

CHILDREN'S HEART NETWORK Of BC Society Heart Matters

WWW.CHILDRENSHEARTNETWORK.ORG

FALL 2021





Lenna's Heart Journey

BY MONIKA QUALLY

ne of the hardest challenges we have had to face is discovering our second child was going to be born with a congenital heart defect. When we had our 20-week scan, we thought we would just be finding out the baby's gender. Instead, we also learned that she had transposition of the great arteries, or TGA, and that she would not survive without open-heart surgery.

I remember getting into my car, calling my husband, and just breaking down. The remainder of the pregnancy was hard. because the future was uncertain. But at least when I was pregnant with her, I had a sense of control and of keeping her safe.

After she was born, I had to trust she knew what she was doing, and she did. She arrived a few weeks early. This was not ideal, but that's just Lenna. No one tells her what to do. We almost didn't make it to the hospital. I ended up delivering her in the waiting area at BC Women's Hospital. Our little Smurf rushed into this world, and

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VOLUNTEERS NEEDED

Our families enjoy the spring, summer, fall, and winter gatherings that CHN sponsors. We are always looking for volunteers, so if you have some time, talent, and expertise that you are willing to share, please contact Sam Aitken at saitken@ childrensheartnetwork.org.

The views expressed in this newsletter are those of the authors, and not necessarily those of the board of the Children's Heart Network. The best sources of medical information are your child's physician and the health care professionals who provide care for your child.

@ChildrensHeartNetwork



@Childrens Heart



@childrensheartnetwork

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COFFEE GROUPS NEAR YOU

Our coffee groups are normally held in person; however, due to COVID, we are now hosting virtual get-togethers. Email Sam at saitken@childrensheartnetwork.org for more information.

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SIGN UP TO GET CONNECTED

If you have a child growing up with heart disease, please email us at chn@childrensheartnetwork.org so that we can add you to our mailing list to receive invitations to all our fun events!

THANK YOU

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



CHN would like to thank the CKNW Kids' Fund for their generous support of our Heart Beats and Hearts of Gold camp programs.



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Lenna's Heart Journey, continued from page 1

we got to hold her for a few minutes before she was whisked away to BC Children's Hospital, where an amazing team took care of her.

Lenna had her surgery at seven days old. This was the hardest day of our lives. Watching her get wheeled through those doors and having to wait was excruciating. After her surgery, we learned there were complications and were told she had to go back into surgery. This little human that we had only known for seven days had already filled our hearts with love. I couldn't comprehend that she may not come home with us. After what felt like an eternity, we didn't know if she was still with us. Finally, a nurse told us she was in recovery with Dr. Gandhi, who was by her side, monitoring her excessive bleeding.

The minute I saw her, this tiny little thing, barely taking up a quarter of the bed, relief just rushed over me. She was still with us. My husband, however, broke down seeing how helpless she was hooked up to all the machines. He had been my rock all day, and now that he knew I was safe, it was his turn. It was a long night, but Lenna just kept getting stronger and stronger. And then just like that, they sent us home!

Lenna is a fierce, strong-willed, defiant, and determined girl with the heart of a lion, for which she is named. We are so proud of this amazing little human who has already tackled so much in life. She looks up to her big sister, Everlie, who has been looking out for her from the beginning. Together, they are something mighty.

Her scar used to be a symbol of pain and fear, but it has slowly turned into one of strength and pride. It is her heart-warrior badge. It will always be our reminder. We tell her to wear it with pride and never let anyone tell her otherwise.

Lenna has been our teacher. She has made our family stronger and made me find a strength in myself I didn't know I had. It has really been an amazing thing to talk to her about it now and see that she understands. The other night I read her a book about a girl with a congenital heart defect. At the end, Lenna saw me crying. She put her hand on mine and said, "It's okay, Mama. My heart isn't broken anymore. I am okay." It was an eye-opening moment. We knew she understood and could communicate to us if she needed to. We have grown as a heart family now, and we can continue to communicate together.

