

# ccanetwork



newsletter of children's craniofacial association

2025: ISSUE 2

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“no matter who we are, or where we are - our voices deserve to be heard - whether on the playground or within the halls of academia.”

*by Kariym Joachim | Toronto, Canada*

hello from the great white north! My name is Kariym Joachim, and I'm a 37-year-old adult living with Treacher Collins syndrome (TCS) in Toronto, Canada. Many of you may already know what TCS is, but very briefly, it is a congenital, genetic condition that impacts the structure of my face. Simply put, my facial bones and some of my soft tissues did not form fully, leaving me with underdeveloped cheekbones, a small bottom jaw, and microtia - my outer ears never fully developed. As a result, I am mostly deaf without my bone-anchored hearing aid (BAHA). One of the unique things about TCS is that it can be almost unnoticeable, such that people may not know they even have it, while in other cases, it can be far more severe. My TCS is relatively mild, though I've had more than 20-plus operations... I honestly lost count after 24.

see kariym, page 2

## letter from the program director



I don't know if it was the stunning scenery, the perfect weather, or the amazing location of our hotel, but I can honestly say this was one of my favorites—if not the favorite—Retreats to date. Over four incredible days, long-lasting memories were made, and for the third year in a row, we had the joy of gathering in a brand-new state!

This year's 35th Annual Retreat was hosted at the beautiful Hyatt Regency Bellevue in Bellevue, WA. With so much to see and do just steps away, many of our families were able to explore together before the Retreat began and again after it ended. We welcomed 135 families from 35 states, plus families from Canada, Switzerland, and the United Kingdom. Of those, 30 families were attending for the very first time.

Thursday morning, the hotel lobby was already buzzing with excitement as families gathered before the 17th Annual Educational Symposium. It's one of the

see letter from PD, page 6



## kariym, continued from the cover

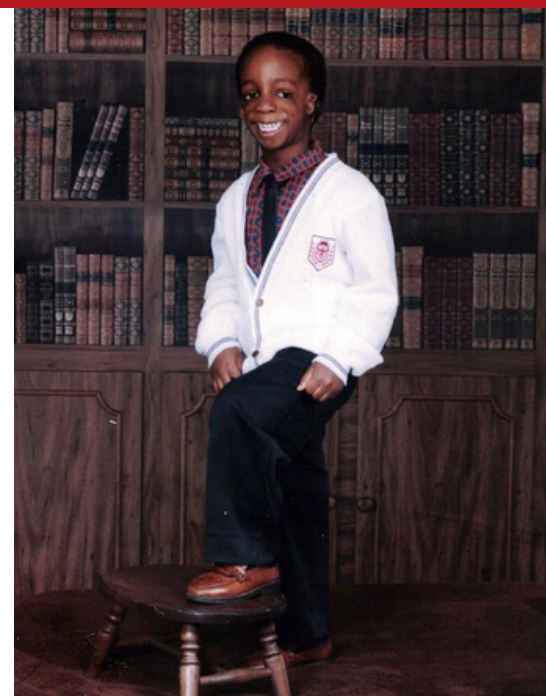
As an adult, these surgeries feel like long-ago memories that I think about from time to time. As with many others in the facial difference community, my healthcare experiences include both positive and negative ones. When I was a baby, my parents had some difficulty acquiring a diagnosis for me. At the time, they were told that I had “a little problem with the ears.” Fortunately, a very wise pediatrician took one look at me, confidently gave me the diagnosis of TCS and immediately had me referred to SickKids Hospital where my journey began in earnest.



At a relatively young age, my parents and I got to meet a plastic surgeon to chart out my medical future. Much like the pediatrician from before, this gentleman took a single look at me - but he immediately decided that I was inoperable. What he said next still upsets my parents to this day - to “grow his hair long [like a particular pop singer] to cover his ears, put on a cap and go to a baseball game.” His message to my parents was that there was no hope for me and I would never be able to speak. Despite such a negative prognosis, I am incredibly grateful to my parents for pushing onwards. Speaking up and advocating is something they were passionate about then, and it continues to be a passion for me today. These days, I admit that it is nearly impossible

2 for me to stop talking at times!

