



Ariel's Heart Story

BY CAPRI RIETEL

I began writing this thinking that it would be easy to tell our story. Our little girl is at home with us, sitting on the couch with my husband and watching her favourite show. Things are normal. She is a typical three-year-old who plays with her brothers, rides her bike, and loves to see her friends. She is beautiful, funny, loving, and so kind.

We couldn't imagine our lives without her.

I guess that's why it's hard to say what our story is. I feel like Ariel's heart journey has just begun.

She was diagnosed, in utero, at 20 weeks, with an interrupted aortic arch and ventricular septal defect, which

doctors believed was caused by a genetic disorder known as 22q deletion or DiGeorge syndrome.

We literally went from celebrating with our family and friends that we were having a girl to getting a life-changing phone call telling us something wasn't right with our baby's heart.

The weeks leading up to her delivery were filled with scans, appointments, and uncertainty.

But no amount of concern could overshadow the pure joy we had the day she was born.

The name Ariel means "Lion of God," and she came into this world a fighter.

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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.

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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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MEGAN MADSEN – Vancouver Island Hearts of Gold youth coordinator

Ariel's Heart Story, continued from page 1

At five days old, Ariel underwent an extensive heart surgery performed by Dr. Sanjiv Gandhi, who is, by far, one of the most amazing human beings. He is someone for whom we are forever grateful.

As they rolled our baby away into the operating room, my husband and I walked out into the hallway, holding on to a pager and our faith.

After the surgery, she started the long road to recovery.

Ariel spent the next weeks recovering in the hospital. We watched her grow stronger and begin getting closer and closer to coming home. We were so blessed to have the support of family and friends who helped us. We had two boys at home, and my husband would make daily trips into Vancouver to be with Ariel and me.

She came home on a feeding tube and still has a gastrostomy tube to this day. While she struggled to gain weight in the beginning, she is doing well and at a healthy weight now.

The first year was by far the busiest. Ten different specialists, our pediatrician, and other support therapists all followed her progress. We are always beyond grateful for the amazing team at BC Children's Hospital and the level of care they provide to children and their families.

The phenomenal Children's Heart Network has reached out in so many ways to make us feel like part of a bigger family and to let us know that we are not alone.

Ariel is now three years old, is starting preschool, and, for the most part, leads a normal life.

I find it hard to tell our story, because I don't know how far to go into the events and the experiences. As with many things, only people who have been in similar situations will

ever truly come close to understanding what we have gone through and what lies ahead.

The truth is that what our family has gone through in the last three years will forever change our lives.

Our perspective on life has changed. We are able to appreciate small things that may have seemed insignificant not too long ago, because we have now experienced much bigger things.

Every heart family has a story of a diagnosis, treatment, and recovery. I think what really changes us is the journey along the way. Ariel was diagnosed before she was born, but our family began to change that day.

We found friends who would be there with us through the hardest times, and we lost friends along the way. Our children had to learn patience as they sat through countless appointments and scans.

We went from living in a place of total fear and worry to a place of complete peace after an experience at the hospital gave us the revelation that she is here to fight and win.

The nature of Ariel's heart condition is that she will need more surgeries throughout her life. We don't know what the future holds. What we do know is that one phone call can change your life. One moment or experience can bring new understanding and change. We know that other families who have gone through this with their children have tremendous strength and courage. We know that Ariel is a lion who, through it all, has conquered any limitations put on her.

So this is not Ariel's story. It's the beginning of her journey and of our journey as a heart family.

Bert, Capri, Coen, Evan, Ariel, and Reiner Rietel ♥





The Beat Goes On

Three Years After Heart Surgery

BY JENN WINT

Last week, my oldest, three-and-a-half-year-old Declan, took a tumble at the bike park, landing right on his tummy. The fall wasn't too hard, but he was stunned and got up with tears in his eyes, looking for Mama as he brushed the dirt off. I ran over, and after a quick hug he was happy again, back riding the track. Declan is a pretty tough kid who recovers quickly, bouncing back into play, but sometimes, especially when he lands on his front, I'm instantly thrown back in time to how sensitive that area once was. Three years ago, he had a 10 cm incision in his chest as he recovered from open heart surgery.

