



Dakota's Heart Journey

BY MERCEDES CARRIGAN

I often get asked when I first knew about our daughter's heart condition. Most people assume found out the day she was born.

Our story is long and never ending but I'm always glad to share it because it has a happy outcome. We found out something wasn't right at our 20-week ultrasound. I went to my local ultrasound office in Langley. After my ultrasound I called my husband to let him know everything

was normal and we would hear from our midwife in a week to learn the sex of our baby. We were very excited, especially after a very rough start to my pregnancy. I had hyperemesis gravidarum (severe nausea) for the first and second trimester. I was surprised when I received a phone call from my midwife that day, a few hours after my appointment. She explained that there were some abnormal findings, and I would be sent to




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Heart Matters is the newsletter of the Children's Heart Network, which works to educate, support, and enhance the lives of children, youth, and families living with congenital heart disease.

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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

5151 Canada Way
 Burnaby, BC V5E 3N1
 604 521-3037 | 1 877 833-1773
chn@childrensheartnetwork.org

COFFEE GROUPS NEAR YOU

If you would like to organize a coffee group for heart parents in your community, please contact Sam Aitken at saitken@childrensheartnetwork.org and we can get you set up with a coffee card for drinks and treats!

ABBOTSFORD – Rupe Brah
rupe3395@gmail.com

CHILLIWACK – Jenna Winterhoff
jennawinterhoff@gmail.com

NANAIMO – Sandy Barlow
sandygbarlow@gmail.com

PRINCE GEORGE – Veronica Vandermeulen
veronicav0603@gmail.com

VANCOUVER – Samantha Aitken
saitken@childrensheartnetwork.org

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.

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 HeartBeats and Hearts of Gold camp programs.



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!

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MEGAN MADSEN – Vancouver Island Hearts of Gold youth coordinator

Dakota's Heart Journey, continued from page 1

Women's Hospital in Vancouver for a more detailed ultrasound. They booked me for an ultrasound at 10am and another appointment at 12pm with a genetic doctor. My husband took the morning off work to join me. But we never made it to the 12pm appointment. I knew something was wrong when the tech spent a lot of time scanning over our baby's heart. She informed us she would be right back and 20 minutes later a second tech walked in with three doctors in tow. They explained to us that there were abnormal findings of our baby's heart. They cancelled our next appointment and instead the genetic doctor joined us along with the other doctors.

We were then brought into a tiny room and to this day I can only remember one person in that room. Her name was Janet or Jan (the cardiology nurse) and she is the only reason we got through that day. We were told our daughter would be born with Transposition of the Greater Artery (TGA), a Ventricular Septal Defect (VSD) and possibly either Downs Syndrome or Cystic Fibrosis. I didn't know what that all meant; I just cared about our baby's survival and outcome. I was so thankful to have Janet in that room with us. She gave my husband and I all the reassurance we needed. With her experience and knowledge, we knew our baby would make it and that we would be able to handle whatever was thrown at us. The next step was to have an amniocentesis done to rule out any other possible medical conditions.

We left Women's Hospital that day feeling overwhelmed and scared as we had difficult choices before us. Our baby's life completely changed that day, or at least the vision of the life we had for her. The tears began (the start of what would

be a million tears over her lifetime) and we decided to go through with the amniocentesis. It was a difficult decision due to the potential complications that can arise from this test. I didn't sleep for days leading up to it, I was terrified I would lose my baby. The next appointment was for another ultrasound, to meet with the geneticist to go over the test results and to take a tour with Janet to meet the cardiology team.

Our world would be shattered one more time. We waited anxiously after our ultrasound for Janet to come with her warm smile and comforting spirit, to tell us good news and take us on our tour to meet some of our team. She never came, and sadly we learned of Janet's tragic passing (due to an avalanche in Nepal.) It was like our world came crashing down all over again.

