

♥♥ Heart Matters ♥♥

The Newsletter of the Children's Heart Network
"Working together in British Columbia...
to enhance through education and support,
the lives of children, youth and families, who
are living with congenital and acquired heart disease"



**CHILDREN'S
HEART
NETWORK**

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Heart Matters

5151 Canada Way, Burnaby, BC
V5E 3N1

Tel: (604) 568-3005

Toll Free: 1-877-833-1773

Email:

chn@childrensheartnetwork.org

Website:

www.childrensheartnetwork.org

www.facebook.com/childrensheartnetwork.org

Heart Matters February 2013 Edition

Mattea's Heart Journey

by Joelly Segal

On April 9, 2009, my birthday, I received the most incredible gift imaginable: the birth of my son Shae and daughter Mattea, healthy twin babies. My husband Jory and our older boys Zane and Emmett were equally thrilled.

We were home from the hospital after two short days and our hectic life resumed. About a week later I started to notice that Mattea didn't seem right. Her chest was rising exaggeratedly as she breathed and she would fall asleep during feeds. A pediatrician had been monitoring Mattea as her weight gain was slow. When I raised my concerns I was told that her nostrils were small and that I should rinse them with saline. My night nurse told me that was normal breathing for a baby. I knew something was not right. I brought her to our trusted family doctor; she sent us to Children's Hospital immediately.

We arrived at Emergency, where doctors urgently examined Mattea and came back with the world-shattering statement, "your daughter is very sick." I thought, "This can't be happening." Mattea was diagnosed with a significant VSD with multiple minor ones as well. But she was too sick and too small to undergo immediate major repair surgery. In order to gain strength, Mattea would urgently undergo a pulmonary artery banding surgery. This, along with medication, would slow down the flow of blood, allowing her to grow and get stronger for the major repair surgery ahead.



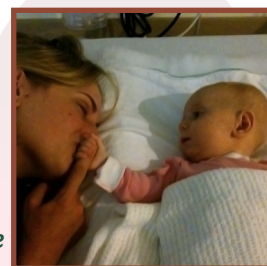
Mattea and Daddy

I was scared. Overwhelmed with all this new information, which was at times terrifying. I didn't know quite how to process everything. I wrote lists,

Continued on Page 2

questions. After her first surgery and a stay in the hospital we were sent home with our medications and the hefty Growing Up With Heart Disease manual. Suddenly our hectic world became so simple; my focus was getting Mattea through this. In a strange way I looked forward to our many appointments at the heart clinic, to measure Mattea's growth and gather information as to when she would have her repair surgery. It was my job to be fully informed with her condition and to take an active role in her treatment and recovery.

September 2009, the day of her major surgery finally arrived. We had a preoperative visit with Dr Campbell, during which he explained the open heart surgery. He told us he would call when the surgery was finished and I said, "we aren't going anywhere, we'll be in the waiting room." He mentioned that some parents go to the mall, or go home; and that we should do whatever makes us feel comfortable. Jory and I, together with our family, waited anxiously in the waiting room. The surgery took much longer than we expected. I was flooded with fears and did my best to focus on positive thoughts. I paced the hallways of the hospital. I understood why some parents chose to go to the mall.



Mattea and Mommy

Finally we got word that Mattea was out of surgery. Surgery went well but because the hole was in such a delicate area they were not able to fully close it and two holes remained on either side of the patch. Mattea was in stable condition, recovering in the ICU. But halfway through the first night her kidneys started failing. She was going to have to go on dialysis. The doctors were puzzled. And then, just as inexplicably, she took a turn for the better and started to recover. She is a fighter.



Mattea as a big girl!

We made it out of the ICU and up to the ward. I wanted her to finally be better and I was so happy the surgery was behind us and that she was okay. But she wasn't okay. She cried a lot. I kept asking for more pain medication for her. Doctors could not explain why she would still be in pain now, days after surgery. I wanted so badly for her to finally be okay. On the day we left the hospital I dressed her up and Jory took a photo of me holding her. I looked so happy. But she still did not look like the healthy baby girl I imagined.

