



KARTER'S STORY

Waiting for a miracle

BY BRANDEE BROWN

Excited and impatient, we awaited the news of the gender of our second child. We did manage to find out eventually, but what we found out with it was the furthest from our minds. Our world was immediately shattered. Our unborn baby, if he made it, would be born with congenital complete heart block, a severe problem with the heart's electrical system. Devastated, we took the necessary steps to learn all we could and fight to see him through to delivery, as we were told many of these babies didn't make it to their birthday.

Karter quietly entered this world by C-section at 36 weeks. I had the chance to kiss him and snuggle him for only a moment before he was whisked away. I was so incredibly grateful for that quick embrace.

Karter's heart rate was at a mere 53 BPM, far too slow for any baby. The team told us that the heart rate could possibly come up a bit after delivery. Unfortunately for Karter, this was not the case. He slept through the first week of his life, too weak to eat or open his eyes. It was the hardest thing to watch; he wouldn't nurse and would barely acknowledge our existence. It hurt so badly. As a mother, knowing I couldn't make it better for

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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.

Heart Matters

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/ChildrensHeartNetwork

him was the most difficult thing in the world. After 8 days and no change in heart rate, Karter was given a pacemaker. After 2-½ weeks of recovery, we finally headed home, excited and terrified to start this journey into unknown territories.

Karter's journey was difficult from the very beginning. He didn't want to eat, didn't want to sleep, but couldn't stay awake. He failed to thrive. He was constantly vomiting and soon his heart failed him.

By 6 months, Karter was knocking on death's door, desperately needing intervention. Before the towel was thrown in and he was given a heart transplant, he underwent another implanted pacemaker (biventricular device) and many new meds in a last ditch effort to regain function. We were lucky he was so determined to live, as the doctors had never seen someone his age with such poor function still fight the way he had. The odds were in his favour! Or so we thought.

Sadly at 8 months, there was no change again, he was listed for transplant, and declared dependent on continuous IV meds through his PIC line (peripherally inserted central catheter) to keep him alive while



THE 15th ANNUAL

CHILDREN'S
Heart Network

Wine Gala & Dinner

Benefitting Children And Youth With Congenital Heart Disease
Hor-d'oevres with bubbly • 4-course dinner with wine pairings • Silent and live auctions

FRIDAY, MAY 5th, 2017

6:00pm - 11:00pm

THE DIAMOND BALLROOM

1495 West 8th Avenue, Vancouver

Please take advantage of the complimentary valet parking.

THE EARLY BIRD TICKET PRICE OF \$150

(Available until Feb 28th) Regular priced tickets are \$175
A portion of the ticket price will be issued as a tax receipt (\$75)

To purchase tickets visit www.chnevents.org

www.childrensheartnetwork.org



Karter has defied the odds many times. Today he's a spunky firecracker of a 4-year-old.

we waited at home.

The dreaded wait began.

Karter was so sick his entire little life that he never had the energy to eat and had been tube fed exclusively from 6 months old. He spent so much time in a hospital bed that we had nonstop therapy. Feeding therapy, physiotherapy.

As a mother, watching over him 24/7, administering meds, taking care of our 3-year-old daughter, and trying to spread myself out to be the best mom I could be, I was worn thin. These last few years have been the hardest years of our lives.

Our new normal meant constant admissions, blood draws, living in a bubble, PIC line dressing changes, no contact with the outside world or normal family time, as we were so nervous of him catching anything and everything, possibly jeopardizing his transplant, if that dreaded magical call came. Because we live in Kamloops, we lived out of suitcases for nearly 2 years, ready to leave at a moment's notice.

When Karter was listed there wasn't a transplant program in BC and we were prepped to head to Alberta. I slept with my phone, I showered with my phone, I took my daughter to her swimming lessons with my phone. Yet I was terrified to answer my phone.

Many nights (most every night really) I lay awake watching his every breath and heartbeat; making sure he didn't strangle himself on his IV and feeding lines. I had never known a love and a stress all at once, to this extreme. Love, unity, strength, persistence, and a

strong-willed baby boy is what kept us all hopeful!