Dakota "Janet" Margaret Kovacs was born January 2nd, 2015, on what felt like the busiest day of the year at the Hospital. Dakota was rushed to the PICU where she stayed for 2 weeks. I quickly learned the difference between expectations and reality. What we had been told was going to happen was very different from what really happened in those first few months. Her valve was a lot narrower than they had predicted, and the VSD in her heart was actually helping with the blood flow. We expected she would be born and then in a couple of days she would have her surgery to correct her valve and fix the VSD. That didn't happen. As her valve was too narrow, the surgeon couldn't just do the planned atrial switch. Instead, it would now have to be a Rastelli procedure (involves using a conduit) and her VSD would stay open as it was helping with her deoxygenated and oxygenated blood flow. They wanted her



to grow more to have the best outcome for her arterial switch.

Looking back on all the sleepless nights and thoughts of uncertainty for her future it's hard to believe where we are now. We spent a few weeks in the PICU and up on 3M and then we went home. Our first month out of hospital was full of worry and me doubting myself. Will I notice if she is going into heart failure? Will she stop breathing in the middle of the night? Dakota's saturation levels were always in the low 60's and the Doctor's told me "don't worry you will know when something's wrong; you will be able to tell". As a new mom with a heart baby that was terrifying, but I knew they were right.

One morning Dakota woke up and I felt something wasn't right. I called the on-call cardiologist's number and was told to bring Dakota in. After hours in emergency with no indication of a problem, the on-call cardiologist came down and told one of the nurses to just watch the screen. Sure enough, after 20 minutes, her saturation levels dropped down to under 50. Dakota was then taken into surgery to have a balloon put in. The balloon procedure worked for about two weeks and then at a check-up her surgeon found it wasn't working as well as they had hoped so Dakota went in again for a stent. With the new stent in, it brought her saturation levels back up to mid-70's. During her first year Dakota had multiple follow-up appointments and then at 10 months she had her first big open-heart surgery. It was Oct 20th, 2015 and I will never forget this day. Dakota was scheduled for 7:30am. I remember thinking about every possible outcome. Her surgery was expected to take most of the day, so when we got the page at 12:30pm to meet Dr Gandhi outside the PICU in

the waiting room, I was very anxious. As soon as he said those four magical words "the surgery went well", I was overwhelmed with emotion and tears of relief.

I was shocked how fast the human body can recover from major surgery. We only spent 48 hours in the PICU and 3 days on 3M. Dakota only had one complication from her surgery; a little wire that came loose months later. It started to poke out and it formed a blood clot so she had to be anesthetized to get it removed.

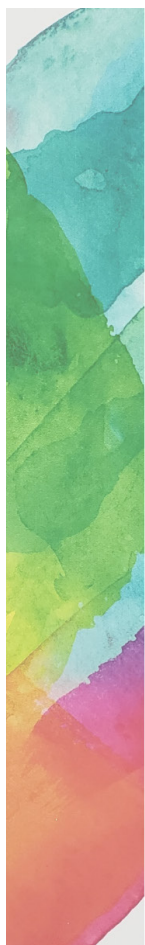
The years that followed were very quiet and nicely uneventful. She started horseback riding and got into gymnastics. She was an ordinary child that was growing and thriving, one would never guess looking at her that she has a heart condition. We welcomed our second child in 2018 and about this time, I noticed Dakota getting more tired and losing her usual zest. She had her annual checkup with the cardiology team at Surrey hospital and nothing abnormal was found. At our next appointment with her pediatrician, I asked for a referral to BCCH. When we had our appointment in October, I was shocked to learn she would need her valve replaced within months. This was much sooner than expected. I think back to when I was told, "trust me, you will know when something's not right" and sure enough, mothers' intuition, I knew something wasn't right.

Dakota was scheduled for her second open heart surgery on February 11th, 2019. It snowed so much, and I was worried her surgery would be postponed. We were in the newly built hospital; the cardiology ward looked very different and the PICU allowed parents to stay overnight. The stay wasn't as terrifying, and it brought new memories. Dakota remembers when one of the nurses let us wheel her up to the outside patio where we had a snowball fight.



Within some of the most terrifying moments of our lives are hidden some fond memories!
Today Dakota is 8 years old, in grade 3, and she has many exciting adventures ahead of her. She loves life and you can tell that nothing scares her (which scares me!) If I could tell my younger, scared self anything, it would be that it's all worth it. Janet was right; every tear cried and every scary thought I had for her future were all worth it, she is perfect

in every way. Dakota has a beautiful life now and we are a part of a special club. The heart community is full of the most amazing people and families. We are thankful to share our journey with all of you.



