

Heart Matters

NOVEMBER 2013

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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



We acknowledge the financial support of the Province of British Columbia.

Heart Matters

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Childrens Heart Network

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"

ERIC: My story BY ERIC O'BRIEN hen I was born in November 1996, the doctors heard a murmur. They did some tests on me and, unfortunately, they had to tell my parents that I had a serious congenital heart condition called tetralogy of Fallot (which meant that I had four defects involving my heart). This was not something my parents were expecting to hear. This was very upsetting to them as I was their first child. Fortunately, the cardiologist and cardiovascular surgeons knew they could help me. If I had been born 10 years earlier, I probably would not have survived for very long. When I was 2 months old, Dr Jacques LeBlanc performed a Blalock-Taussig shunt operation to help improve my oxygenation levels so I could get bigger for the really big operation that was coming. When I

Unfortunately, on one of my check-ups, my cardiologist Dr George Sandor realized that I had developed complications. A heart catheterization showed that I had developed a stenosis (narrowing) around my aorta and the patch used to repair my septal defect was leaking. The pressure in my heart was very high because of the narrowing. My heart had to pump very hard to get my blood through this narrowing. I was in danger of going into cardiac arrest. So, it was back to the operating room for me. This news was devastating for my parents. They had thought all that surgery stuff was behind me. Dr LeBlanc said to my parents in his very succinct manner, "Don't worry. You won't lose him." It just happened at this time that Children's Hospital also wanted to do a vignette of a family dealing with a child requiring heart surgery and they filmed my parents and me the day before and on the day of my surgery. They showed this vignette on the Children's Hospital Telethon.

was 10 months old, the doctors felt I was ready for my reconstructive

open-heart surgery that would finally fix my heart.

Dr LeBlanc was able to remove the stenosis and repair the leaking septal patch. Unfortunately, when they tried to get me off the bypass machine and get my heart started again, they discovered that I was in heart block. The electrical signals between the atria and ventricles had been cut. My ventricles were not pumping. This meant that they had to put me on a temporary pacemaker. They had hoped with time my ventricular function would return, but it did not. So, back to the operating room and a permanent pacemaker was put in my abdomen and leads attached to the outside of my heart. Now everything was working as it should be.

ERIC'S STORY CONTINUED ON PAGE 3

WHAT'S UP

CONGRATULATIONS to our Hearts of Gold coordinator. Kristi Coldwell and her new hubby Kenny, on their wedding on June 30th at the Granville Island Hotel! Kristi and Kenny were joined by their puppies, Mugsy and Katie, who walked down the aisle with the bridesmaids in custom made outfits. We wish Kristi, Kenny, Mugsy, and Katie an exciting and happy future!



HEART MAMA/PAPA COFFEE GROUPS

These groups meet monthly, come and meet other heart parents while enjoying treats provided by us! For more information please contact:

VANCOUVER – Samantha Aitken saitken@childrensheartnetwork.org

BURNABY/COQUITLAM - Sarah Kertcher sarah.kertcher@outlook.com

RICHMOND – Kate Walker kwalker@childrensheartnetwork.org

LANGLEY/ABBOTSFORD - Tecia Beulens tbeulens@telus.net

MAPLE RIDGE/TRI-CITIES – Amy Watkins amylouwatkins@hotmail.com

CHILLIWACK – Chantelle Bisschop bissch18@telus.net

VICTORIA – Teri Godin | terigodin@gmail.com

NANAIMO – Andrea Van Rossum 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

VANCOUVER – Corey Zinger | zinger92@telus.net **VICTORIA** – Lauren Fougner | lfougner@uvic.ca

HOW CAN YOU HELP?

Can you help with donating or collecting donations for the Christmas Party raffle?

Please contact Sam at saitken@childrensheartnetwork.org



CHN STAFF

Samantha Aitken – Provincial Coordinator Danielle Segur - Administrative Assistant Kristi Coldwell - Lower Mainland HOG Youth Coordinator Krista Molia - Vancouver Island HOG Youth Coordinator

CHN BOARD

Mandy Johnson – President Kate Walker – Vice-President Bindy Sweett – Secretary

Sarah Kertcher, Jeff Cornell, Sam Birkenhead – Members at Large

DATES AT A GLANCE

December 7th – Lower Mainland "Breakfast with Santa" Christmas Party at the Metrotown Hilton Hotel. Always a huge success with over 300 CHN family members enjoying brunch, arts & crafts, children's entertainer and special guests Mr. & Mrs. Claus! An email invitation will be going out shortly.

