

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”

- Volunteers Needed -

Our families enjoy the spring, summer, fall and winter gatherings that the 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

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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

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**CHILDREN'S
HEART
NETWORK**

June 2013

HEART JOURNEYS

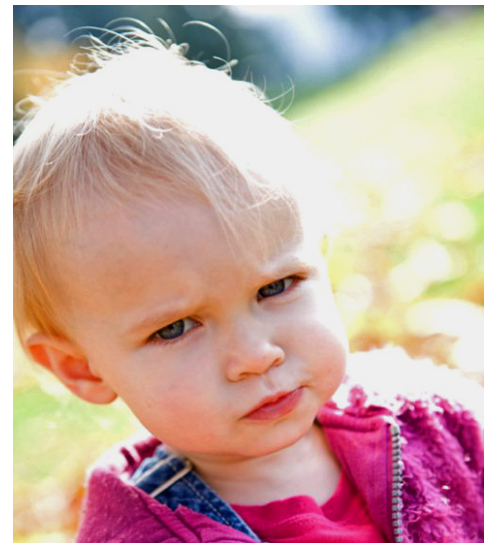
Avery Carpenter and the Very Lucky Ladybug

by Tracey Carpenter

Tracey Carpenter gave the following talk to a rapt audience at the 2013 CHN Wine Gala, and has given permission for it to be reprinted here.

Avery Violet Carpenter was born March 17, 2007. One way to describe Avery would be with this old nursery rhyme, “I knew a little girl who had a little curl right in the middle of her forehead and when she is good she is very, very good and when she is bad she is horrid.” That rhyme describes Avery’s personality as well as her health, which has varied from really good to sometimes horrid.

The first two years of Avery’s life were like a roller coaster. We knew something was really wrong with her but we felt like no one would listen. We went repeatedly to two family doctors and a pediatrician, so much so that Avery became terrified of doctors. I kept bringing her back with more and more symptoms. She had a hard time nursing and would scream, she would sweat profusely, she had all kinds of digestive issues and would throw up all the time, she would catch every cold and flu that came near, and would be so sick for so long. We also noticed her rib cage had become distended on her left side. Repeatedly it was decided that Avery had a dairy intolerance and her diagnosis of “failure to thrive” was because of it. Actually, the finger was always being pointed at me, her mom, for “not being diligent to keep dairy out of her diet.”



I was very diligent about everything that Avery ate and feeding her became my full-time job. The guilt of having a child who was so obviously failing was monumental.

One day Avery and I were headed to the doctors and Avery was upset, saying “No doctor mommy,” and she went from having a temper tantrum to screaming in pain and throwing up. This was my breaking point. It wasn’t that she was having a temper tantrum or that she was sick—it was that I was prepared for it. I had a change of clothes and a change of car seat cover; this just struck me as absurd. She was two and potty trained, why should I need to bring an extra set of clothes with me everywhere? This was not normal. I went into the doctors and with great

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conviction I told her she was wrong, Avery was not failing to thrive because of me, she was sick and not getting better. Someone had to figure out what was really wrong. She sent us on for some other testing and on to a gastroenterologist.

Avery's big sister Chloe came with us to the appointment at the gastroenterologist and Chloe, unbeknownst to me, brought a lucky little ladybug in her clutches. This ladybug escaped Chloe's hands and flew across the room, much to Chloe's horror. Dr Riley very kindly caught the ladybug and made it a home in a little plastic container. In a moment of great generosity, Chloe shared her ladybug with her little sister so she wouldn't be scared during the examination. For the first time, Avery's heart murmur was heard. This heart murmur led us on to our first appointment at BCCH.

On September 22, 2009 Avery had her first appointment at the Heart Center at BCCH. Shaun and I had taken the day off of work and we also let Chloe miss school and come with us. We had planned to go out for lunch and shopping down to Granville Island after Avery's appointment. The first person we met was Jessica, who was going to do Avery's echo. She asked what had led us to this appointment, I said Avery has a dairy intolerance but that I was certain there was some underlying problem that has been missed, and I thought she was really sick. This was when our world changed; I had no idea how right I really was.