**CHILDREN'S
HEART NETWORK**
of BC Society

2023 - 2024

GALA FUNDRAISING COMMITTEE

HELP US RAISE FUNDS!

Join Our Committee!

Do you have a few hours per month to meet over ZOOM with a fun, collaborative group and to help take our Gala to the next level?

Whether you have prior fundraising experience or simply a passion for helping those in need, your dedication and enthusiasm are what we're looking for!

If you're ready to embark on this incredible journey with us and help create a brighter future for children with congenital heart defects, please email us: saitken@childrensheartnetwork.org.

Kid's Up Front with Nate



Nate was born on April 13, 2013 he was our first child and we couldn't wait to meet him. Nate was this beautiful perfect red headed little guy. We had no idea that he had a congenital heart defect until April 15 but throughout my pregnancy I was very worried something was wrong with him. Being a maternity nurse, I was concerned with how he was breathing at birth and while nursing him his hands and feet went such a dark blue, I thought they appeared almost black. Nate was admitted in the NICU whereupon it was discovered he had Total Anomalous Pulmonary Venous Return (TAPVR). We were rushed to BCCH where a team met us and did almost 3hrs of ECHOS, they determined that Nate was stable enough to make it through the night and have surgery

in the morning. On April 16, 2013 Nate underwent his first open heart surgery with Dr. Gandhi, handing over our newborn was the hardest thing we have ever done. The surgery was about 6hrs and we were expected to stay in the PICU for a week, Nate surpassed all expectations and was transferred to the ward on day 3. The team at BCCH was unbelievable; Dr. Gandhi and Dr. Harris saved our child's life, and gave us the greatest gift. Nate was home at 8 days post op which was unheard of since they expected us to stay at least 2 weeks.

In December of 2015 Nate underwent a second OHS at which point he suffered a stroke from bypass. Nate again showed everyone how strong he was and even though he lost the ability to move his left hand and side of his face. he worked hard to regain all motor function.

Nate has persevered through so much and he's an incredibly happy, intelligent, confident 10-year-old with a bunch of friends, he's on lots of sports teams and is doing so well.

Recently Nate was diagnosed with epilepsy as a result of the brain injury he acquired in 2015, but that hasn't stopped him, he's just adapted, accepted and pushed through like he always does! Nate makes us proud every moment and we know he was put here to do great things.

We are so grateful to the Children's Heart Network for all of their wonderful support and to Kids Up Front for the tickets to events for our family. Creating beautiful memories and spending time together is so important. Watching Nate's enthusiasm for life has given us a new perspective and has made us better people, parents, and friends.

Thank you,
Janelle Johnston



Hearts of Gold Camp

BY EMILY COTEY

Zajac Ranch, Mission, BC

Hello, my name is Emily and this is about my experience at Camp Zajac. My first time at the HOG Zajac Camp was in July 2022. I was nervous about camp because I didn't know anyone from the mainland. I made friends quickly at the camp, everyone there was super friendly and welcoming. When I had the opportunity to go again this year in May, I was excited to see all my friends from the previous year at camp and catch up on what had happened over the year. There are a lot of fun activities at the camp, one of my favourite parts is the pudding fight where we get covered in pudding. Other fun activities are the Skynet, and the high ropes course. A new activity they did this year was bubble soccer where we had a blast running into each other and watching people bounce around. There's a movie night and a grad dinner for those teens who are graduating from the HOG program. We do a slideshow on the Grad dinner night of all the fun moments at camp and then do a slideshow for the grads.

It's a really good bonding experience for us teens and it's nice for us to have a camp where we are around other people who have similar medical backgrounds and scars and we get to share our stories behind them if we wish. We can talk about how we feel about them and how they make us who we are. The staff are really great and many of them get right into the activities with us. All in all, I recommend going to the camp and experiencing the fun that we have there and all the different activities we do.