December 14th – Vancouver Island Christmas Party at Butchart Gardens. Come and meet other heart families while enjoying the festive location, carousel, lunch and surprises for the children! An email invitation will be going out shortly.

May 9th, 2014 – 12th Annual Wine Gala dinner to be held at The Jewel Ballroom at 8th and Granville.

ERIC'S STORY CONTINUED FROM PAGE 1

Every year, I would go in and have my check-ups and get my pacemaker interrogated (a computer talks to my pacemaker and asks how everything has been over the year). Most of the time, it is fine. Sometimes the generator needs a little tweaking with the settings. The battery doesn't last forever and I had to have the generator replaced when I was 10 years old. This was just a day surgery and everything went as planned. This June, I had to have the generator replaced again. I thought it would just be another day surgery; but, as things would have it, when they got me into the operating room the leads that are attached from the generator to my heart failed. This meant another operation. So, out with the old generator and a new generator was put up in my chest with new leads going through a vein into my heart. The surgeons (Dr Campbell and Dr Gandhi) and cardiologist (Dr Sherwin) were very pleased with the new pacemaker. It is so wonderful that we have such technology, like pacemakers, that can keep my heart beating.

This year in June, my family and I got to go fishing at Critter Cove Lodge on Vancouver Island with other families who have a child with heart disease. This event has been put on for the last 12 years through the generosity of the Forbes family (Critter

Cove's owners) and so many other people. Everything is donated including the ferry ride to the island, bus, food, and accommodations. Even the fishermen donated their time. boats, and equipment to



take us out fishing for 2 days. It was so much fun. Apparently, this was the best year for fishing they had ever had. All of the families caught lots of fish. I was lucky to catch two of the biggest fish—two 24-pound spring salmon.

I am grateful for all the help, support, and expertise of the staff at Children's Hospital. I appreciate the Hearts of Gold support group that I attend with other cardiac youth. It is nice to meet other people who have heart issues and understand what you have been through. Thank you for all you have done for me and my family and continue to do. I cannot adequately express my appreciation for all that has been done for me.





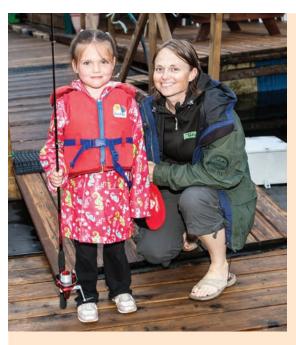
Brother Sydney, Layna and their dad, Al with part of the morning catch!

BY TANYA LAWES

ur family was lucky enough to get an email earlier this year inviting us to Critter Cove. We had been invited the previous year, but had to decline due to other commitments, making us extra enthusiastic to attend the event this year. This trip had meant that we had to take 2 1/2 days off of work and be away from home for 5 whole days. We had made all the necessary arrangements to make this possible for us. My husband Al and I, packed and ready, picked up our two kids from their last day of school. Layna, our daughter, had just finished kindergarten and Sydney, our son, finished grade two.

There was lots of excitement in the air because it was finally the last day of school, the first day of summer holidays, and we also got to leave for our trip. Fifteen minutes after leaving our hometown, Princeton, we were stopped in a highway construction line up. Luckily this only lasted half an hour as we still had a long journey ahead of us. Five hours later, we checked our tired family into a Vancouver hotel. We all headed up to our room and tried to rest our excited minds and prepare for the early morning ferry ride.

CRITTER COVE CONTINUED ON PAGE 4



CRITTER COVE CONTINUED FROM PAGE 3

The family arose from a great night's sleep and headed out. We arrived at the terminal with plenty of time to spare, and began to see many other families roll into the ferry terminal. We were all going to walk onto the

ferry together. A couple of the dads took care of packing our luggage into a few carts, so we didn't have to carry it on. The ferry departed with all the passengers loaded, heading toward our destination, Critter Cove. We would see someone from the Heart Network and acknowledge them with a friendly nod and smile but were too shy to talk. After the ferry ride we got onto a bus. There was still a bit of hesitation to talk to one another, as most people were busy with their own families. The journey up the island was beautiful and reinforced my opinion on how it always rains there. Everything was lush and green and we caught glimpses through the fog both on our bus windows and outside, of all the beauty that Vancouver Island has to offer.