As time passed, she did not get any better. She was pale and weak. We returned to the hospital. Tests showed that she was severely anemic. The patch was sheering her blood and destroying her blood cells. What Mattea had was a very rare complication from surgery called patch hemolysis. Essentially her body was rejecting the patch. She needed an immediate blood transfusion. Doctors were uncertain how this would be resolved. The hope was that together with medication her body would eventually form a protective layer over the patch, which would allow blood to easily flow. When this would happen and how many blood transfusions she would need we did not know. She required four.

It is not clear if Mattea will need further surgery to fully repair her remaining VSDs. My hope and expectation, based on how well she is doing, is most likely not. Mattea is now a thriving, active, and spunky 3 year old. She loves ballet, princesses, dresses, family, and candy. At her last cardiology appointment I was asked if Mattea could keep up with her brothers. The truth is, they have to keep up with her!

- Volunteers Needed -

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Meet the Cardiologists

BC Children's Hospital has been lucky to attract a number of great new cardiologists over the last year or so; with all the new faces around we thought you might like to learn a little bit about them, both personally and professionally.

Dr Libby Sherwin

Where did you grow up?

I grew up in the suburbs of Washington, DC, in Northern Virginia. I've lived on the east coast for my entire life, either in Virginia, New York/Connecticut area, or Boston. I relocated to Vancouver in August 2012.

What made you want to be a pediatric cardiologist?

From the beginning of medical school, I have been fascinated by cardiology. The cardiovascular system is logical—once you understand the plumbing and electricity, then it's easy to understand the way it functions and malfunctions. My first day rotating through the pediatric cardiology clinic, I instantly knew I'd found my specialty. I was and still am amazed by the complex ways in which the heart can form anomalously and the constantly advancing palliative and corrective procedures available that allow children to grow and thrive despite their heart condition.

What are you most excited about in working at BCCH?

Getting to know the families and patients in British Columbia and having the privilege of being involved in their care, and being a part of the growth of pediatric cardiology and cardiovascular surgery here at BCCH.

Tell us about any specialties you have within cardiology.

My subspecialty is electrophysiology. This is the study and treatment of heart rhythm and conduction problems, including electrophysiology studies and ablation procedures to cure arrhythmias, as well as pacemaker and defibrillator therapies.

Did you have a mentor?

I have several great mentors in medicine, from medical school in Virginia to pediatrics, cardiology, and electrophysiology at Boston Children's Hospital.

Outside work, what do you like to do for fun and what are you good at besides being a cardiologist?

I'm a proud aunt to three nieces and a nephew, two of whom live in the area. I love to run, travel, and am a foodie. In order to become a true Vancouverite, I've started to learn to ski so that I can enjoy the beautiful winter playgrounds in British Columbia.



Dr Elizabeth Sherwin

Dr Kevin Harris



Dr Harris and his son Cole

Where did you grow up?

I was born in Saskatchewan but headed west at an early age with my family. I grew up here in the Lower Mainland and went on to post-secondary education at UBC. As a long-term Vancouverite I was very excited to come back and join the group here at BC Children's Hospital.

What made you want to be a pediatric cardiologist?

I have always enjoyed working with children and therefore pediatrics was a natural fit. Very early in medical school I became fascinated with cardiovascular physiology. As such I began working with Dr Sanatani on a research project in my first year of medical school. Once I began working in the hospital I was inspired by the children and families that I met.

What are you most excited about in working at BCCH?

BC Children's Hospital is a fantastic institution. I knew many of the cardiologists, nurses, and technologists from my years in training and knew that it was an excellent group of people to work with.

Tell us about any specialties you have within cardiology.

After my basic pediatric cardiology training I moved to the United States to pursue advanced training in cardiac catheterization. Currently I spend much of my time in the cardiac catheterization lab doing interventional procedures. In addition, I completed a master's in epidemiology with a focus on preventing and treating childhood obesity. I'm in the process of starting a preventive cardiology clinic to help children at risk of developing early adult type cardiovascular disease.

Did you have a mentor?

I've been very lucky to have a number of mentors. All of the cardiologists at BCCH helped me immensely during my cardiology training with both clinical and academic work. After I left BC, I was very lucky to work with two very skilled interventional cardiologists, Dr Bob Vincent and Dr Dennis Kim.