Most days I don't think about the fact we spent much of the first six months of Declan's life in the hospital. These days he's an active, curious, creative kid who drives me crazy but makes me laugh to my core. He pushes limits, jumps off of things he shouldn't be climbing, and often requests scrambled eggs and then refuses to eat them. Typical "three-nager." But from time to time, something will trigger the understanding that he's not typical; he's been through more than most his age. And as his parents, so have his dad and I.

It was at week 22 of my pregnancy that we found out Declan would need open heart surgery to have a chance at a healthy life. After our initial 20-week scan, the doctors ordered another scan, and then another, and then scheduled a day at BC Women's Hospital, without giving us too much explanation. Over a series of appointments, we were told our unborn baby had a congenital heart defect called TGA, transposition of the great arteries. This means the two main arteries that bring blood out of the heart—the main pulmonary artery and the aorta—are swapped, causing blood not to circulate around the whole body. Declan also needed surgery to repair a ventricular septal defect and an atrial septal defect. My husband and I were speechless and devastated hearing this news.

The remainder of the pregnancy was tense. There were a lot of appointments and a lot of unanswered questions. We had incredible support from the cardiac team at BC Women's Hospital but so much fear around our ability to cope with an uncertain future. I dealt with the grief of not having a normal, healthy baby by pushing down the fact I was pregnant, not buying baby things, not talking about the baby, not planning a baby shower. I could barely picture my life as a parent, let alone my life as the parent of a sick child. But our little baby continued growing inside me and made his debut in December 2016, weighing in



at 9 lbs., 5 oz. He was taken straight to the BC Children's Hospital pediatric intensive care unit and hooked up to the machines that would keep him alive.

For the next six months, we were in and out of hospital on a regular basis. Declan was put on a feeding tube and required various medications throughout each day and night. The feeding and medication schedule was gruelling, and reinserting the feeding tube was a regular trauma for all of us. As most new parents are, we were sleep deprived and trying to figure out life as a family of three. Honestly, I don't remember much of those first few months. It was a never-ending cycle of feeding and medicine and doctors, hoping for weight gain at each appointment. Declan had to reach a certain size before they would attempt the surgery, because his condition was more complicated than his original diagnosis.

In June 2017, Dr. Gandhi gave the thumbs-up, and we were ready for surgery. That Tuesday at 6:30 am, we dropped our baby off at BC Children's Hospital. We were told to hope for the best but to understand that there may be complications. The nurses gave us a pager and instructed us to be back in five hours.

My husband and I went for brunch, somewhere we'd wanted to go but where there was always a line on weekends. We window-shopped and hugged each other. We walked around Queen Elizabeth Park. We laughed a lot and talked nonsense, about unimportant things, something we'd almost forgotten how to do since becoming parents. The day was surreal.

Declan's surgery was a success, although initially his temperature was too high and there was ice all over his little body, in addition to the tubes and monitors and stickers. It was scary to see, but the relief that it was over, and that it had gone well, was powerful. We were cautiously optimistic and confident we were in good hands.

We spent a few days on 3M, the heart ward at BC Children's Hospital. Shout-out to the incredible staff of nurses and doctors who kept us informed and made us feel supported throughout the experience. Kudos also to the friends and family that dropped food off at the hospital, called us and checked in, and helped us feel the strength of the village around us.

Declan recovered from open heart surgery incredibly well; it was amazing to watch. After two weeks, he was able to leave the feeding tube behind and grew stronger than he'd ever been. At six months old, prior to his surgery, he was unable to sit, roll, or do much that other babies his age were doing. By 10 months, he was caught up, crawling, and pulling himself to stand. His scar has healed very well and is only noticeable if you're up close. Declan knows that he had surgery when he was a baby and understands that Dr. Gandhi "fixed his heart," but he'll never remember the details, and for that I am so grateful.