We reached Gold River, and started down a gravel road that our driver did a wonderful job navigating. We arrived at Cougar Creek and were met by a crowd of very friendly volunteers. Before we knew it our luggage was all loaded and we were ready to head over to Critter Cove by boat. I wasn't sure what to expect of Critter Cove, but as we pulled in it far exceeded anything I had imagined. Everything was floating: the cookhouse and store, multiple floating cabins and docks, and fish-cleaning stations. We all headed to the cookhouse to find our guides for the week. Our guide's name was Captain Hook. The kids loved this. He and his wife Mavis had been volunteer guides since the beginning of the Critter Cove/Heart Network adventure 12 years ago. The conservation officers were there to give all the kids licenses, a goody bag, and a free T-shirt. After a full day of traveling, we were all ready for dinner and the volunteers did a wonderful job with that, it was so nice to be catered to.

We arranged a meeting time with Captain Hook for the morning, and before we knew it we were out trying to catch salmon. While we were fishing, we saw a seal, a bald eagle pick a fish right from the water, and heard about the history of Friendly Cove. We were even lucky enough to catch two salmon. When we got back to Critter Cove, all the kids got their very own fishing rod and tackle box. They were all trying to catch something off the dock. There were star fish, ratfish, and dogfish all being caught. For dinner that night there was a true feast. There were clams, salmon, halibut, and prawns all donated and all delicious. The Coast Guard came and opened their boat for tours to all the families. People were starting to talk more to each other and become friendly. There was time to visit and

compare stories at the wharf and in the cookhouse.

The next morning, we fished our way over to Friendly Cove and had time to explore this old Native settlement once we arrived. There was an old church, almost like a museum. There were old photos of what had been there before, amazing us with all the change that had happened. There were two beaches, a protected one and another looking out toward Japan. Coming from the interior both were very interesting, filled with different sea creatures, odd rocks, and logs and just unlike anything we were used to. The Chief and his family, the only family still living at Friendly Cove, hosted a barbecue, cooking salmon for us on an open fire. It was a beautiful afternoon for enjoying everybody's company. The police boat showed up to take people for rides on their zodiac. Only three guests at a time could go, fully strapped in. The Zodiacs could reach the speed of 100 miles per hour, with razor sharp turns. The ride on them was more exciting than any amusement park ride.

Later that evening after supper when it had darkened, the owners of Critter Cove had arranged for a July 1st celebration including fireworks. Imagine being in this secluded location, enjoying almost half an hour of an incredible fireworks display. The kids were in awe and so were most of the adults.

The next morning it was time to head back to Cougar Creek to catch our bus. In years past, people hadn't had a lot of luck fishing, so the weekend before, Critter Cove had frozen a bunch of salmon from their fishing derby. Their plan was to send everybody home with fish. This year, the fishing had been great, so not only did everybody have a full cooler, some people had two. The bus was a little late getting there, but we managed to make it back to the ferry in time to walk right on. Thank heavens our host had made us a reservation, as we walked by a lot of other people who had to stay and wait for the next ferry.

We got back to Horseshoe Bay around 7 p.m. and said farewell to our new friends. We started our 5-hour drive home. This gave us time to reflect on how many people had been part of this weekend and all the things that needed to take place behind the scenes in order to make it happen. The trip was about so much more than the 3 days at Critter Cove. It was about the time it took to make it all happen, all the people involved and how much people are willing to share and give. It was about embracing the journey and all that it may hold for us. Having a heart child has brought perspective to our lives and made us realize that every day is a good day and we are happy that we got to share some of the precious days with other heart families.

Layna is our heart child. The short version is she was diagnosed with a large VSD when she was 2 days old. She had the repair done at 6 months and now has a pacemaker (with one broken lead) and tricuspid stenosis. She is like most other 5-year-old girls, likes to draw and colour, in the winter she's in skating and in the Manning Park Ski Club, and in spring she plays soccer. We are a lucky family.