As soon as Avery's echo was done we met Jan Rooks and Dr Hosking. Dr Hosking, in a very calm, kind, and understanding way, told us that Avery had a rare congenital heart defect called ALCAPA (anomalous left coronary artery from the pulmonary artery). In short, Avery's coronary artery was not attached in the right place and consequently her

heart muscle had been denied oxygen since birth. ALCAPA affects 1 in 300,000; even more shocking was that it has a 90% mortality rate if not diagnosed in the first year of life—Avery was 2 ½-years old. She was in congestive heart failure; her heart was the size of an adult man's in her little chest, and instead of pumping like we know a heart should, it barely twitched. Dr Hosking went on to explain that Avery was so sick that she needed to have surgery as soon as

went outside in the sunshine near the Second Cup in the front of BCCH. There we made the hard phone calls to the grandparents to tell them the news. While we were making these calls, Chloe was teaching Avery how to do summersaults on the grass. How could our kid be so sick she needed the ICU but was learning to do summersaults?

We went to the ICU and the following morning Avery went in for surgery. We were numb when we first



possible—and that was the next morning. She needed to be put on IV heart support medications before surgery and they were going to have a bed ready in the ICU in an hour. I had been standing, holding a dozing Avery in my arms; this is when my legs collapsed and I crumpled into the chair that Jan had been offering me.

We then met with Dr Campbell and had our first discussion about what I call the four Ps of surgery: procedure, probabilities, possibilities, and percentages. Oh my goodness, how did we get here? We were supposed to be going shopping at Granville Island, not learning about open-heart surgery! We had a little time until her bed in the ICU was ready so we went to get the kids something to eat and

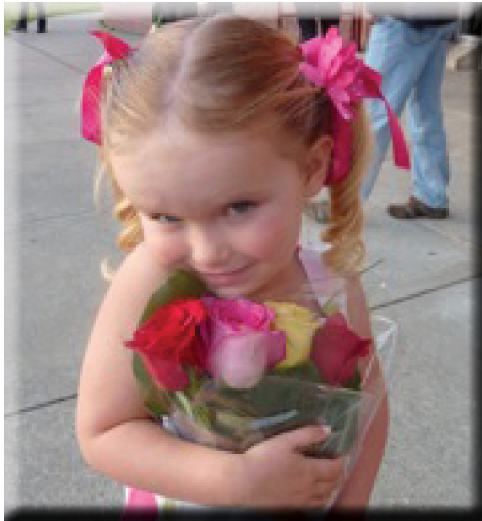
talked to Dr Campbell after the surgery; her surgery had gone very well. We spent four weeks in the ICU trying to get Avery stable again... intubated, extubated, intubated again and extubated again. Avery's pictures and numbers looked so bad, but Avery did not agree that she was sick, and was quite vocal about not wanting to be there. After four weeks we went up to 3M to learn again how to look after our daughter. We had to learn all of her medications, INR blood monitoring, and most importantly, CPR before we could go home—this took us exactly one more week. Avery finally went home the day before Halloween and went trick or treating the next day; only four doors, but that was okay. What

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mattered was that she went.

We were on the way to finding our “new normal.” I would describe “new normal” as when someone says, “Hi, how are you?” and you don’t feel like that’s a loaded question and you don’t feel like you’re lying to them or yourself when you say “good.” “New normal” included a daily medication



schedule, many doctors’ appointments, and Chloe saying to a little boy on the playground, “Be careful of my little sister, she’s on blood thinners and she just had heart surgery.” “New normal” included losing some friends who just couldn’t understand what we had gone through and are still going through. “But she’s fixed, right?” Avery is not fixed. Avery now has cardiomyopathy and a leaky mitral valve. It’s like Avery’s heart is a balloon blown up past its normal capacity, and slowly the air was let back out over a year or so. Her heart will never be the same ever again; it’s scarred. Avery will likely always need medications and future surgeries.

On the other hand, we gained a whole new group of friends that could understand, friends that we met through the CHN, like the Drapers who we knew even before Avery was born. Their daughter Sophia became Avery’s big heart sister, and when Avery had to go back to surgery in April 2012 to have her mitral valve repaired Sophia made Avery an amazing book about her

heart journey and how not to be scared. As well, we went to Critter Cove and connected with some amazing heart families, including Avery’s BFF Hannah Schneider.