These days, anyone who meets him would never guess he had once been so weak and compromised. He is strong and fearless. His check-ups have gone well, and we're told there should be no long-term effects of his condition. He's been given the green light to live life to the fullest, and he does. For the most part, we do too, managing the challenges that come with a cheeky preschooler and trying desperately to stay one step ahead of his development and increasingly interesting questions. But now and again, like at the bike park last week, the fear rushes through me and I'm back in intensive care, hearing the beeps of the machines and smelling the powder in those plastic gloves. There's not much I can do with these memories but be grateful for where we are today and spare a thought for the parents currently in the thick of what we're lucky enough to have survived. ♥

This story was originally published on vancouvermom.ca.



Heart Boxes for Children Living With CHD



Dee and Winston.



Safiya, age 7.

One of our heart moms, Dee De Los Santos, has started an initiative called “Heart Boxes.” Dee’s son, Winston, recently turned two. He lives with double outlet right ventricle, transposition of the great arteries, and a straddling mitral valve. He had his Glenn last year in July at BC Children’s Hospital.

Heart boxes are care packages sent to children living with CHD who are celebrating a heartiversary or a birthday. In the box, there are items to help celebrate the special day (heart-themed plates, cups, cake-in-a cup, balloons, etc.; enough for four people) and a surprise gift for the heart warrior.

These boxes are provided free of charge to kids living with congenital heart defects and are delivered to their home or to BC Children’s Hospital. CHN is covering the postage costs to ship heart boxes anywhere within BC!

If you are a business that would like to donate items for the heart boxes, or if you would like to sponsor a box, please get in touch with Dee at domenicdls@gmail.com. If you would like a heart box delivered to your child, please fill in the form at <http://geekparty.ca/services/heart-boxes>. Please give at least four weeks’ notice.

So far, Dee has sent out over 15 boxes. Here are a few of the lucky recipients celebrating their heartiversary!

Safiya lives in Maple Ridge and has tricuspid atresia. She’s had nine surgeries, with three major open heart reconstructions.

Nathaniel lives in Richmond and has double outlet right ventricle. He has had two open heart surgeries.

Memphis lives in Enderby and has transposition of the great arteries, tricuspid atresia, pulmonary atresia, and atrial and ventricular septal defects. She’s had two open heart surgeries. ♥



Nathaniel, age 2.



Memphis, age 2.

HOG Youth Group During COVID Times

CHN has two youth groups that would normally get together on a monthly basis, one in Victoria and the other in the Vancouver area. Up to 25 teens, along with our coordinator (a child life specialist), would meet at a fun venue to laugh, socialize, and connect with others facing similar challenges. A typical event would be an afternoon at Playland, an evening painting ceramics, or skating followed by dinner at Red Robin.

During these COVID times, our teens have been missing each other, so they now get together via Zoom! Once a month, CHN mails out a “party in a box,” and then our coordinators host a virtual party, typically on a Friday or Saturday evening. August’s box featured a mini s’mores kit (tea light candle, toothpicks, mini marshmallows, and chocolate chips), and September’s box included bingo cards, a bingo dabber, Play-Doh for a virtual Pictionary game (get your clue, build your shape, and your friends have to guess what it is), and an array of candy! A big surprise is on the way for the Halloween kit. If you are a teen between 13 and 18 years old with congenital or acquired heart disease, please join our group. Email Sam at saitken@childrensheartnetwork.org for more information. ♥



Mandy Johnson Steps Down From the Board

Many of our CHN families know Mandy Johnson as the calming presence and nurse clinician in the heart centre at BC Children’s Hospital (BCCH). Mandy started at BCCH in 1989 and is still a valuable part of the heart centre team. She has helped thousands of families through some of their toughest days, supporting them through tests, diagnoses, surgeries, and hospital stays. She is also often the reassuring voice at the other end of the phone when we call the nurses’ line with a question about our heart child. Mandy always offers a loving hand to hold when we are in the hospital needing support.

Did you know that Mandy has also served on the board of the Children’s Heart Network for almost 20 years? Mandy has filled the role of president, vice-president, past president, and member at large and has stewarded the financials for many years. This involves applying for critical grant funding that keeps CHN running. Mandy was on the board when there were only three members, at a time when CHN’s future was uncertain. She was instrumental in bringing new members to the board, finding increased funding, and developing new programs to support heart families in BC.