Scar management for cardiac surgery patients

DR CYNTHIA VERCHERE

'n almost everyone who undergoes surgery, there will be a period of several months when the scar is "immature" - it will be red and ropy, and sometimes raised up from the surrounding skin. Usually, the scar matures over the course of about 12 to 18 months and will lose its pink colour slowly over that period. Most scars will settle significantly over time even if you do absolutely nothing to them. That is why there are so many types of scar creams, dressings, and potions on the market; most scars will be much better in a few months whatever you use or don't use and we can't tell what made the scar better – time using a product or time itself.

Surgical scar quality varies with location, orientation, skin type, wound healing environment, and time since surgery. Even an ideal scar will be visible forever, but it would be narrow, flat, coloured the same as the adjacent skin, and freely move over the underlying tissue.

Problematic scars

There can be several ways that a scar is more problematic. It can be widened significantly in sections or in its entirety, be thickened or raised, be uneven, have bulges at the ends, be tethered to the fat, bone, or muscle beneath it, be permanently red or purple or brown, or be painful or itchy. Sometimes part of a scar may be barely visible, while other parts where there is more tension, may be raised and itchy. Some of these less-good features can be fixed, some cannot.

If there was any delay in wound healing (infection, multiple open and close, etc.) the scar has a higher chance of being more permanently "hypertrophic," which means more raised and red and ropy than usual. Certain skin types (usually the more pigmented skin - Asian, olive, black, or brown) also have a higher chance of making these type of scars. There are also people that heal with "true keloid" scars where too much scar tissue is made and the scar is even bigger than the borders of the original incision. Picture chicken pox scars that grow to the size of ping pong balls, or a part of a sternotomy scar that mushrooms up an inch. Many times this tendency runs in families, is more common in certain parts of the body, and most times happens again if the scar is re-operated on.

Scar management techniques

There are early scar management techniques that can be helpful to reduce the hypertrophy of scars if started in the first weeks to months after the surgery. Once a scar is mature about a year later, these techniques aren't effective. These include taping, massage, pressure garments, gel inserts, and steroid injections. Taping is cheap and easy and effective. If Steri-Strips are used at the time of surgery, I usually recommend leaving them well stuck on as long as humanly possible; sometimes this may be 6 weeks! The tapes take tension off the wound and put a bit of pressure on them. After the Steri-Strips, a strip of 1-inch white micropore paper tape stuck well onto the scar and changed every day or two as it loosens can prolong this positive effect. Some people do this for months while the scar matures. Starting at about 3 weeks

after uncomplicated wound closure, massage of the scar is very helpful even if you are also taping it. This involves pressing down on the scar and also moving and stretching the scar tissue away from the deeper structures and breaking up and lengthening the scar fibres. Pressure garments, silicone gels, and steroid injections are usually reserved for scars that are really rising up despite normal healing conditions and massage and taping. There are some relatively inexpensive silicone gel products that can be purchased over the counter that some patients choose to use, but they are not necessary if a scar is healing with its normal temporary enlargement.

Creams and lotions: One that works

There are thousands of oils and lotions that make claims to make scars better if you massage with them. It is very difficult to find any true science that supports any one product making a significant difference, but most are not harmful, and recently popular ones are bio-oil and vitamin E. I don't recommend spending significant amounts of money on any one product - we just don't have enough evidence to say that a \$50 cream is any different than drugstore hand lotion if you massage the scar with them. One lotion we do recommend though, especially for the first year, is sunscreen. While a scar is still red, it has a good chance of turning permanently brown if exposed to sunshine, so your best bet is to wear good sun protection until the colour has faded. Remember that any cream, lotion, gel pad, or tape can be the source of allergic reactions or contact dermatitis and they should be discontinued if this happens.

Surgery to improve a scar

For mature scars, there are some cases where a surgical revision will be helpful, but it is certainly not applicable to everyone's scar. Those who had complicated wound healing the first time may benefit from a second chance of healing the wound in better conditions. If the scar is widened, tethered, uneven, or unstable or not well oriented with potential wrinkle lines, removing the existing scar and realigning it, combined with the early scar management interventions mentioned above, may give a better chance of making a good scar. Revisional surgery may not, however, make a difference if your skin type is one that has a tendency to make thick scars or keloids – it may just happen again. Also, sometimes you have to trade a widened or poorly oriented scar for one that is longer (but hopefully better quality) and there is always the risk that infection or poor wound healing may occur again.