A Trip of Legends: Critter Cove

BY ANDREA MARRIOTT

I was excited for the chance to go to Critter Cove since reading about it in a CHN Newsletter when Reid was a baby – this year it happened! In July we had the incredible opportunity to join 9 other heart families on a wild and wonderful adventure.



My son, Reid was born with pulmonary atresia with intact ventricular septum and tricuspid atresia. In easier terms, it is called hypoplastic right heart syndrome. This defect meant 3 major surgeries at a young age. The last one - his Fontan, was just before he turned four. Since then, life has brought many changes. Reid has found himself with two bonus sisters, Jaiden and Emery, and a stepparent, Jeremy. They knew he was born with a congenital heart defect, but they hadn't experienced the many events with the Children's Heart Network and the community of Heart Families that we know.

We met in Gold River, where our Heart Mama Critter Cove Tour Guide Extraordinaires, (yes, that is their official title) Kerry and Colleen took attendance and handed out name tags. Then we started our trip, we boarded the MV Uchuck III for a private cruise over to Critter Cove Fishing Resort. All the kids quickly got over any sense of being shy - they were running around, playing games, and laughing. The amazing kitchen staff filled us full of freshly baked cookies, muffins, and endless soft drinks, while the captain rotated the kids giving them each a chance to steer the ship and learn about the area we were sailing through. Parents exchanged the traditional "So, which one is your heart kid? Tell me your story!" The trip was already a huge success, and we had yet to see the docks of Critter Cove.

After we arrived and settled into our floating rooms, we

were introduced to the staff and volunteers, most of whom have been participating in this weekend for the past 20 years. We all admired the wall of photos from all of the CHN Critter Cove trips. The volunteers came around with a wheelbarrow full of brand-new fishing rods and tackle boxes for all the kids; they were SET for the next few days. I wonder how many collective hours were spent fishing off those docks.

The next few days were the perfect mix of adventure, relaxation, connection, and nature as well as untying lots of knots in the kid's lines. So. Many. Knots! Our fishing guides were prepped and ready to give the kids the full experience of reeling in their own fish. At one point Emery came over the radio to announce, "We've got 20 in the box" and every boat cheered! Our shared joy quickly turned to good natured competition. Lures were changed, routes re-directed, and rally caps were readied. The excitement of the kids catching fish doubled when they realized that it meant they also had more bait to fish off the docks!



There were so many fun activities: swimming, a fishing derby, "gummy bear stories", face painting, a picnic at Esperanza Inlet and a private fireworks display! The memories from this trip will last a lifetime. After 3 nights, it was time for a group photo and then we boarded the MV Uchuck III which took us back to Vancouver Island. After hugs and thanks, we waved back to the most amazing group of volunteers as we sailed away from Critter Cove.

But that wasn't the end of our adventure! There was one stop left: Friendly Cove on Nootka Island. We had a couple of hours to explore the lighthouse, church, local artist studio, and beach. Most families made their way to the

beach, and we relived special moments of the past few days, expressing gratitude for the experience and commenting on how it was perfect. Just when we thought our hearts couldn't hold any more, a whale appeared close to shore to rub its belly and back on the smooth pea gravel on the beach. The energy of this beautiful creature so close to us had many speechless, others hollering to others to look,

and then there was Mike – swimming within 20 feet of the whale, completely unaware of it all. I will never forget watching the group of kids running along the shore as the whale moved up and down the beach. When they all stopped the whale lifted a fin to wave to them. It was nothing short of magic.



Parent Resources

Back to School

Below is a link to a factsheet that you can download, print, and complete for your child's teachers. Please follow these guidelines when filling in your child's school factsheet.



- Include a photo of your child.
- Fill in your child's name in the relevant spaces.
- Signs to be aware of: This is to highlight the general signs teachers and schools should be looking out for with any child who has congenital heart disease. You know your child best—let the teacher know which of these are common with your child and what is not normal.
- This specific section is for you to fill in based on your individual child. Your child's consultant cardiologist will be happy to help you with this. A good idea is to bring the factsheet to your next appointment so you can write down all the relevant information.
- Every child with congenital heart disease has different care requirements. Even children with the same heart condition will require individual information. Examples as below for the sections:
 - **Medications and side effects:** e.g., Warfarin can cause bruising.
 - **Exercise:** Ask your child's doctor what exercise your child can do.
 - **Other notes:** Upcoming surgery / equipment needed / feeding issues and anything else that may be relevant for your child.
- Include the best way to contact you in an emergency.
- It is important to update the factsheet as your child's condition or requirements change. Your child's teacher and school need to know the nature of your child's heart condition and any implications it will have in school.