Mandy has recently decided that it is time for her to focus on her family and her son, Ben, so she is stepping down from the board. We are so thankful for all she has done to provide the clinic connection to CHN and for the time and energy that she has devoted to heart families in BC. We will miss you dearly, Mandy!

Gratefully,

All of our CHN families and the board of directors ♥



Meet Amelia (Amy) Hart Hinds, BCCH Electrophysiology Technologist

Where did you grow up and go to school?

I grew up in Maple Ridge, BC, and did my post-secondary at BCIT.

Can you describe your job and explain what made you want to be a pediatric electrophysiology (EP) technologist?

Cardiac EP is an interesting field that helps you to understand the mechanisms of arrhythmias. The children that we see in the EP lab usually have an extra electrical (conduction) circuit/pathway in their heart that causes their heart to beat abnormally fast. In the EP lab, we use 3-D mapping technology and an EP recording system to locate exactly where that circuit is, and we use heat energy or cold energy to carefully destroy the small area of heart tissue that is causing the abnormal rhythm. As an EP tech, it is my job to manage the EP lab and operate the EP system. I also manage and book the patients that need to come to the lab and provide support, and I'm a resource person for patients and their families.

It was Dr. Sanatani who gave me the opportunity to pursue cardiac EP. I was working as a cardiology technologist at the time and had always wanted to branch out into a more specialized area. Dr. Sanatani gave me the chance to do so when he approached me 10 years ago and asked if I wanted to learn about EP. Since then, I was able to finish my advanced certificates in EP and cardiac rhythm devices.

What do you like most about working at BCCH?

I have been blessed to work with such a wonderful team at the heart centre and in the EP lab. Everyone has patient care at the forefront of our minds. It is also a great learning environment. But best of all, I enjoy meeting the wonderful patients and their families. I am thankful that I can be a small part of a child's care that helps them live a better quality of life.

Tell us about any specialties you have within your department.

In addition to working in the EP lab, I also work in the device clinic at the heart centre, where we check/interrogate and program pacemakers, implantable cardiac defibrillators, and loop recorders.

Do you have a mentor?

Dr Sanatani. He gave me the opportunity to pursue EP and took the time to teach me. He also gave me the tools to grow within this field. Without him, I would not be in the position I am today, and for that I am very grateful!

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

I like to do anything that involves spending time with my family.

What are you good at besides being a pediatric EP technologist?

At home, I am good at cooking and baking! I surprised myself, because when I was younger, I never had any drive to cook or bake, because my mom was incredible in the kitchen. But after getting married and having a child of my own, I have grown to love it and have a knack for it!

Do you have any pets?

Yes, a lovely and gentle German shepherd named Koda, who is 14.5 years old. ♥





CHN's 2020 Online Silent Auctions

Thank you to all those who participated in our online silent auctions over the past few months. They have been a great success. We would like to also send a “heart-felt” thank you to all the individuals and companies that supported us with a donation, especially during these difficult times. On October 24–25, we will have the final phase, which will feature over 60 unique Sid Dickens tiles with ceramic hearts painted by our own CHN kids and

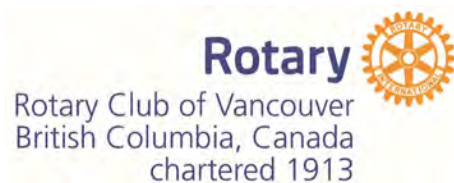
teens. Sid created this tile just for CHN and has autographed the back of each one. Sid Dickens collectors from all over are excited to bid on these special memory blocks. The auction will start on Saturday, October 24, at 9:00 am, and will finish on Sunday, October 25, at 8:30/8:45/9:00 pm. To access the auction, please go to <https://chnevents.org/>.

With your help, we are able to continue our many programs that support BC's heart families. Thank you! ♥

The Rotary Club of Vancouver is CHN's Newest Supporter!