After 19 months of endless waiting, we never got the call. Miraculously, at one of our routine clinic visits, test results showed improved function, which baffled all of us—his team of doctors included. This little boy was about to beat even more odds than he already had! His heart recovered enough to stay with him a while longer. He was unlisted!

Today he is 4 and doing better than any of us could have ever imagined or hoped for. You would never know just by looking at him, all that is going on in his tiny body, or the things he has endured.

We will always have a cloud over our heads as things can change at

any moment. Now we take this time, and appreciate his comparatively good health with his own heart, and cherish every minute. We don't know what tomorrow may bring and we know we aren't guaranteed tomorrow. He will need regular surgery to update pacemakers due to battery life, and we are as okay as one can be with that. He still has his own heart, and that's amazing.

We are so grateful to have him here with us. We can't thank everyone involved in his care enough for allowing us more time with our spunky firecracker of a boy. We are so lucky to have him in our lives. He continuously reminds us to stay humble, and to never, ever, lose hope.

No one ever imagines themselves embarking on a journey such as this. You join an elite club no one ever wants to be a member of. But if it weren't for this crazy rollercoaster we wouldn't have found ourselves blessed with getting to know so many amazing families and their children, not to mention the organizations that go above and beyond. One of our favorites is the Children's Heart Network. They truly help families get together and be able to speak to others who understand the struggle and the language of this lifestyle. We all share a common bond and can find comfort in knowing we are all in this together. We've become such a tightly knit community. We are grateful for events held by CHN that keep our kids together (as well as us parents) and allow all of us to forget, maybe just for a day, about the hurdles each one of our families face. It certainly helps you make it through some of those extremely tough times, knowing you're not alone. Words will never suffice for how truly thankful we are. With all of our hearts, thank you CHN! 🍓



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

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

CHILLIWACK – Melissa Martz
mellymartz@outlook.com

KAMLOOPS – Miranda Brown
cmazn2003@yahoo.ca

KELOWNA – Karla Allan
kdvk@hotmail.com

LANGLEY – Tacia Beulens
tbeulens@telus.net

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

NANAIMO – Andrea Van Rossum
andrea.vanrossum@gmail.com

PRINCE GEORGE – Veronica Vandermeulen
veronica0603@gmail.com

RICHMOND – Kate Walker
kwalker@childrensheartnetwork.org

VANCOUVER – Samantha Aitken
saitken@childrensheartnetwork.org

VICTORIA – Teri Godin
terigodin@gmail.com



YOUNG ADULT HEART NETWORK COFFEE GROUP

We have a group for young adults living with heart disease. For more information please contact:

Lauren Fougner | lfougner@uvic.ca

THANK YOU

CHN would like to thank The Province of BC for its continued support of CHN through its Community Gaming Grants program.



The Province of BC

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!

CHN BOARD

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MANDY JOHNSON – Past president
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BARBARA JOHNSTON – Member at large
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LINDA ADAMS – Member at large

CHN STAFF

SAMANTHA AITKEN – Provincial coordinator
PATTY RIPPEL – Administrative assistant
KRISTI COLDWELL – Lower Mainland Hearts of Gold youth coordinator
MEGAN MADSEN – Vancouver Island Hearts of Gold youth coordinator

Mila's Fund in action

Mila's Fund was started in 2013 in memory of a very precious heart angel, Mila Dickout. Her parents, Lisa Lalsingh and Dustin Dickout, were overwhelmed by the outpouring of love and support by family, friends, and others who wanted to do something in Mila's honour. One of the things that Mila looked forward to and would have loved was camp.

Mila's Fund exists to provide funding that will ensure that the CHN will continue to provide quality camp experiences for members' children on an annual basis, and that all children, regardless of family income or geographical region, have access to apply for and enjoy CHN camp experiences. In addition, Mila's Fund may be used, when other options do not exist, to support family attendance at Critter Cove or Family Camp by covering travel or accommodation expenses incurred in order to get to the site. This fund essentially guarantees that CHN camps will continue to provide therapeutic experiences for children in BC living with heart disease.