I will always worry just a little bit extra. There are things that can bring me right back to that day, and it can hurt. But I just look at her now and see her beaming face looking back at me, and I know how lucky and blessed we are. I like to think we are part of a VIP club, and the Children's Heart Network really helps to make that feel true. We are so grateful to have the opportunity to connect with other heart families through the events offered by CHN. ♥







An Invisible Condition and Mental Well-Being

BY ELENA MAGER, AGE 17, VANCOUVER, BC

have learned many important life lessons from a young age, growing up with postural orthostatic tachycardia syndrome, or POTS, which is a form of dysautonomia. Every day, I advocate for myself to family, friends, doctors, and teachers. The physical toll on my body is hard at times, despite my healthy-looking appearance, and this can be deceiving. Many people don't understand what it's like to have an invisible condition.

The relationship between physical and mental health is often overlooked. Through talking to other teenage heart patients, I realized I am not alone and this sparked the understanding that change was necessary. I had the ability to make a difference and connect people to each other as well as share information!

I co-founded Youth Mental Wealth due to a lack of existing resources. This became more apparent as the COVID-19 pandemic hit and the people around me began to reach out. Youth Mental Wealth (@YouthMentalWealth) is an Instagram non-profit initiative created by youth for youth. We developed a peer ambassador program to provide a safe space for teens to share their stories and experiences regarding mental health in hopes of actively reducing the stigma around mental health disorders. This helps provoke conversation and promote the realization that people's lives aren't as perfect as they look on social media, and that's okay. The "monthly topic" posts aim to share mental



health literacy and spread awareness.

I highly recommend everyone (parents and teens) take advantage of this resource available to you on Instagram: https://www.instagram.com/youthmentalwealth/.

I am ecstatic that the Children's Heart Network and BC Children's Hospital are taking further action to recognize the crucial connection between mental and physical health. Heart-related conditions can be lonely, and this will go a long way in helping patients feel supported and connected to each other!

Celebrate Your Heartiversary with a Heart Box

BY DEE DE LOS SANTOS

Hello, fellow heart families!

We are reaching out because we want to help your special heart child celebrate their heartiversary. A heartiversary is a special celebration that marks a person's last open-heart surgery. Thanks to the wonderful folks at the Children's Heart Network, we are able to provide heart boxes to members across BC. And as always, heart boxes are free!

If you'd like to receive a box, please fill out the form here: https://domenicdls.wixsite.com/heartboxes/request-a-box.

Please allow 2–4 weeks for delivery. If it's any sooner, please get in touch and we'll try our best to accommodate.

Donations

Love what we do? We are always looking for donations to put in boxes too. Please contact Dee at heartboxesca@gmail.com or message us on Instagram (@heartboxprojectca) for more information.

You can also become a monthly donor (or even donate once) here: https://ko-fi.com/heartboxesca.

Thank you!

Dee and Winston ♥









Heart Heroes: Sophie Montalbano

his September, one of our North Vancouver heart warriors, Sophie Montalbano, decided to host her first lemonade stand, and she donated all the proceeds to the Children's Heart Network. Sophie is eight years old and was born with an atrial septal defect (ASD) and right atrial isomerism. She had surgery when she was three years old and has been thriving ever since. Sophie is one of the strongest and fastest in her class. She is a great gymnast, and she loves many types of dance.

The Montalbano family has participated in many CHN events, and Sophie's mom, Tanya, is a volunteer for the CHN gala as well as a resource parent, connecting with and supporting newly diagnosed heart families.