Avery is so very strong and brave, she is fearless. She loves to show people how a heart does not look like a love heart, that a real heart has all these rooms and tubes that come off of it. She has amazed me recently when she was in the Heart Center to get a 24-hour Holter monitor put on. In the hallway we ran into another heart mom and friend Shauna, Grady’s mom. Grady was there for his pre-op day so Shauna invited Avery to visit him while he was working with Claire, the child life specialist. When we walked in the room you could see that Grady wasn’t into playing—he was nervous. Avery gave Grady a huge hug and said, “Hey Grady, you have met my friend Claire, I love Claire, she is so much fun. I see you are working on your doll—Grady I made a surgery doll too.” Then Grady’s walls came down and they really played together with Claire and giggled. It was amazing to see. We walked out of there and Avery said, “Mom, today is a good day, I made Grady not scared.” Yes Avery, you did. This was a beautiful day; Avery who was six helped little Grady who was three with open-heart surgery. They were two amazing little kids who could relate to each other in a unique way. If a picture is worth a thousand words, what was their experience worth?

Avery is doing very well; she loves Kindergarten, dance, music, digging in the garden, playing with her dog, and keeping up with her big sister. She also now loves her doctors and has become quite outgoing. Our journey has been hard—hard on us as individuals and really hard on us as a family. It has been heartbreaking and tragic at times, and at others it is so beautiful and poignant, it has made us who we are. ❤️

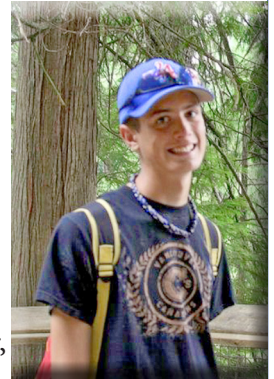
HEART HEROES

CPR training pays off in unexpected way

Last September the Children’s Heart Network hosted a CPR course for our families.

Heart mom Tecia Beulens and her teenage son Dominik decided to take advantage of this course.

Dominik has a 3-year-old sister, Kayla, who was born with heart disease.



Only a few months later, Dominik and a friend were sitting on a bench outside a local community centre in Aldergrove when the school bell rang. As they started to walk back to class they heard a thud and looked back to see a woman collapsed outside the community centre. She had hit her head, was bleeding, and appeared not to be breathing. A staff member ran out and started to do light CPR while trying to call for help. Dominik took over doing CPR while his friend held the woman’s head in C-spine. Many minutes later help arrived and the boys set out to find the woman’s lost dog.

As Dominik says, “After you realize what’s going on, instinct just kicks in.” He doesn’t deem himself a hero and was glad that he had the training he needed to help out. Dominik’s plans, even prior to this incident, were to become a paramedic.

We are very proud of you, Dominik!

The CHN hopes to host another CPR course in the fall; watch for more information via email and this newsletter.

HEARTS OF GOLD CORNER

HOG goes to Camp Summit

by Kristi Coldwell

Hearts of Gold Coordinator

This past May long weekend marked the Hearts of Gold annual camping expedition. With 25 teens, one youth coordinator, and one great nurse—Megan—the group boarded the Shriner's bus and headed up to Camp Summit, just outside of Squamish.



The weekend proved to be eventful. There were numerous exciting and challenging activities, such as mountain biking, high ropes, and archery. It was inspiring how supportive and encouraging everyone was of one another. New friendships were created while old bonds were strengthened. Evening campfires allowed everyone a chance to reflect on the day's events and wind down with a few camp songs and evening snack.

"Camp was really fun. I had a great time bonding with some old friends and making new ones. The activities were great and the scenery was gorgeous up in Squamish. What an amazing weekend!"

—Daniela Lester

A highlight of the weekend was the talent show. In fact, there was so much talent that the show needed to be extended to two nights! Who knew our group had such diverse skills? There was plenty of singing, a couple of riddles, some skits, a Bieber dance impersonation, and a very popular harmonica diddy.

Needless to say the bus ride home was considerably quieter than the ride up to camp as the majority couldn't keep their eyes open. It was a truly memorable weekend!

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/Coquitlam – Sarah Kertcher at sarah.kertcher@outlook.com

Richmond – Kate Walker at kwalker@childrensheartnetwork.org

Langley/Abbotsford – 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

Nanaimo – Andrea Vanrossum at andrea.vanrossum@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!