This past summer Mila's Fund helped transport over 20 teens to Camp Zajac, helped a family come from Vancouver Island to Family Camp, and covered transportation costs for two families to get to Critter Cove. We are grateful for the support from so many people in Mila's memory!

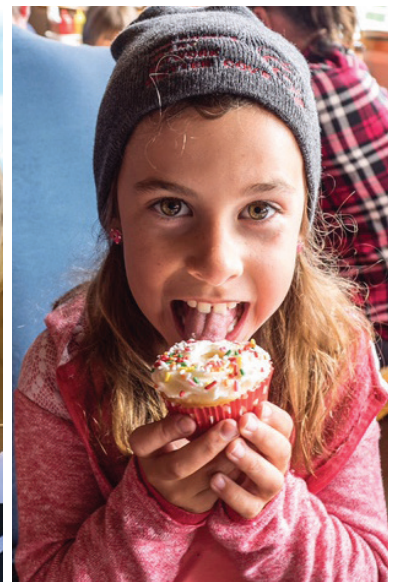
If you would like to donate to Mila's Fund please visit: www.canadahelps.org/en/charities/childrens-heart-network/#donate_now and change the drop down menu to choose Mila's Fund. 🍕



Heart Heroes

A heartfelt thank you to Helena Allen from Kelowna as well as brothers Rhys and Drew Isaac from Vancouver. Helena chose to donate part of her birthday money to the CHN to help support other heart families. Rhys and Drew asked their friends and family to make a donation to the CHN on their birthdays in memory of their very special cousin, Mila Dickout.

Thank you Helena, Rhys, and Drew, you are heart heroes! 🍕



How to help your heart child at school

BY JEN BELESHKO

Starting school can be an exciting milestone for children and their parents. It can also be a time of stress and frustration when you factor in a chronic illness or special needs. Navigating the school system and advocating for your child can seem overwhelming. The bottom line: communication between parents, children, and the school is essential to optimize a child's education.

Educating the educators!

It is important that the family not try to hide the child's heart problem so that the child can feel normal. Let the school know about exercise restrictions (if any) and signs that the child needs medical attention. You may want to work with the school to plan how to handle a medical emergency. Children who miss a lot of school may have trouble keeping up with their schoolwork. Most hospitals have a teacher available who can help the child keep up-to-date while in the hospital. Schools can arrange for schoolwork to be done at home if the child is too ill to attend school, or for extra work before surgery.

Keep in mind that teaching staff are not medically trained and may require multiple explanations in order for them to fully understand the child's physical and emotional needs or limitations. Teachers may feel overwhelmed with the responsibility of having a child with a heart condition in their class. Teachers have a whole classroom of children, and often have several children with special needs, so the teacher must learn about all of them individually. It is important for the teachers to treat all children equally while meeting their educational needs. A wonderful hand-out for teachers from Sick Kids can be found online at:

www.aboutkidshealth.ca/En/HealthAZ/LearningandEducation/InformationforTeachers/Pages/Congenital-Heart-Defects-Information-For-Teachers.aspx

Explaining your child's heart condition to classmates

According to Barb Roessner, physician assistant and coordinator of the Heart Failure and Transplant Program at Children's Hospital & Medical Center in Omaha, Nebraska, many



parents of kids with heart conditions say they want their children's peers to treat them the same as any other kid. But that can be hard when their peers sense that something is different about your child. A great way to ensure your heart kid is treated no differently than any of her friends is to address the situation outright. Barb Roessner offers these suggestions on how to explain your child's heart condition to his or her classmates.

Explain the truth behind common fears kids may have about heart conditions. Depending on their age, your child's classmates might not have a solid understanding of what having a heart condition even means. For instance, explain to them that most kids with heart conditions are born with them. Also share that they cannot get them just from being friends with someone who has one. A good way to demonstrate this is to compare heart conditions to another medical issue they may be more familiar with—like asthma or a food allergy. Explain that a person with asthma or allergies may feel sick sometimes because something in their body isn't working right. This person didn't do anything to cause the condition and can't pass it on to other people.