Thank you, Sophie, for your \$200 donation and for all vour hard work! ♥



Sid Dickens Memory Blocks Auction Brings in over \$15,000 for the Children's Heart Network

BY HEGE BOLTHOF HOEGLER

n the last weekend of September, CHN held our annual Sid Dickens Memory Blocks Auction. This is one of the highlights of our annual Wine Gala and Dinner, but due to COVID-19, the gala has been cancelled the last two years. The online auction allowed us to reach a much bigger, international audience. This year, our Hearts of Gold youth group could not get together to paint the ceramic hearts for the blocks, so we mailed them out instead. The teens painted them while online during one of their monthly Zoom get-togethers, which resulted in many

beautiful works of art. The Sid Dickens team then mounted the hearts to unique rainbow-coloured tiles designed especially for CHN. The memory blocks were more popular than ever, raising over \$15,000!

Sid Dickens has partnered with CHN every year since 2015, and we are so blessed to have his support. The memory blocks are collector items, and it is incredibly fun to see them being shipped all over North America. We would like to thank Sid Dickens and his team for their generosity and continued support.

Sid Dickens grew up in the remote surroundings of Prince Rupert. He became a fisherman and then attended Emily Carr College of Art and Design. After a backpacking trip to Europe, he found himself unlocking a door he never even knew existed. He started working with ancient imagery and felt a connection to it all. Sid then enrolled in an art school in Mexico for two years and returned to Vancouver to open a small east-end studio. When a Hong Kong designer visited, he was drawn to a grouping of small pieces and ordered 400 of them. This was the start of Sid Dickens' Memory Blocks success, which has brought recognition all over the world. His amazing work can be viewed both in his studio and online, and is a fun and unique way to add local art to your home.



We would also like to thank Christina Amara Cusella, one of the winners from last year's auction. She runs California Tile Hangers out of San Jose, and this year she donated a few of her items to the auction. Christina graciously also took care of the shipping of these items.

We are humbled by the support from everyone who took part in the auction and to all those who bid on

these special memory blocks. The teens are so proud of their work, and they love the thought that they too have contributed to CHN, an organization close to their hearts. The Sid Dickens Auction continues to be one of our favourite collaborations, and we are so thankful for the funds raised from these amazing memory blocks over the last seven years! \bigvee



Seven Easy Tips for Overcoming Bedtime Battles with Your Kids

BY MARY VAN KEUREN

If the title of this article piqued your interest, then you may be sitting down to read it after your 717th reading of *Goodnight*, *Moon* and the fourth glass of water tonight. If that's the case—we understand. Getting young children to bed isn't always easy, especially when you're tired yourself after a long day.

Those bedtime wrangling sessions may go down in

history as some of your least favourite memories of your kids' early days—and we're sure that pandemic anxiety hasn't made it any easier. But they don't have to define your relationship. In this post, we'll look at some of the reasons why your children seem to be doing their best to drive you crazy at bedtime, as well as expert-backed ways to counter that craziness and create a smooth bedtime process.

Why do kids resist going to bed?

Why do kids make bedtime such a battle? You've probably asked yourself this question more than once. In truth, there are a number of reasons for your young child to suddenly become a wailing tyrant at bedtime, from a mattress that isn't comfortable¹ to the imaginary monster under the bed. It may be any one of these—or a combination of several.

They don't want to be alone

In many cultures, children routinely sleep in a room with their parents or siblings.² Being alone can be scary, especially when you're too young to differentiate what's real from what's imaginary. Having someone else with you can make all the difference between a night filled with terror and one of peaceful sleep.

The timing isn't working for them

"There are biologically appropriate times when sleep is easier for babies, and when you go against this natural rhythm, you will see resistance from little ones," says Kate Curry, a certified infant and child sleep consultant and owner of Kid-sulting, LLC.³ "Possibly the bedtime is too early or late. Maybe the nap schedule is interfering as well."

They want to be with you

Kids and babies are hard-wired to want to be with their parents, who protect them and nurture them. Being alone is when they are most vulnerable. Even babies realize this and react with fear or anger.