<https://www.childrensheartnetwork.org/resources/factsheet-for-schools/>

Inclusion BC

Inclusion BC is a non-profit provincial organization that advocates for the rights and opportunities of people with intellectual disabilities and their families. We are a federation of members that include people with intellectual disabilities, their families and organizations that serve them. Please see link below to "A Parent's Handbook on Inclusive Education."

<https://inclusionbc.org/our-resources/inclusive-education-handbook-6th-ed/>



Preparing Your Child for Surgery



Child Life Department
4480 Oak Street, Vancouver, BC V6H 3V4
604-875-2345 • 1-888-300-3088
www.bcchildrens.ca

Be honest with your child.

Being honest will help your child to trust you and the hospital staff. When you are honest with your child they will know what to expect and will have time to process the information. Ask your child open ended questions about their surgery, such as “tell me about your surgery.” This will allow you to clear up any fears or misconceptions they may have.

Infants:

Infants will be hungry and may react to the change in routine and environment.

- **Bring familiar items from home.** Comfort items such as a blanket, pacifier, stuffed animal, rattle, or a familiar toy can create a more comfortable and familiar environment.
- If your child has a special sippy cup or bottle, bring it to use after the procedure.
- **Your presence will provide the most reassurance to your infant.**

Toddlers:

Toddlers will be hungry and may react to the change in routine and environment. They may be frightened of medical equipment and unfamiliar people.

- **Talk to your toddler about their procedure 1 to 2 days before.** Toddlers do not understand the concept of time, and will benefit from preparation closer to the time of the procedure.
- **Use simple words your toddler will understand.** Talk about how their body will feel after their procedure.
- **Bring familiar items from home.** Comfort items such as a blanket, stuffed animal, or a favourite toy or book can create a more comfortable and familiar environment.
- **Give your child a sense of control.** Offer them choices when possible, such as allowing them to choose what stuffed animal to bring with them.
- **Your presence will be reassuring to your toddler.**

Preschool Age Children:

Children often fear the unknown and may imagine the experience to be scarier than it is. It is important to explain to your child what they can expect. Preschoolers may believe surgery is a punishment for something they did wrong. It is important to reassure your child they did nothing wrong. Make sure they understand why they are having the procedure.

- Talk to your preschooler about their procedure 3 to 4 days before. This gives them enough time to process the information and express any feelings or questions they may have.
- Use simple words they will understand. Talk about what body part will be fixed. Explain if anything will be different after the procedure, for example, if they will have a cast afterwards.
- Explain only what your child will experience. Too much detail is not necessary. Use the 5 senses as a guide to explain to your child what they will feel, see, hear, smell, and taste.
- Play with your child prior to their procedure. This will give them a chance to express any thoughts or feelings they may have related to their procedure. They can show you what they know about their procedure and you can clarify any misconceptions they may have. Medical kits, pretend play, and colouring are great expressive outlets for children.
- Give your child a sense of control. Offer them choices when possible, such as allowing them to choose what stuffed animal or toy to bring with them.

School-Age Children:

School age children have a better understanding of their bodies and may want more details. School age children may have concerns about the anesthetic and how the procedure will change their appearance. They may worry about not having control over their body.