CHN is excited to announce a new partnership with the Rotary Club of Vancouver. This past spring, the Rotary Club of Vancouver became an official donor by putting \$2,500 toward our “Send a Kid to Camp” campaign. Sadly, due to COVID-19, our heart kids were not able to go away to camp this summer but are eagerly looking forward to going as soon as possible! In addition, the Rotary Club of Vancouver has donated another \$2,400 toward our Hearts of Gold program. These funds will allow us to continue supporting teens between the ages of 13 and

18 in connecting with other heart kids that are also experiencing the challenges of growing up with heart disease. Our monthly get-togethers are temporarily virtual. The teens are receiving an exciting kit in the mail filled with games, crafts, and treats that they can enjoy together online via Zoom on a fun weekend night. During these difficult times, these packages and happy get-togethers are bringing a lot of joy into the lives of our youth. We would like to take this opportunity to thank Dr. Abi-Rached and the Rotary Club of Vancouver for their generous gift! ♥





COVID Q&A Series with BCCH Cardiology Team

Dear BC heart families,

We know that the last six months have been a difficult time for families bringing up children with heart disease. Many families are looking for some guidance in regards to COVID-19 and keeping their heart child safe as we approach the start of the school year.

Every child's situation is unique, but we wanted to get the most common questions answered by the cardiology team at BC Children's Hospital.

If you have additional questions, please contact your child's doctor.

We will get through this together. Be kind, be calm, be safe!

1. Is my child immunocompromised due to their heart condition, and does this put them at increased risk for getting COVID-19?

The vast majority of babies and children with congenital heart defects (CHDs) are not immunocompromised and therefore are not at greater risk for contracting COVID-19. Some children with CHD have other associated syndromes or conditions, such as asplenia, that can affect their immune function, but this is not directly related to their cardiac condition. If your child has an immune disorder, it

is best to ask your pediatrician for specific advice, as each child's situation will be unique.

2. I've read that people with underlying heart disease are at greater risk for severe illness. Does this hold true for kids with CHD? How about kids with heart rhythm issues?

The good news is that the evidence so far is that children with CHDs and/or heart rhythm issues who do contract COVID-19 do not fare any worse than their peers. In fact, COVID-19 causes much more mild illness than other better-known respiratory diseases (such as influenza) in the vast majority of children.

3. Are cardiac patients at greater risk for multisystem inflammatory syndrome (MIS) than other children? And is the consequence of MIS in children (MIS-C) more severe for kids with cardiac conditions?

No—we don't have any evidence that children with CHD or those with a history of Kawasaki Disease (KD) are at increased risk of MIS-C. In BC, we haven't had any cases of MIS-C to date.

MIS-C has been in the news recently after Dr. Henry spoke about the condition during the COVID-19 BC update on August 27. She described eight cases that have been reported and investigated since the beginning of the pandemic in BC. However, after extensive investigation, these children did not have evidence of recent COVID-19 infection nor of close contacts with COVID-19.

While MIS-C can result in serious illness, it is exceedingly rare. The recent reports of “suspect” cases did not have any link to COVID-19. The report of “suspect” cases in BC may sound alarming at first, but it speaks to how carefully the public health office in BC is monitoring the pandemic in our province. The signs and symptoms of MIS-C overlap with several other conditions, including Kawasaki Disease, and reporting any and all cases in this category of illnesses means that we are casting as large a net as possible so that nothing flies under the radar. This approach allows the public health office to quickly identify any patterns of illness and adjust its guidance if necessary, while also contributing to the worldwide understanding of this rare condition.

4. How do I decide whether my child should return to school/daycare?

This is a question that is keeping parents across the country up at night. This anxiety is understandable, and it can be heightened for heart parents whose children have been through so much already and are still under the care of our cardiac team.

The vast majority of children who contract COVID-19 have very mild illness and recover at home. Other infectious illnesses that children are exposed to at school every year are more likely to result in severe illness than COVID-19.

As such, most families are encouraged to send their children to school, as there are many important benefits to attending school, including education, physical activity, social interaction with peers, etc.