They sense your own diminishing patience with them

"Children can sense that impatience, and it makes them feel insecure; thus they want their parents' attention that much more," says Dr. Sarah Mitchell, a pediatric sleep consultant at Helping Babies Sleep and bestselling author of *The Helping Babies Sleep Method*. "Misbehaving is a way to get attention. Negative attention is still attention."

They are overstimulated

Watching an exciting TV show, playing computer games, or engaging in physical and active playtime too close to bed can leave your child with an elevated heart rate and little interest in quieting down.

They're afraid they'll miss something

If your child knows that Mom and Dad are planning to watch the latest DVD in the Marvel cinematic universe

after they go to bed, they may resist all efforts to keep them tucked in.

They're genuinely fearful of something

It's usually something imaginary but very real to them. Even if the cause doesn't seem reasonable to you, it may cause them to fear going to sleep.

Expectations during our new normal

Added on to all the age-old reasons for resisting bedtimes has been a new one this past year: the COVID-19 pandemic. Pandemic distress comes in many guises and has multiple reasons for kids and adults.

One significant reason is the change in schooling. Children may be learning at home now, either partially or fully, and that can increase anxiety. They have less time on the playground or with their friends and lead more sedentary lives, with less of an outlet for their energy. Since their parents are working from home, there's often less time to spend with the kids to provide a sense of security to counter all these changes in their world.

Homeschooling and less time spent outside playing lead to increased screen time, and that's not good either. The blue light that our devices emit interferes with a hormone called melatonin,⁵ which signals our body that it's time to sleep. That's why kids and adults should switch off the technology an hour or so before bedtime.

All this means that you're likely to be dealing with a wound-up, energized kid at bedtime who's trying to cope with a new and different world—just like their parents. Unlike their parents, however, kids don't have the emotional maturity to handle the changes.

"Parents are likely to see various forms of regression and resistance," says Marissa Denig Palatas, owner of juniperdays.com, a site that features play objects and toys for children. "Depending on the age or situation, this could be due to new fears, new adjustments with schooling, or even the new sense of uneasiness that is an undercurrent in the home."

How can you engage with your children to minimize these challenges? There's no one set answer. Kate Curry suggests talking to them about their fears. "They may have real fears that can be validated by acknowledging that their emotions are real," she says. Do it during the day, though, when they feel safe, rather than just before bedtime. Curry says that it can also help to have a family meeting to discuss bedtime routines and rules to be on the same page.

Staggering the bedtimes of multiple children can help, says Dr. Mitchell. Children want their parents' individual

¹ https://myslumberyard.com/best-mattress-for-kids-children-small-person/

² https://www.psychologytoday.com/us/blog/freedom-learn/201110/why-young-children-protest-bedtime-evolutionary-mismatch

³ https://kid-sulting.com/

⁴ https://www.helpingbabiessleep.com/

⁵ https://myslumberyard.com/sleep/sleep-and-blue-light/

and undivided attention, so staggering bedtimes so there's one-on-one time with a parent can make a big impact. With less socialization during the day, Mitchell says, children want more social time with their parents at night.

Consider ways you can help your child be more active during the day too. They may not be able to play with friends, but if there is a park nearby or you have time to go for a walk with your child, do so—it's good for both of you. Turn your outdoor time into a scavenger hunt or "I Spy" game to make it more fun.

What are the best ways to prevent battles before they start?

What are the best ways to fight bedtime reluctance so that your children can get a good night's sleep and you can have some downtime? Here are a few factors that may help.

Create a sleep diary

For several weeks before you make any changes, keep a diary where you jot down the activities your child engaged in during the few hours before bedtime, noting how long it was before they actually got to sleep. This will help identify any points of conflict that need to be addressed.

Set the right bedtime

If you're getting continued resistance to bedtime, maybe it's time to set it a bit later in the evening. Try giving your child another half-hour, letting them spend it in quiet, non-technological ways such as reading or snuggling with you.