- **Talk to your school age child about their procedure 1 to 2 weeks before.** This gives them enough time to process the information and ask questions. Make sure that they understand why they are having a procedure.
- **Use the 5 senses as a guide when explaining their procedure.** Explain what they will feel, see, hear, smell, and taste.
- **Talk about the anesthetic, or sleep medicine.** Make it clear that this is a different sleep than sleeping at home. Remind them they will not feel anything and they will not wake up during the surgery. Avoid using the term “put to sleep” as children may have experience with a pet being euthanized.
- **It is normal for your child to feel scared, anxious or angry.** Encourage them to express their feelings and thoughts, and to ask questions. Reassure them it is okay to cry.
- **Make a coping plan.** Help your child identify any concerns they have, then brainstorm ideas of what will help make it easier for them. Practice your coping plan before you come to the hospital. Share your coping plan with the staff.
- **Give your child a sense of control.** Offer them choices when possible, such as allowing them to choose what to pack to bring with them. Your child may wish to bring a robe to wear over their hospital gown.

Teens:

Teens may want more detailed explanations about their procedure. Teens are becoming more independent, and may worry about loss of control and privacy. Reassure them that the hospital staff will respect their privacy.

- **Involve your teen.** Encourage them to be an active participant by learning about their surgery, making decisions about their care, and asking questions along the way.
- **Talk about the anesthetic, or sleep medicine.**
- **Make sure your teen understands the procedure.** Teens may not want to ask questions, leading adults to believe they understand more than they do. It may be helpful to have your teen explain to you what they understand about the procedure.
- **Encourage them to identify their concerns.** They may be concerned about the procedure changing their appearance, not having control of their body, or being in pain after surgery.
- **Make a coping plan.** After identifying their concerns, brainstorm ideas with your teen of what will help make it easier for them. Practice your coping plan before coming to the hospital. Share your coping plan with the staff.
- **Reassure your teen that it is normal to feel scared, anxious, or angry.** Some teens may want to keep their feelings private. You can encourage them to write in a journal or talk with friends.
- **Bring items from home.** Allow your teen to pack items that will help them relax or feel more comfortable, such as an ipod or a favourite blanket. Your teen may wish to bring a robe to wear over their hospital gown.

Developed by the health care professionals of the Child Life Department with assistance from the Department of Learning & Development

BCCH 1653 © 2013 (2) BC Children's Hospital

What's Happening?

Hearts of Gold Events – Lower Mainland

After 11 years of being our amazing Hearts of Gold coordinator Kristi Coldwell is stepping down. Words can't express the gratitude we feel for all her hard work and for her commitment to our CHN youth. Kristi has spent over a decade planning fun and engaging events for so many teens as well as leading our Hearts of Gold camp each year. It is during these events and at camp that our teens have built new friendships and connected with others that are experiencing similar journeys with heart disease. Kristi's words *"Over the last 11 years in this role I have had the privilege of getting to know many remarkable teens and have watched them grow in their heart journeys. My time with HOG has been incredibly rewarding and filled with cherished memories."* - We will all miss you Kristi!

We are thrilled to announce that our new Hearts of Gold coordinator for the Lower Mainland is Emily Deimling. Emily is currently working as a Child Life Specialist at BCCH and brings with her many years of experience working with children and youth. Welcome Emily!

Hearts of Gold Lower Mainland teens (ages 13-18 years old) will get together in October for their Halloween event. This will be Kristi's final event. If you are a heart teen or heart teen parent and would like more information on joining the HOG group please contact Kristi Coldwell at Samantha Aitken at saitken@childrensheartnetwork.org for more information.

Pumpkin Patch Events

Lower Mainland - Oct. 7th at 1:30pm – Hazelmere Pumpkin Patch in Surrey

Victoria – Oct. 21st at - Galey Farms in Victoria

Nanaimo – Oct. 15th – McNabbs in Ladysmith

Kelowna – Oct. 21st – McMillan Farms in Kelwona

For more information, please email Samantha at saitken@childrensheartnetwork.org

CHN Holiday Parties - Save the Date, watch for more information and an email invitation

Lower Mainland – Saturday, Dec. 2nd at 9:30am at the Grand Villa Hotel in Burnaby

Island – Saturday, Dec. 9th at 3:00pm – Butchart Gardens Carousel Room

Okanagan – Saturday, Dec. 9th at 9:30am at the Coast Capri Hotel





**CHILDREN'S
HEART NETWORK**
of BC Society

20TH



SAVE THE DATE

TERMINAL CITY CLUB

APRIL 26, 2024