If you think you may fit into the surgical category, explore the options with your surgeon or a plastic surgeon. You may benefit from waiting for your scar to mature, or you may want to choose the timing of your revisional surgery based on your lifestyle, the chance of you needing further cardiac surgery, your age (there is a slightly higher risk of making hypertrophic scars in early active puberty or pregnancy), and how much your scar affects your life.

DR VERCHERE IS A PLASTIC SURGEON AT BC CHILDREN'S HOSPITAL

Are youth and families ON TRAC? Taking responsibility for adult care

he ON TRAC Initiative is a collaborative partnership to improve continuity of care for youth who are leaving pediatric care to enter the adult health care system. It is provincial in scope – with the aim to support transitions for all youth wherever they live in the province.

This work began in April 2011 with a workshop funded by Child Health BC. Stakeholders from throughout the province including youth and families – shared their stories, concerns and needs to successfully prepare and leave pediatric care - to safely attach to care providers in the adult system.

Working with youth, families, pediatric and adult specialist teams and community family physicians and nurse practitioners – the ON TRAC team has developed prototypes of tools to guide the planning, preparation and transfer into adult care. Some tools have been designed for the health care providers to guide the process, other tools are being designed for youth and families.

The ON TRAC Initiative is very much a partnership and the parents and youth from Hearts of Gold, BC Children's pediatric cardiology clinic, the staff at the PACH clinic at St Paul's, and Dr. Brian Sinclair from Vancouver Island, have been significant contributors to name a few. Your youth and

parents have shared with us their concerns and needs around transition – "we need information; not only health information and records but also tell us how to better prepare for leaving BC Children's and getting ready for the differences in adult care". Youth have told us - the way to communicate with them is through their phones! We have listened and are working hard to meet these requests.

Later in October 2013 we will be launching a website www.ontracbc.ca that will house a Toolbox – with a toolkit designed for the youth, the families and the care providers. There will be feedback surveys attached to every toolbox for your ongoing input. At this time, we are looking for interested parents and families of youth who are currently transitioning or have completed the move to adult care, to assist in the development of the adult toolkit! If you are interested – please contact Mary Paone mpaone@cw.bc.ca Nursing Lead for ON TRAC Transition Initiative.

ON TRAC ONTRACBC.CA

TRANSITIONING RESPONSIBLY TO ADULT CARE





Transition Workshop attendees!

Transition workshop

'n September the CHN held the first Transition Workshop at the Vancouver Aquarium. Twelve members of the Heart of Gold Youth group from the Lower Mainland and Vancouver Island participated in an educational discussion focused on preparing to transition from a pediatric hospital to an adult hospital. We hope to hold more of these workshops in the future.

We are grateful to the Vancouver Aquarium for their tremendous support in making this event happen!

RESOURCE PARENTS AVAILABLE

Resource parents are available in a variety of regions with children who have a range of diagnosis. If you have a heart child and would like to connect with a family that has had a similar journey with their child, please email Samantha at saitken@childrensheartnetwork.org.



Heart heroes supporting CHN

Chloe Isaac remembers cousin Mila with donation

Out of the kindness of her heart, Chloe Isaac decided to do something very special at her recent 9th birthday party. In memory of her adored cousin Mila, she had her friends come and celebrate with her at Pony Meadows and suggested they forego bringing birthday gifts and instead make a donation to the Children's Heart Network. Chloe's friends and family raised \$550! Thank you Chloe, we are very grateful.

Chloe at Pony Meadows >





Cops for Kids sends Joey for a ride

CHN was lucky enough to receive a grant from Cops for Kids which allowed us to cover the transportation costs for our heart kids to come from the Okanagan area to camp this past summer. On September 15th, Joey Dachwitz, one of our Hearts of Gold teens, was able to present a thank you card on our behalf as the Cops for Kids ride came to a close in Kelowna. A huge thank you to Joey and to Cops for Kids!