Make some memories—read a book

Getting your child in the habit of reading at an early age is one of the greatest gifts you can give them. Check out these listings of the Caldecott Medal winners for the most distinguished picture book, or, for older children, the Newbery Medal,⁶ for most distinguished children's book. Many of these will be available at your local library.

Avoid screens before bed

From cell phones to gaming consoles, your screens release blue light, which stops melatonin from telling your body it's time for sleep. Have your kids leave their cell phones at the charging station (which should not be in the bedroom) at least an hour before bedtime.

Set the stage

Create an environment that is sleep-inducing. Your child's bedroom should be painted a soft colour and feature lighting that can be dimmed. Make sure your child likes

their mattress and blankets and finds them comfortable. For infants, a quiet mobile hung over the bed or an ambient noise machine may help relax them. A rocking chair in the bedroom may help for nights when all else fails.

Have a plan B

"The job of kids this age is to test boundaries," says Curry. Determine beforehand when it's okay to cave in to their entreaties and when it's time to draw the line. Maybe you're good with one glass of water or a book, but draw the line at two. Know your limits before you're in the situation of needing them.

Be confident!

As the parent, the decision on bedtime is yours to make—not your child's, no matter how much they might like it to be. Your behaviour at bedtime can set a great example for them, though. Be kind, understanding, and flexible—but also firm, without getting angry. In time, your kids will understand and be grateful for the limits you set.

My Slumber Yard's bedtime routine activity

Our team understands that changes in routine can be difficult for anyone, especially for a child. In an effort to make an empowering activity for children participating in the creation of a healthy sleep routine, our team created additional printable templates families can begin using tonight to co-create their child's very own personalized bedtime routine. Creating a bedtime routine is a fun activity that can involve the whole family while arming your child with a renewed sense of independence and control during the adjustment period to follow. Simply print the templates below and allow your child to begin creating their own routine with the tiles provided, or use the blank tiles for more personalized routine elements.

In preparation for this activity, we recommend parents use safety scissors to precut the tiles for their child and work alongside them to place their routine elements (up to 10) into the visual bedtime routine template using nontoxic glue or tape.

Download these resources here:

- Visual Bedtime Routine Template⁷
- Visual Bedtime Routine Tiles (A)⁸
- Visual Bedtime Routine Tiles (B)⁹

Bedtime battles vs. bedtime fears

It's often difficult to determine if your child is genuinely afraid of something or just stubborn. If your child is a

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 $^{{\}bf 6} \quad http://www.ala.org/alsc/awardsgrants/bookmedia/newberymedal/newberyhonors/newberymedal/newberymedal/newberyhonors/newberymedal/newberymedal/newberyhonors/newberymedal/newberyhonors/newberymedal/newberyhonors/newberymedal/newberyhonors/newberymedal/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhonors/newberyhon$

⁷ https://myslumberyard.com/wp-content/uploads/Visual-Sleep-Routine-for-Children-with-ASD_Schedule.jpg

⁸ https://myslumberyard.com/wp-content/uploads/Visual-Sleep-Routine-for-Children-with-ASD_Icons.jpg

⁹ https://myslumberyard.com/wp-content/uploads/Visual-Sleep-Routine-for-Children-with-ASD_Icons-Pg-2.jpg

toddler or younger, they may not be able to articulate their thoughts and fears well enough for you to understand how best to help them.

"Imagination starts around age three, and that's really when fears can manifest," says Dr. Mitchell. Children younger than three who seem afraid are usually just repeating what they've heard their parents say. If a parent asks the child, "Are you scared?" that may plant the idea and create a new stalling effort, she says.

According to Dr. Mitchell, children older than three can have genuine fears. "I would truly listen to the concern and try to meet it," she says. "For example, a lot of kids develop a fear of the dark, and there's nothing wrong with leaving the light on and seeing if that alleviates the fear."

On the other hand, if you address the child's stated fear and different needs keep coming up, it may be a stall. Ask yourself these questions to help you determine your response:

- Have I met the child's initial need (by giving them a glass of water, for example, or installing a night light)?
- Are they sticking to the same story or changing their story each time I go in their room to see what works?
- Am I willing to leave them alone for 20 minutes to see if they quiet down?