That all said, the proverb that ‘it takes a village to raise a child’ is appropriate in my case. My parents - with the help of a great hearing resource teacher, countless educators and healthcare professionals - encouraged my development. In time, we met a new surgeon who I still have a long-standing, positive relationship. In sharp contrast to the previous surgeon, he approached my case with positivity. His approach was to be both a realist and an optimist. Yes, there would be setbacks, and yes, there would be canceled surgeries due to difficult intubation, but we would always regroup and move forward. What is most important to me is that after speaking with my parents, he would always talk to me. He would get to my eye level to explain what was going on, using props like X-Rays or model skulls to describe what was going to happen and when. This, along with his spiky hair earned him the nickname “Dr. Cool.” All of the various craniofacial, ENT, ophthalmologic and orthodontic team members were always willing to answer my questions and feed my innate childhood curiosity, which only bolstered my interest in the sciences and continues to impact me to this day.



My story isn't all about surgeries, though. When I was around 7 or 8 years old, I began to experience bullying and became aware that I looked different from the other kids at school. Through all that, my family continued to be a source of great strength for me. My mother gave up her career to raise me and my sister and continues to be a huge support for the both of us. Even today, my sister and I often find ourselves calling Mom to chat when we've had a rough time. She always reminds me about the long trips via public transit to SickKids where we would spend the entire day going from clinic to clinic. She always ends with **“We've gone through so much and you've come this far. I know things are hard, but I know that you're going to make it through this too.”** My Dad too, continues to be a source of strength - often unbothered (except if you mess with his family), he has a tenacity and stubbornness that has rubbed off on my sister and myself. He always reminds us about the value of being independent and to avoid following trends just because everyone else is doing so - **“Friends take you away, and they never bring you back”** is one of his favorite sayings.

## kariym, continued from page 2

I'm so happy that I could have their support as a child and well into adulthood.

I think our collective experiences with the medical establishment have had a profound impact on both my sister and me.



She is now an operating room nurse who loves interacting with patients, supporting ophthalmology procedures one day, orthopaedics the next, and so forth. Though she is very much an adult, I still greet her every time with the childhood nicknames I've been calling her since she was a baby (if I shared them here, I'd never hear the end of it!).

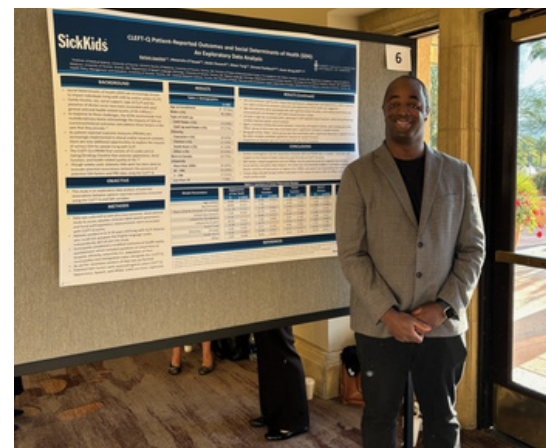
This is all a lot of words to say that my facial difference has had an enormous impact on my life. In Canada, the closest organization we have that can compare to CCA is **AboutFace** - an organization that has provided so much support through to my adult years. Ever since I was 12 years old, I have been a volunteer for the organization. I have had numerous public speaking opportunities to educate clinicians and the broader public about facial differences, volunteered as a camp counsellor at a camp for kids with facial differences, and served as president and chair of the board of directors. Having recently gotten to meet and interact with the folks from CCA, I am so happy to see the work they do, and the meaningful and outsized impact that they and other U.S.-based facial difference



organizations have. **No matter who we are, or where we are - our voices deserve to be heard - whether on the playground or within the halls of academia.**