Outside work, what do you like to do for fun and what are you good at besides being a cardiologist?

I enjoy spending time with my wife and two sons. We enjoy being active whether it's swimming, biking, or heading up to the mountains.

Do you have any pets?

I don't have any pets presently although I'm sure at some point my children will convince us to get one. Our youngest son, who is not yet two, absolutely adores dogs of all shapes and sizes.

Dr Paul Brooks

Where did you grow up?

I grew up in Australia. Initially on the coast at the beach and later in a suburb of Melbourne.

What made you want to be a pediatric cardiologist?

I spent two years working as a volunteer doctor in Vanuatu in the Pacific and observed the heart team visiting from Australia performing cardiac surgery on an aid mission. It was the most interesting group of patients I had seen trying to work out what their cardiac lesion was with clinical examination and simple tests then being able to observe the echo and surgeries performed by the team.

What are you most excited about in working at BCCH?

The opportunity to live in Vancouver.

Tell us about any specialties you have within cardiology.

Fetal cardiology and echocardiography.

Did you have a mentor?

Professor Dan Penny was my mentor in Melbourne, he is now the chief of cardiology at Texas Children's Hospital in Houston.

Outside work, what do you like to do for fun and what are you good at besides being a cardiologist?

Outside of work we like to be outside when the weather is nice, walking in the bush or swimming. I play golf and like woodwork and building furniture. I am currently building a canoe.

Do you have any pets?

We have a planted aquarium.



Dr Brooks and his daughters Ashley and Ella

Hearts of Gold Corner

This is the first installment of what we hope will be a fun and interesting series of contributions from our Hearts of Gold kids. We've asked them to fill this space in whatever way they would like in the future—comics, illustrations, interviews, reports, articles? It's up to you, bring it on!

Vancouver Island Hearts of Gold

by Krista Molia

The Hearts of Gold Vancouver Island has enjoyed several seasonal monthly events from go-karting, mini-golf, batting cages, a hockey game, and our annual feast (Christmas dinner) at the popular Glo Restaurant. Did you know teens really do enjoy dressing up every once in a while?



Montana and Brandon

This year we have welcomed some new youth to our group who have just turned 13 and we had to say good-bye to our graduates, Taylor Holroyd and Brandon Stashewsky.

This spring we look forward to some interesting events. We will be partnering with Power to Be for an outdoor adventure, and we'll be hosting a "make your own pottery" event. We are all hoping that this year's trip in May to Camp Summit will see many youth from the island, old and new.

Hearts of Gold fun—Lower Mainland

by Kristi Coldwell

Hearts of Gold Coordinator

This fall and winter has proven to be an eventful and busy time for the Hearts of Gold group. This past fall the group enjoyed a Halloween-themed event by partaking in the Ghost Train ride down at Stanley Park. A guided Creatures of the Night tour was also on the agenda. Strolling through the dark forest with only candles to light the way, while learning about animals that walk the woods at night, was a perfect way to embrace the spookiness of the Halloween season! Everyone got a little more than they bargained for as it poured with rain the entire evening. With the aid of umbrellas and hot chocolate the night was a success!

Dinner at Boston Pizza in November afforded the youth a chance to get together before Christmas to share and discuss everyone's holiday plans. The first event of 2013 was ice skating down at Robson Square in January. A live band played music throughout the night as everyone made countless laps around the ice. Not wanting to miss out on the fun, I joined in too, despite not having skated in over 20 years. This resulted in a slight role reversal for the evening as the youth needed to supervise their group leader!



HOG at BP Kids

Help our teens have fun! Our Hearts of Gold (HOG) teen group gets together monthly. We are always looking for fun and interesting things for them to do but everything costs money! Do you work at an interesting place or have a hobby you'd like to share? Perhaps you have connections through family or friends? If so, please contact Kristi Coldwell at chnheartsofgold@gmail.com Perhaps with a graphic that attracts attention?