When you feel you've met the child's true needs, and now they are just fussing, it may be time to leave them alone, hard though it might be, to see if they quiet down.

If you have children, you probably face the bedtime battles at least occasionally—it goes with the territory of being a parent. The key to success is remaining calm and in control while determining the root cause of your child's distress and how you need to handle it. We know—easier said than done. But though it may not seem that way, your child is looking at you for reassurance and structure, and providing it will leave you well on your way to a calm and peaceful nighttime experience—for both children and parents. \checkmark

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My Slumber Yard's Sample Bedtime Routine



What's Happening?

Heart Mamas & Papas Virtual Coffee Nights

We have had great success with our virtual heart parent get-togethers since COVID-19 hit. It is wonderful to have both mom and dad attend in some families and to have folks join in from all over the province. At our most recent







gathering, one of our new moms, who is just looking into daycare after maternity/paternity leave, learned about some great resources available in BC from one of our other heart parents. Do you have questions or concerns that you would like to share with other heart parents? Watch for emails inviting you to join!



Parent Education Series: Upcoming Sessions

November 2021

Understanding and Managing Medical Traumatic Stress in Children, Youth, and Families

Dr. Winnie Chung, Registered Psychologist, Medical Psychology, BC Children's Hospital

February 2022

Exercise and Nutrition

Astrid De Souza, Clinical Exercise Physiologist and Research Associate

April 2022

Hearts of Gold Youth Program

Kristi Coldwell, Cole Renner, and the Hearts of Gold Teen Panel

June 2022

Cardiology Advances

Dr. Shreya Moodley and Dr. Shubhayan Sanatani

October 2022

Transitioning Your Heart Child into School *TBA*

CPR/AED Courses for CHN Members

The Children's Heart Network will arrange for you and/or a caregiver of your child to take a St. John Ambulance CPR/AED course in the location of your choice. If you wish to learn CPR that covers adults, children, and infants, as well as two-rescuer CPR, you need to take CPR-B.

Classes are being held in the following cities:

- Abbotsford
- Kamloops
- Kelowna
- Nanaimo
- New Westminster
- North Vancouver
- Penticton
- Port Moody
- Richmond
- Surrey
- Vancouver
- Vernon
- Victoria

If you would like to register for a course please go to www.sja.ca and choose the location and date of the course you wish to register in. Then email Sam at saitken@childrensheartnetwork.org and send your request with participant names. We will confirm details.

Note for families living in other areas: if you can find a certification course in your area please feel free to email Sam at saitken@childrensheartnetwork.org with the details.



Family Camp

Sadly, we had to cancel our fall family camp planned at Camp Stillwood near Cultus Lake due to COVID-19. We had 16 families from different parts of BC that were very much looking forward to having some fun while connecting with other heart families. We sent some fun and cheer to our disappointed kids and parents to enjoy together: a game, a craft, and some treats to share. We hope to be planning two family camps for 2022, one in June and one in September! Watch for the invitation in the new year.

Hearts of Gold

Our Lower Mainland Hearts of Gold youth group had their first in-person outdoor event since COVID began. It took place at WildPlay in Maple Ridge and was attended by many teens excited to see their heart friends after so long apart. They started with a training session on the ground to get comfortable using the ziplines and the continuous belay system. Then, they climbed up a ladder and made their way from tree to tree by walking across tightropes, climbing up cargo nets, sliding down ziplines, flying through the air on rope swings, leaping onto swinging logs, and balancing on wobbly bridges. Everyone had different levels of comfort and could adjust how much they challenged themselves. Lots of confidence was gained while everyone cheered each other on! We would like to thank one of our sponsors, MyLens.ca, for donating a fabulous box lunch for our hungry teens to enjoy after the event. ♥