Sunday, June 23rd - Scotiabank Challenge Half Marathon and 5 km walk/jog/run in Stanley Park! Come out and have some fun with other heart families.

Free registration e-mail skertcher@childrensheartnetwork.org

Saturday, August 25th CHN Annual Cultus Lake Waterslides picnic. Invitation will go out in July, please ensure your CHN

membership is up to date.

Sept 27/28th – The 2013 Canadian Marfan Association Conference. For more information: www.2013cmavancouver.com

Tips for heart families on purchasing health insurance

by Tecia Beulens

Tecia Beulens is a heart mom and insurance services representative with Charlesworth Insurance Services. She has provided this article as a service to other heart families, and has offered to look over any policy and answer any questions you may have. Contact her at 1 888 699-9555, 604 852-2565, tbeulens@insurebc.ca.

I feel very strongly that people are not well enough educated about travel insurance, and when you're travelling with a child or youth with a heart condition, it's important both that you have good health insurance, and that you understand what coverages it actually provides.

While price is important, in fact the most important factors when choosing travel insurance are the coverages and exclusions. And the only way to know what those are is to actually read the paperwork!

Most companies have a 90-day stability requirement (see the "Definitions" box) for pre-existing conditions. Travel Underwriters only requires a 7-day stability period for anyone under 59, at no extra charge.

Anyone can make insurance sound like a good deal, but I know a number of moms who have paid an extra \$30 (through Travel Underwriters) for the "pre-existing conditions coverage," which brings the stability period down to 7 days. But this is unnecessary because it's automatically part of the policy through Travel Underwriters because of the age of the children (who of course are under age 59).

When you're looking into the coverage provided for travel insurance, be sure to ask these questions:

- What's the maximum amount of travel insurance coverage?
- Will the coverage of the people traveling with me be the same as mine?
- Are we covered for pre-existing medical conditions? Does age affect coverage?
- What's the stability period?
- While on vacation, are we covered if we parasail, scuba dive, or bungee jump?
- Who do we call in an emergency? Will we be penalized if we don't call our assistance provider immediately?

Questions to ask for credit card plans:

- Do I have to pay for the trip in full with my credit card to be covered?
- What's the maximum number of days covered for one trip?
- Does the plan offer trip cancellation or trip interruption coverage?

Questions to ask for group plans:

- Does the plan provide trip cancellation or reimburse you if you need to return early due to a family emergency?
- Will the plan coordinate payment with the provincial government or pay the hospital directly?
- If you lose your luggage in transit, is it covered?

One final tip before you go:

- Be sure you have an insurance certificate with plan details, and know where it is!

If you'd like some help understanding the plan being offered to you, I'm more than willing to look over the wordings from any insurer to make sure our kids are covered in the event of an emergency.

Definition of "stable" for travel insurance

For Emergency Medical Insurance means that within the period specified in the policy before the commencement date of a covered trip:

- a) There has been no deterioration of your condition as determined by your physician, and
- b) There have been no new symptoms or more frequent or severe symptoms, and
- c) You have not experienced symptoms related to the condition that remain undiagnosed, and
- d) There has been no change in medical treatment or no alteration in any medication for the condition, and
- e) There has been no new medical treatment prescribed or recommended by a physician or received.

For Trip Cancellation/Trip Interruption Insurance and Trip Interruption

Insurance only: means that within the period specified in the policy:

- a) There has been no deterioration of the condition as determined by a physician, and
- b) There have been no new symptoms or more frequent or severe symptoms, and
- c) There have been no symptoms related to the condition that remain undiagnosed, and
- d) There has been no change in medical treatment or no alteration in any medication for the condition, and
- e) There has been no new medical treatment prescribed or recommended by a physician or received.

Newsletter Editor - Jay Draper
Graphic Design - John Sikorski

Which medic alert bracelet is best for your child?

The Canadian MedicAlert Foundation is the most well-known company in the medic alert field, and can be found online at www.medicalert.ca. You order your bracelet/necklace and register your child's medical information. They have an annual fee as the info is accessible from all over the world. Anyone can call the number on the bracelet/necklace to get current medical problems and medications. This is good for someone who has lots of changing, serious medical issues or for someone who may travel a lot.