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is produced by the Children's Heart Network
5151 Canada Way, Burnaby, BC
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Tel: (604) 568-3005



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Toll Free: 1-877-833-1773

Email: chn@childrensheartnetwork.org
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donation, please contact the CHN.

Follow CHN on Facebook and to check the web site for updates and news. Website: www.childrensheartnetwork.org

First Aid Attendants. In the Vancouver School Board, there are always first aid attendants with CPR training on site. Typically, they are office staff. If you wish your teacher or child's aide to be trained in CPR, there is a department at the Vancouver School Board called "learning services" where the principal of your school can apply to in order to get funding for the training. If you are interested, please talk to your principal.

HEART MAMA/PAPA COFFEE GROUPS – These groups meet monthly — come and meet other heart parents while enjoying treats on us! For more information please contact:

Vancouver – Samantha Aitken at saitken@childrensheartnetwork.org

Burnaby – Sarah Kertcher at sarah.kertcher@outlook.com

Richmond – Kate Walker at kwalker@childrensheartnetwork.org

Langley – Tecia Beulens at tbeulens@telus.net

Maple Ridge/Tri-Cities – Amy Watkins at amylouwatkins@hotmail.com

Chilliwack – Chantelle Bisschop at bissch18@telus.net

Victoria – Teri Godin at terigodin@gmail.com



YOUNG ADULT HEART NETWORK COFFEE GROUPS – We are thrilled to announce our two new groups for graduates of the HOG program or any young adults living with heart disease. For more information please contact:

Vancouver – Corey Zinger at zinger92@telus.net

Victoria – Lauren Fougner at lfougner@uvic.ca

Mark the Dates

- * CHN Easter Egg Hunt for Island families – email invitation to come!
- * CHN Easter Egg Hunt for Lower Mainland families - Saturday, March 9th at Queens Park in New Westminster, email invitation to come!
- * The 11th Annual Wine Gala Dinner – Wednesday, May 1st at The Vancouver Urban Winery
- * The Scotiabank Challenge SKM Family Fun Run/Half Marathon – Sunday, June 23 at Stanley Park, join the CHN team and run/walk/stroll, join other heart families and make it a fun event for your entire family!
- * Hearts of Gold Youth Camp (ages 13 to 18) – May 17th to 20th at Camp Summit, to get more information please email Kristi Coldwell at chnheartsofgold@gmail.com
- * Heartbeats Camp (ages 8-12) – July 9th to 13th at Camp Zajac, invitation to register will be emailed out shortly.
- * Canadian Marfan Syndrome Conference – Sept 27/28 at the Chan Centre, BCCH. Registration on-line in the spring. For more information or to volunteer contact Leslie Raffin at lraffin@cw.bc.ca

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To make a tax deductible donation, please contact the Children's Heart Network
Registered Charity Tax Number: BN139462394 RR0001

Graphic Design Services by John Sikorski - JonCom Design— Cell: 604.726.5037

CHN Board Priorities for 2013

by Bindy Sweett

CHN Secretary

On behalf of the CHN Board of Directors

This update comes with the best of wishes for you and your families as we begin another year. For many of us, life becomes busier as we take on new challenges in a new year, and our families continue to grow. For those of us serving on the CHN Board, many more challenges remain the same. Uncertain funding continues as we wait for grant application responses. Questions about program prioritization persist. For this year at least, we have decided that instead of creating and developing new programs, we will concentrate on programs we already have in place, and do the best we possibly can.

To that end, we have focused on the following priorities.

We reorganized staff responsibilities and hired our new part-time office assistant, Danielle Segur, a parent of a teen with heart disease. Many of us have known Danielle for many years, and watched her raise her family. With her terrific organizational and computer skills, we are happy to have her with us, keeping a presence in the CHN office. When you call or email the office, Danielle will be sure to get back to you within a couple of days, or ensure that messages pass to the appropriate person.

Another goal regards improved responses to the support needs of our members, and to families coping with a new diagnosis. We are holding Resource Parent training sessions in three regions, Victoria on January 26, (already completed), New Westminster on April 20, and Kelowna in early July. We hope to add a fourth session in Nanaimo if our budget allows. We have developed a system for referral, matching, and evaluation based on best practices as set by Parent-to-Parent USA.