Some families may have particular circumstances where COVID-19 could be more serious for other family members (e.g., elderly grandparents living in the house, another family member who is immunocompromised). In these cases, the concern of children being exposed to COVID-19 at school and bringing it into the home must be considered and weighed against the benefits of attending school in person. Consulting with your GP or pediatrician may be worthwhile in these cases.

We are extremely fortunate in BC to have the world-class leadership of Dr. Henry and her team of public health experts to guide us through this pandemic. The cardiology team at BC Children's Hospital (BCH) relies on this guidance to instruct how we do our day-to-day work in the hospital and how we counsel our heart families to navigate through this stressful time. We've included links to the BCCDC website and the BCH website below, and recommend that you visit them for more information to guide your decisions.

RESOURCES:

<http://www.bccdc.ca/health-info/diseases-conditions/covid-19>

<http://www.bcchildrens.ca/health-info/covid-19-and-children-information-for-patients>

<https://keltymentalhealth.ca/info/parenting-during-covid-19>

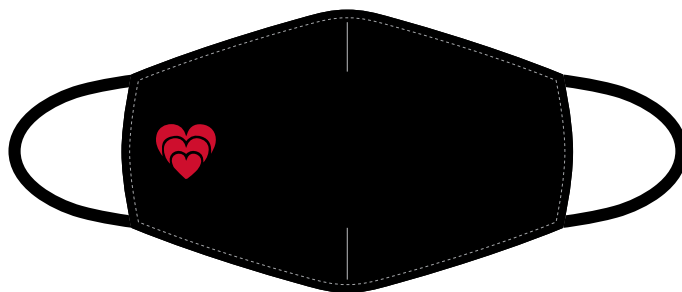
Face Masks Available for Purchase from CHN Website

CHN has ordered face masks that are available to our members at a discounted rate.

There are two sizes available, one for adults and teens, and one for kids under 12. The cost for both sizes is \$6.00. Prices are subsidized by CHN and include free shipping anywhere in BC.

CHN would like to thank Greengrass Productions Inc. and Tribe Solutions for their generous assistance with sourcing top-quality masks.

Please visit our website to purchase: <https://www.childrensheartnetwork.org/masks/>. ♥



What's Happening?

Pumpkin Patch Visits

We know these COVID times are difficult, so we are hoping to send some joy your way. Sadly, we cannot host our typical pumpkin patch events that allow heart families to connect, so we have come up with another option. We will send you a certificate or promo code that your family can use at one of the pumpkin patches listed below. These facilities are operating under COVID guidelines. Celebrate the fall season with your family and enjoy a special day out of the house! Corn mazes, hayrides, and pumpkin picking! Visit our website for locations and registration details.



CPR/AED Courses

Would you like to take a CPR/AED certification course in your local area with St. John Ambulance, sponsored by the Children's Heart Network? If you are an up-to-date CHN member, we 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. Visit our website for locations and registration details. ♥



Helpful Links: Virtual Fun to Keep Kids Busy

Julie's Library

Mary Poppins herself is here to save your children from going completely stir-crazy. Since shortly after quarantine began, Oscar winner Julie Andrews has been crawling into a closet soundproofed with pillows in order to host story-time for kids 10 and under. Andrews has published more than 30 children's books with her eldest daughter, Emma Walton Hamilton, and the two take turns reading aloud from both classic and new kids' books. As Andrews makes her way through her personal collection of children's stories, her dulcet voice is bound to soothe rambunctious people stuck at home, whatever their ages. Every story comes to life with sound, music, and activities. Authors, kids, and other special guests chime in, too! It's a show that will inspire lively conversations and a lifelong love of reading.

<https://julieslibraryshow.org/>

Kids at Home Weekly Updates

Are you looking to start a new routine? The change in seasons is a perfect time to develop new habits and explore new interests! Spend the month of October practising self-care with a full calendar of tips and activities (all ages). Enjoy a new fitness routine by moving to the sounds of some of your favourite artists (ages 4–12). Celebrate the autumn season with some fresh-air fall activities (ages 3–10).

Visit Kids at Home to see all of these activities and hundreds more. Check in each week for newly curated games, crafts, and other activities!

Sponsored by Kids Up Front.

<https://kidsupfront.com/kidsathome/> ♥