Anyone with a stable, unchanging issue (such as an allergy) may want to opt for the non-enrolled version. Here are two sites where you can order many different styles of pediatric and adult bracelets and necklaces: www.identifyyourself.com or www.laurenshope.com.

To make a tax deductible

donation, please contact the Children's Heart Network Registered Charity Tax Number:
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- Volunteers Needed -

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Scar rehab for heart surgery patients

by Don Schwartz

After my daughter's first heart surgery in 2004, my wife asked me if there was any way to lessen the scarring from the incision on her chest. Having been through serious facial burn rehab myself, I have become a bit of an expert on scar healing, and had the perfect answer for her.

We went to the drugstore and bought some of the large silicone burn treatment sheets. They are a bit expensive now, but are well worth the price. We cut the sheets into 2-inch wide strips that are the length of the incision on her chest.

She wore them for about 18 hours a day. We took it off from nap time until bed to let the skin breathe and not become too moist from sweating.

Today her scar has almost completely faded, and it's soft, smooth, and has no discoloration. Every time we see the cardiologists, they can't believe how well the scar has healed. She wore the silicone pad for 4 years straight and would only rarely miss a day without it. We believe the constant wearing of the silicone pad is the main reason the scar has turned out so well. We did not use any other creams, or rubs, or oils, or vitamin E. Just the silicone pad!

How the pads work

After the incision is made and starts to heal, the skin growing forms a lumpy, discolored scar because it does not have any skin layers above to help it grow flat and smooth. The skin then grows in a random shape that can be tough

and bumpy. This is called a keloid scar.

The silicone pads do several different things for the rehab of the scar tissue. First, it acts like a layer of skin and helps the scar tissue grow flat and smooth. The silicone applies a slight pressure to the scar, which is why it will cause them to be flat instead of bumpy.

Second, the pads add pressure to the scar that helps keep the discoloration out of the tissue. Over time this makes it so that the scar is a much closer color to the surrounding skin instead of the darker colors usually seen.

Don't forget the sunscreen

Sunscreen is also a must for these children. If the scar tissue gets exposed to too much sun, then it will become permanently discolored. A sunscreen with titanium dioxide or zinc oxide is the best as it is a physical block instead of a sun filter.

There are many different ideas on the best treatment of scars--this article describes one of many that one family has found helpful.

Please note that this may not be the same advice that your cardiologist or other physician gives you, so you'll need to consider the options and make the choice that is best for you and your child.

We know that scar care is an important issue to heart families, so in the next issue of *Heart Matters* we will provide another article on the subject, this time by Dr Cynthia Verchere, a plastic surgeon at BC Children's Hospital.

MEET THE CARDIOLOGIST: Dr Brian Sinclair

Where did you grow up?

I was born and raised in Vancouver, attending UBC for my undergraduate degree in zoology and physiology. I went on to medical school in Calgary, and returned to BC for my pediatrics residency and cardiology fellowship. I moved my family to Portland, Oregon for a year of advanced echo to finish my training.

What made you want to be a pediatric cardiologist?

It started with a combination of interests, including exercise and cardiac physiology, some elective work in ultrasound (I considered being a radiologist as a med student), and a great cardiology professor in Calgary. I realized fairly early on that I was really interested in pediatrics, and from there, cardiology was just a really great fit. It was a long haul in terms of training and hard on my young family at the time. After almost 20 years, it still works—I am very lucky to really love what I do.

What do you like about in working at Victoria General Hospital?

I spent my first 7 years at the Children's Hospital of Eastern Ontario in Ottawa. Dr Duncan gave me my first job, and Dr Hosking was one of my partners. The chance to come back to BC, and our extended family was very exciting. Victoria specifically provided me with both challenges and opportunities in terms of building a cardiology service and practice. We have made a lot of progress, and the hospital and health authority have been really supportive. I have gone from working in a typical doctor's office and "begging" for time in the echo lab to having a more robust and comprehensive service for children and families. We have an excellent working relationship on many levels with the Children's Hospital cardiologists, surgeons, and nurses. We are now in the early phases of building on the work in specialty pediatrics that we do here on the Island. As a department head for Pediatrics, I am very

involved in this process, and really excited with the potential for better space and services that we can offer families in the future.