Joey making the presentation

Louisa and Douglas Cassidy's lemonade stand

CHN would like to send out a heart-felt thank you to Louisa and Douglas Cassidy of Vancouver (recently moved from Scotland) for their \$100 donation. This young, thoughtful, entrepreneurial brother and sister team ran a lemonade stand this summer to raise funds to support CHN. Louisa learned of the Heart Network through her friend Rhys, whose cousin Mila had heart disease. Mila is working in special ways!

Louisa and Douglas hard at work



More supporters

Thanks also to the following amazing CHN supporters:

- Lydia Schwartz for collecting \$215 in donations in lieu of birthday presents. Thank you Lydia!



Are your kids getting enough exercise?

BY ASTRID DESOUZA

Did you know that all children, even those with congenital heart disease (CHD) need 60 minutes of moderate to vigorous activity per day for optimal growth and development, general health, and prevention of adulthood diseases? The activity habits that are developed early on in life teach children how to be active in the future, so it is important to start developing good habits now!

Why is exercise important to my child's health?

Exercise influences various systems of the body. Regular exercise increases the output of blood from the heart as well as the oxygen delivery to the working muscles. It also helps to maintain a healthy weight, which is important for the prevention of adult heart disease. Not only does exercise improve heart function, it also helps to develop balance, agility, and coordination, a necessary foundation for participation in physical activity. Childhood and adolescence is a key time for bone development. Weight-bearing exercise (e.g., running, jumping, hopping, skipping) is important for the development of strong, healthy bones. Regular exercise also has a role in maintaining a strong immune system, improving self-esteem and confidence, enhancing academic performance, and developing good sleep habits.

What about my child's heart, is it okay to exercise?

All children need to exercise; they just need to do so in a way that is appropriate for their own heart condition. The heart is a muscle that needs exercise like every other muscle of the body. Most children with CHD are able to participate in all types of activities; they just need to be able to take breaks when needed. As sports become more competitive in adolescence, a decision may need to be made with your cardiologist as to whether participation at higher levels of sport is appropriate.

My child is not good at sports and they don't want to participate in anything. What should I do?

Try to expose your child to different types of activities. Have them try sports that require different skills; this may be achieved through different team sports, martial arts, and individual sports. Remember they don't have to be the best at the activity; they just need to enjoy participating. There are lots of different activity choices!

Be a good role model. It is more likely that kids will be active if their parents are active as well. Think about pursuing active habits as a family. Go for a family walk or bike ride, go for a swim or play tennis together. Think of opportunities in your daily life where your family could be more active.

What is the best type of exercise for my child?

The best type of exercise for your child is the one that they enjoy doing! One goal of exercise in childhood is for kids to develop many different skills (e.g., running, jumping,

throwing, kicking). This provides them with the foundation for many different activities as they move into adolescence and adulthood.

Do they have to get 60 minutes of continuous exercise? No. Exercise can be accumulated throughout the day in bouts of 10 to 15 minutes at a time.

What does moderate-to-vigorous activity look like?

Generally, we want kids to be participating in activities where they are increasing their heart rate and they are sweating!

As parents, what warning signs do we have to look for? Children are good at pacing themselves; they will stop when they are tired and will re-start when they are ready. As children move into adolescence, they have more of an ability to push themselves and should be reminded to stop if they need a break. Start a dialogue with your child to ensure that you are aware of whether they are experiencing a "pressure" feeling in their chest, having a difficult time catching their breath, have unexplained dizziness, or a sensation in their chest where their heart feels like it is beating abnormally fast, slow, or irregularly.

What happens when my child goes to school? What should I tell the teacher to look for?

Make sure the teacher is also aware of the symptoms you are looking for. Have them also pay attention to where the child is in relation to the rest of the group if they are participating in a group run. Can they keep up with their peers or are they lagging behind? I am happy to provide more detailed instructions if the teacher needs them.

What should I do if I have any questions?

If your child is experiencing any symptoms during exercise or if you have any questions regarding your child's activity levels, please contact your doctor. You can also contact the exercise physiologist, Astrid De Souza (adesouza2@cw.bc.ca), if you need more detailed instructions on appropriate activity choices for your child or ideas on how to get your family to be more active.

> ASTRID DESOUZA IS AN EXERCISE PHYSIOLOGIST AT BC CHILDREN'S HOSPITAL