See if a science teacher at your child's school or a physician at your child's hospital can speak to his or her classmates about how the heart should work—and how it actually works in people with his heart condition. For a more in-depth look, PBS has a detailed circulatory system lesson plan with activities ideal for middle school-aged kids. http://www.pbslearningmedia.org/resource/tdc02.sci.life.stru.lp_circula/the-circulatory-system/

Even though your child has a heart condition and may miss a lot of school because of illness, surgery, hospitalization, or doctor's appointments, he or she is just like any other child in the sense that she still feels the need to belong, so the efforts you make to help integrate your child into school will be well worth it. 🍎

Children's Heart Network Conference 2017

Growing Up with Heart Disease

4 – 5 November 2017 (Saturday – Sunday)

Chan Centre for Family Health Education (at BC Children's Hospital)
950 West 28th Ave., Vancouver, BC

The Children's Heart Network is pleased to announce the ninth Growing Up with Heart Disease conference. This is a collaborative conference by and for families and health care professionals. It's an opportunity to learn from the experts—physicians, nurses, psychologists, researchers, fellow parents, and other heart kids—and connect, share, support each other.

Volunteers needed

If you are a heart parent and would like to be part of the Conference Planning Committee please contact Samantha Aitken at saitken@childrensheartnetwork.org. Monthly meetings will begin soon.

Parent and Health Care Professional Program

Plenary speakers, concurrent sessions, and workshops on:

- Current research and innovations in pediatric cardiac care
- Strategies for supporting children with heart disease
- Heart health and physical activity
- Dealing with issue like hospital discharge, school, and nutrition
- ...and don't miss the conference favorite:
- A special presentation by youth from the Hearts of Gold Youth Program!

Children's Program

The Children's Program will be available for infants (6 months or older) and children up to age 12. (Babies under 6 months can attend the conference sessions with a parent.) The program welcomes children with heart disease and their siblings. Qualified early childhood educators will care for and have a variety of fun age-appropriate art and activities for the kids. You will be able to relax and enjoy the conference while your kids play and have lots of fun!

Hearts of Gold Youth Program

The Youth Program welcomes all youth with heart disease and their siblings aged 13-19 years. The Hearts of Gold Program caters to the needs and interests of youth and provides a forum for expressing their ideas related to living with heart disease.

Watch for online registration coming soon!

Health care professionals, parents, youth, and
children of all ages welcome.

How to protect your baby from RSV (and other infections)

What is RSV?

RSV stands for respiratory syncytial virus. RSV is a very common virus in infancy and early childhood. RSV infects almost all children by the age of 2-3 years. It can cause pneumonia and is the most important cause of bronchiolitis during the first year of life (bronchiolitis is an inflammation of the smallest airways of the lungs). Babies with a congenital heart defect can become very ill with lung infections caused by RSV.

What are the symptoms of RSV infection?

The symptoms of RSV infection may be like a cold at first and can include:

- Fever
- Runny nose
- Other cold-like symptoms

The symptoms of RSV infection may get worse after it gets into the lungs. These symptoms can include:

- Deeper and more frequent coughing
- Difficulty breathing, including wheezing (a whistling sound) and rapid breathing
- Blue lips or fingernails
- Dehydration
- Difficulty breastfeeding or bottle-feeding



Reducing the risk of infections

RSV is a common, highly contagious virus, but there are things you can do as a parent to reduce your baby's risk of being infected.