Tell us about any specialties you have within cardiology.

My main focus has been echocardiography, and this has spun off to the area of prenatal echo. In addition to imaging, this has really pushed me

practice, from teachers and colleagues over the years. I must mention Dr George Sandor, who stopped me in the hall of Children's Hospital during my residency and suggested I think of cardiology, and Dr Patterson who taught me to put the patient first and do right by them from the start.

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



Bronwyn, Dr Sinclair, Nicholas, Lynn and Jackson

to learn about counseling families with a prenatal diagnosis. I recently decided that I needed to spend some designated time learning about adult congenital heart disease, as my patients are heading toward transition, and I am being asked to see young adults in follow-up. This past fall I spent 3 months on sabbatical at the Royal Brompton Hospital in London, working with an excellent group who specialized in long-term follow-up and pregnancy (in congenital heart disease). I hope to make that a bigger part of my practice over the coming years.

Did you have a mentor?

Many, and still do. I have tried to learn both in terms of knowledge, but also in terms of the humanity of

My wife Lynne and I have three children. Nicholas (21), Bronwyn (19), and Jackson (16). So outside of trying to be a good cardiologist, I try to be a good parent. I love to cook, and do lots of it, given both of my boys are competitive swimmers. We loved the opportunity to travel last summer before my sabbatical, and dragged the kids around Western Europe. My daughter is starting nursing school this year, but right now she is still in London and travelling, which makes me an anxious parent as well. I am an avid cyclist, riding with a local club, and trying to figure out if I am going to do one more Ironman triathlon.

Do you have any pets?

Too many cats.

MEET THE SONOGRAPHER: Christine Miller

Where did you grow up?

I was born and raised in Bralorne, BC, a small gold-mining town 112 km west of Lillooet and two hours from Whistler over the Hurley Mountain Pass. The cardiology significance is that Dr Peter Ashmore had a summer cottage at Gunn Lake near Bralorne. My family moved to Victoria when I started high school. I graduated and went to university and subsequently moved to Ottawa where my ultrasound career began.

Where did you train to be a sonographer?

My initial background is radiology and my fundamental ultrasound training is from Johns Hopkins in Baltimore.

What do you like about working at Victoria General Hospital?

My colleagues. Working with both Anne and Brian is a privilege. We all work well together that makes busy days go by smoothly.

Tell us about any specialties you have within cardiology.

I have worked in the cardiac cath lab when I worked in radiology. I loved the intensity of that work environment. I then went on to work in an adult echo lab and subsequently the pediatric echo lab at the Victoria General, which is the most gratifying work of all. I love the children, the parents, and the dynamics of the work.

Did you have a mentor?

I have been privileged to work with many trendsetting sonologists. When I graduated from radiology the Royal Jubilee received one of the first ultrasound machines in the province. I was able to be involved in getting patients to have their ultrasound done by the radiologist. As they say, "the fire was lit." Since ultrasound was so new we were all learning; sonographers as well as sonologists. I have been very fortunate to be on the "leading edge" of my profession. I then moved to Ottawa when my husband was transferred. There weren't any jobs for radiology technologists but I met Dr Henry Muggah, a perinatologist. I told him of my experiences with ultrasound in Victoria. He hired me and subsequently sent me to train at Johns Hopkins. Dr Martin Gillieson, also a perinatologist; Dr Bernard Lewandowski, an ultrasound radiologist, are all on my list as mentors. They have inspired me and taught me a great deal. I began in working ultrasound just as the modality was emerging as a diagnostic tool. I have worked for an ultrasound manufacturer as well so have seen the other side of what is important in equipment design. The variety of choices within ultrasound is amazing, so I bring a very wide perspective to my work.

What do you like to do for fun?

Outside of work I am a very involved parent with three children. My children are all very involved in athletics. Our oldest daughter Emily is a synchronized swimmer while my middle daughter Natalie and our son Justin are rowers. I am a volunteer parent at synchro as well as being a board member of Synchro BC. I volunteer at rowing regattas as well.

Do you have any pets?

Our pets include three cats; Boots, Stella, and Scooter; three fish that are nameless; and a miniature horse who is a silver bay pinto colour. His name is Larkspurs Eagle Feather Warrior, or Maxwell for short.



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