My facial difference also guides much of what I do professionally. As a kid, I always dreamed that I would one day be a scientist or a doctor. While I don't wear a lab coat or a stethoscope, I am very privileged to be working as a clinical research project manager in the plastics & reconstructive surgery division at SickKids Hospital. Though it was a little odd at first to work with the same people who treated me as a kid (imagine calling your surgeon by his first name!), it has been exciting to facilitate research in the craniofacial space. I feel strongly that while there have been great strides on new treatments and surgical procedures for craniofacial conditions, there is still so much more to understand. For example - what is the health-related quality of life for members of the facial difference community? Are the clinical needs of individual facial differences being met throughout the life course? How do we fare when we go out into the world as

adults? I want to find out - and I'm so happy to have found that so many researchers and medical professionals with and without facial differences from around the world want to find out too. To that end, while I work full-time as a research manager, I am also working on my PhD in Medical Science, with the hopes of eventually leading more of my own research projects and answering some of these burning questions.



As I often say though, my facial difference is a part of me - it's an undeniable part of my life that I cannot separate from myself - but it is not all of me. A few little things about me...

I love photography! It's not uncommon for me to be

## kariym, continued from page 3

somewhere one minute, and off somewhere else with my mirrorless camera the next. I love to capture the world around me, whether it is exploring the sunlight through the leaves of a forest, or reflections off of gleaming towers of glass and concrete.



I love to travel! My list of places is relatively small so far, and I've never left North America, but the few places I've been I've just loved seeing! I've been to Chicago, Denver, Montréal, Phoenix, Quebec City, San Francisco, Seattle, Winnipeg and more - and loved every minute. I hope to see more of this beautiful blue marble!

I play piano. Not nearly as much as I would like to, but I've been playing



ever since I was 13 years old. A little bit of classical, a little bit of pop - one of my favourite things to do is to play and learn songs by ear and guitar chords. If there's a public piano, you might see me sneak up to it and play it. My favourite pianos are the ones that are a little worn, maybe out of tune. Each piano has its own story and character!



Living with a facial difference can be a challenge, regardless of your life stage. I am still incredibly hopeful for each and every one of us, it is not insurmountable. **A facial difference is a part of one's unique story, and yet, not the entire novel. I refuse to let anyone write my book but myself!** 🌈

## killin' the battenkill 5k run

by Angela Cronin | Greenwich, NY

**I**t was another successful event even with weather issues!

Unfortunately, we were not able to hold the actual race this year due to weather. In the early summer of 2025, it rained every Saturday for months and on race day it wasn't just rain - it was pouring!

While we were bummed to miss out on our tradition, we switched gears, canceled the race and moved the BBQ at our house to later in the afternoon when the sun was out.

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We had a great turn out at the BBQ and still raised \$2,500 for CCA!

This picture (see right) is of my family in our 'Stronger Together' shirts and somehow, I managed to get 2 young adults and 1 teenage boy to wear for the BBQ and to match their parents! Not an easy feat but they were great sports. **Anything for CCA - that's the motto in our house!**

We will be taking a pause on the race next year because we will have a high school graduate, but will be back in 2027 and hopefully bigger than ever! 🌈



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# meet riley ren

by Haley Hatai | Madera, CA

**m**et Riley Ren, our sweet and vivacious almost four-year-old!

We chose her name because it means “courageous,” but we did not anticipate how early our girl would need to live up to her name. Riley was diagnosed with Crouzon/Pfeiffer syndrome before she was born. Because of this, Riley was able to meet the majority of her beloved craniofacial team on day one. Our girl has endured three major surgeries, her first one being at four months old.

Riley is initially a shy gal to new people and takes a good amount of time to warm up. But once you are in her club, you are a lifetime member. Be prepared to receive a lot of homemade cards. If given the opportunity, Riley will have you read books to her all day long. If no one can read her a book, she will be more than happy to sit with a pile of books and “read” to herself. She also enjoys listening to audiobooks with her Yoto Speaker. Some of her favorite audiobooks are Charlotte’s Web, Little Pilgrim’s Big Journey, Classic Disney Princess stories, and Winnie the Pooh. Her love for books has given her quite a vocabulary. She often shocks us by using big words and dramatic (in the best way) language.