For starters, you can practice basic techniques that have been shown to reduce the transmission of all kinds of infections, including RSV:

- **Wash hands:** Wash your hands frequently with soap and water – especially before you touch the baby. Make sure siblings and visitors wash their hands as well.
- **Avoid exposure to illness:** If you have a cold or fever, avoid kissing your baby, and limit your infant's exposure to people who have a contagious illness.
- **Keep surfaces clean:** Because RSV can live on surfaces for hours, make sure countertops and bathroom surfaces are cleaned regularly with cleanser – especially when someone in the family has a cold. Make sure to clean toys regularly, and always after a child with a cold has played with them.
- **Avoid crowds:** Try to avoid crowded places such as shopping centers, daycares, and large family gatherings where your baby will come into contact with lots of people – and all their germs.
- **Avoid second-hand smoke:** Minimize your baby's exposure to second-hand smoke. Exposure to tobacco smoke can increase your baby's risk of contracting RSV and increase the risk of more severe symptoms if they do contract the virus. Don't smoke around your baby and don't let others do so. 🚭

Children's Heart Network on social media networks near you!



@childrensheartnetwork
facebook.com/ChildrensHeartNetwork



@Childrens_heart
https://twitter.com/Childrens_Heart



www.childrensheartnetwork.org

Connect with other heart parents from all over BC. Find support, ask questions, hear about upcoming events and coffee groups, and support others. It has never been easier to connect with others experiencing the challenges of bringing up a child with heart disease.

Information used with permission of AbbVie Corporation

What's Happening?

Renew your membership & consider a donation

This is the perfect time of year to renew your CHN membership (\$25 per family per year) and to consider making a tax-deductible donation to CHN. www.canadahelps.org/en/charities/childrens-heart-network/#donate_now

Buy chocolates for Congenital Heart Defect Awareness Week

Congenital Heart Defect Awareness Week is February 7-14. We will be selling heart chocolates at BC Children's Hospital on Valentine's Day, Tuesday, February 14 in the Ambulatory Clinic (building across from Emergency Department entrance, near Starbucks). Support CHN and buy gorgeous European chocolates made by Daniel's Le Chocolate Belge for all your loved ones.



CHN annual general meeting

The CHN annual general meeting will be Tuesday, February 21 at 7 p.m. in Room 3D16 at BCCH. We will have a guest speaker, Astrid De Souza, an exercise physiologist from BCCH. Her topic will be Physical Activity and Your Heart Child. Come and join us for this great presentation. Please RSVP to Samantha at saitken@childrensheartnetwork.org or just come last minute.

Easter egg hunts – Save the date!

Lower Mainland – April 8 at Queens Park in New Westminster
Victoria – TBA

The 15th Annual Wine Gala Dinner

When: Friday, May 5 at 6:00 p.m.

Where: The Diamond Ballroom, 1495 West 8th Avenue, Vancouver

Why: Have fun at this gala evening with passed appetizers, a four-course meal, wine pairings, live and silent auctions, and more! Have a great night and help raise funds to support our network, an essential service for children, teens, and their families.

To order tickets or to donate to the auction please go to www.chnevents.org or email Sam at saitken@childrensheartnetwork.org

Growing Up With Heart Disease Conference 2017 4–5 November

Chan Centre for Family Health Education (at BC Children's Hospital)

This is a collaborative conference by and for families and health care professionals. It's an opportunity to learn from the experts—physicians, nurses, psychologists, researchers, fellow parents, and other heart kids—and connect, share, support each other. Watch for upcoming registration information.

Thanks, Kids Up Front

CHN has been lucky enough to partner with Kids Up Front for the past 3 years. Over this time many of our families had been fortunate to receive tickets to fun events that have been



donated by companies and individuals. Canucks, Vancouver Canadians Baseball, Vancouver Giants, Arts Club Theatre, and many generous individuals have donated their tickets and allowed our kids to have experiences they may not otherwise have had. This past Christmas season the Eijbersen family enjoyed a fabulous performance of at the Stanley Theatre.

Shelley and Nathanael Eijbersen write: "Thank you for providing us with tickets to see *Mary Poppins*. We do not get much exposure to the arts in the city and this was a wonderful way to show the children a different "screen"! A great family event. The staff was very friendly, the actors amazing, and the costumes delightful! We have loved being part of the Children's Heart Network, it has been greatly supportive to meet other heart families through different events like this one."



The Eijbersen family at the Stanley Theatre.