In addition, we are working to re-institute the hospital visitation program at BC Children's Hospital (BCH), so that families who find themselves on 3M or in the ICU can access face-to-face support and contact with another parent who has been there. Heart Centre staff met with CHN staff and Board members on February 1 to discuss the best methods for facilitating this program. If you are in a place in your journey that allows you to support others, and would like to volunteer in your region, please e-mail Bindy Sweett at bindysweett@gmail.com.

The Board of Directors is taking a Board Governance three-hour evening workshop to improve the way we function. It is not easy to add a new role such as "board member" into a regime that includes work, raising a family, and enjoying a well-rounded life! Understanding how a board functions, and our roles as members, is something entirely new for many of us. Several members who have dedicated many hours have rolled off the Board at the end of 2012. We are fortunate to have excellent new CHN Board volunteers join since last summer. It is important for us to maintain a balance of experienced and enthusiastic new members as we move forward in 2013.

The CHN believes strongly that we must make a concerted effort to reach out to families living in isolation, and in outlying regions of the province. This is a very challenging goal, as our financial and staffing resources are limited. We must rely on volunteers, and creativity, in order to support members who live anywhere outside the Lower Mainland.

The Heart Mama's/Papa's coffee groups, initiated by parents in their own neighbourhoods, have experienced great success. Please contact our office if you would like to host similar get-togethers. The CHN would be happy to support workable initiatives, wherever they occur. We also have funding from Cops for Kids in the Okanagan region to help youth get to Camp Summit in Squamish in May. Families can apply for assistance by contacting Sam Aitken.

Finally, we have realized that although non-members are not excluded from many CHN activities, paid membership dues provide stability to our financial base. Although they are minimal, dues make a difference to our small overall budget. With that in mind, we plan to institute an annual membership due date, in the hope that reminders will encourage all families and members to keep current, and enable us to count on dues as a stable contribution to the budget.

Family Testimonials Requested

The Western Canadian Children's Heart Network (WCCHN) will be meeting with the western deputy ministers of Health to discuss provincial funding for families who require traveling for their child's pediatric cardiac surgery to either BC Children's Hospital in Vancouver or Stollery Children's Hospital in Edmonton. We'd like to hear your experiences, so that we can share the impact on families in our meeting with the western deputy ministers.

Testimonials should include the following information...

- How travel costs have affected your family.
 - Amount of time spent looking into:
 - ✓ Travel arrangements.
 - ✓ Preparations for home, other children, etc. while away.
 - ✓ Approximate cost of out-of-pocket expenses.
 - ✓ Did you have any financial assistance?
 - ✓ If so, what organization(s) provided the assistance?
 - ✓ Did anyone assist you in applying for assistance?
 - ✓ Any other impacts to you and your family.
- Please submit your testimonials to: wcchn@albertahealthservices.ca.
 Deadline for submission of family testimonials: March 1, 2013



Thank you to all those that helped to make our Annual Christmas Party a huge success:

Metrotown Hilton Hotel

Bob and Dee McLennan

McDonalds

AStar Art Parlour

Bertolt the Magnificent

Martha Mackenzie Photography

Annie White

Lorna Bozic

Murale Cosmetics

Global Container Terminals

Melissa Martz

Ivette Varga

And a heart-felt "Thank You" to all those that made donations to the raffle, donated their time and to those that baked and brought treats to share!

What's Up?

WELCOME NEW STAFF!

The CHN is thrilled to announce that Danielle Segur, heart mom and long-time supporter of the CHN, has joined our staff as our part-time Administrative Assistant.

THANK YOU!

We would like to thank Jay Draper for volunteering his time to be our newsletter editor.

WELCOME NEW BOARD MEMBERS!

We would like to welcome our three new board members: Delia Imola, Jeff Cornell and Sam Birkenhead.

HOW CAN YOU HELP?

We are looking for volunteers for the following things:

- Helping to coordinate the Easter Egg Hunt on March 9th in New Westminster.
- Collecting donations for the CHN Wine Gala silent auction.

If you are able to help with any of the above please contact Sam at
saitken@childrensheartnetwork.org