion of the ticket price will be issued as a tax receipt (\$75)

**CHILDREN'S
HEART NETWORK**
of BC Society

THE 17th ANNUAL
**Wine Gala
& Dinner**