Heart of Gold Events Roundup

Vancouver

BY KRISTI COLDWELL

November's event was a CPR course with St. John Ambulance followed by a fun dinner at The Old Spaghetti Factory. The course took place in New Westminster and ran from 12:30 pm to 6:30 pm. It was a long afternoon so we took a nice break and had pizzas delivered for our hungry teens; it definitely re-charged us! The course was very interactive and involved quite a bit of movement. All participants earned their official certificate in CPR, a fantastic success rate! Following the first aid course we all walked to the restaurant and enjoyed a great dinner. Everyone was hungry and ready to unwind so it was a great way to end the evening as it gave the teens a chance to visit and relax.

December was our always-anticipated annual Christmas Dinner Cruise. We had a fantastic turnout with over 20 teens who were dressed up and ready for a good time. Everyone boarded, we set sail at 7:00 pm and settled into our dining tables. We were thrilled to have our new volunteer join us, Cole Renner, who works with the Canucks and enjoys supporting and hanging out with teens. Christmas carolling followed dinner; all the teens participated and enjoyed the gorgeous lights of Vancouver and other carol ships. The highlight of the evening was the gift exchange; drawing numbers, picking gifts and then swapping and opening! Dancing filled the remainder of the night, everyone got out on the floor, even if only briefly as they did not let their nerves or mobility issues deter them!



Victoria

BY MEGAN MADSEN

In November we went to Paletable Pottery, a paint-your-own ceramics shop. This event was a huge hit; a great opportunity for all the teens to chat and connect with each other. The studio provided a lovely, creative atmosphere and everyone painted beautiful pieces to take home. It was neat to see them help each other and encourage each other as they painted. 🍷



Top: Keilar, Chloe, Kiana, Daniela, Sarah, Eli and Kristi at the Old Spaghetti Factory. Middle: Christmas Boat Cruise group photo. Bottom: Emily, Aina and Shaelyn at Paletable Pottery.

CHN's annual holiday breakfast with Mr & Ms Claus

This year's event was such a fun, festive day! We had over 250 heart family members join us at the Metrotown Hilton Hotel to celebrate the holidays. The decorations were gorgeous and a very entertaining show was put on by Bertolt and his "Adventure of Santa's Missing Hat." 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 Ms Claus, who spent time chatting with children, everyone providing big smiles for the photographer. A huge thank you to Martha McKenzie who once again donated her time and fabulous photos for our families to enjoy!

We would like to thank the following sponsors, without whom this event would not be possible:

- The Metrotown Hilton Hotel
- Fratelli's Bakery
- Martha McKenzie
- Daniel's Le Chocolate Belge
- And all the families and businesses that donated to the raffle



Above: Houston looking dapper in his formal wear. Top right: Keegan and Caleb. Bottom right: the McIntyre family.








CANADA'S PRIVATE THERAPEUTIC NETWORK FOR KIDS & YOUTH WITH HOSPITAL EXPERIENCE



Upopolis is a safe, online community for youth ages 10-18 years who are receiving medical care or are living with a chronic medical condition — a space for youth stay connected with friends and family, share experiences, meet other youth with similar experiences, access age appropriate medical information and create their own content. Upopolis is brought to youth by Kids' Health Links Foundation and its technology partner, Telus.

HOW CAN GET INVOLVED!

-  **POST** The more U and other youth **post** on Upopolis, the more interesting it becomes.
-  **CREATE** Upopolis has lots of great **spaces** created by youth. What space would you like to create and lead?
-  **VOLUNTEER** Ask Krista how U can become a **Upal** or **Umentor**. It only takes a bit of your time and it's all online. If your school requires you to volunteer in your community, we can provide you with a certificate for your role.
-  **ACT:** Watch for more information on our new **We Act** team. Be sure to join!
-  **JOIN:** Be a part of the **Upopolis Youth Advisory Council**. U can help make Upopolis even better!

U are invited to join the Upopolis team for the next Upopolis Youth Advisory Committee call on Thursday February 23. Watch the Upopolis Main Space for all the details. To get set up on Upopolis please contact Samantha Aitken at saitken@childrensheartnetwork.org
www.upopolis.com/login.html