In addition to books, Riley loves to play kitchen. When our family is expecting guests, Riley will cook up a storm in her play kitchen, creating an elaborate meal and setting her table to fill each guest’s belly with a delicious, pretend dish. Like most three-year-old girls, Riley loves

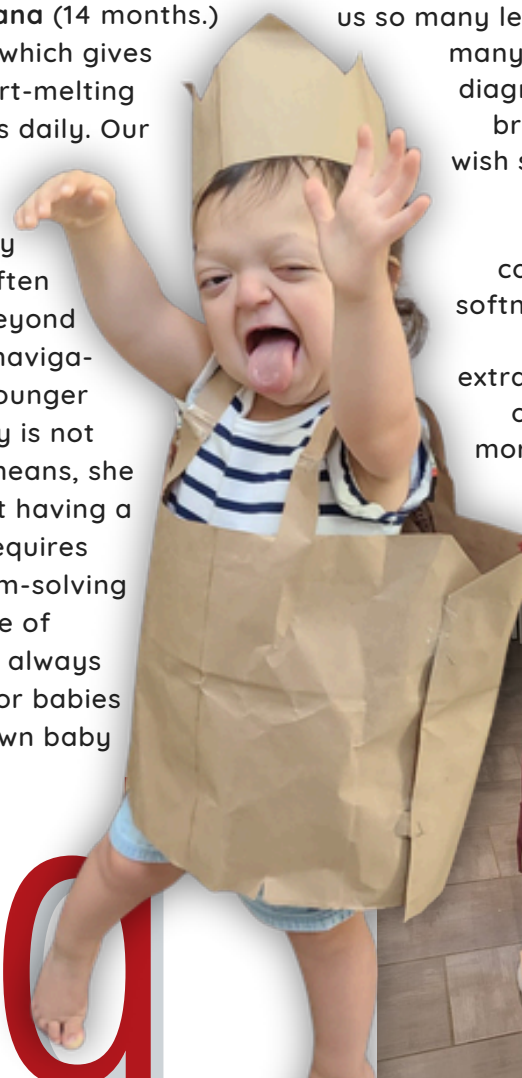


crafts, playing with her doll house, taking care of her baby dolls, exploring outside, and attending her weekly gymnastics class. She has a close core group of friends whom she adores. Riley is constantly creating crafted gifts to give to her friends and is always planning things she can do with them.

Riley’s most prized role is being the older sister to Hana (14 months.) She loves Hana, which gives us countless heart-melting scenes to witness daily. Our house is filled with lots of giggles and giddy screams. Riley often shows wisdom beyond her years when navigating life with a younger sister. While Riley is not perfect by any means, she understands that having a younger sister requires patience, problem-solving and a good sense of humor. Riley has always had an affinity for babies but having her own baby

sister has given her the confidence to interact with other babies while we are out and about, even though she is shy. It has been fun watching her go outside her comfort zone to do things she loves.

Our Riley Ren has put us all on a journey we did not expect, but we would not have it any other way. God has already used her to teach us so many lessons and to touch many people’s lives. Her diagnosis, while it often brings things that we wish she did not have to endure, has also brought new community, bravery, softness, ability to soak in the ordinary, extraordinary moments of life, and so much more. We are honored to be given such a precious gift.



# ccakia

# letter from the PD, continued from the cover

most heartwarming sights—new families meeting face-to-face with people they’ve only known online, old friends reuniting after years apart, hugs all around, laughter, and so much love in one place.

We were honored to welcome outstanding professional speakers in the field of craniofacial research and medicine for our Symposium. We extend our heartfelt thanks to the following experts from Seattle Children’s Hospital for generously sharing their time, knowledge, and compassion with our families:

- Maida Lynn Chen, MD
- Srinivas Susarla, MD, DMD, FACS, FAAP
- Cindy Olva Trevino, PhD
- Carrie L. Heike, MD, MS
- Jessica Lea Meikle, MD

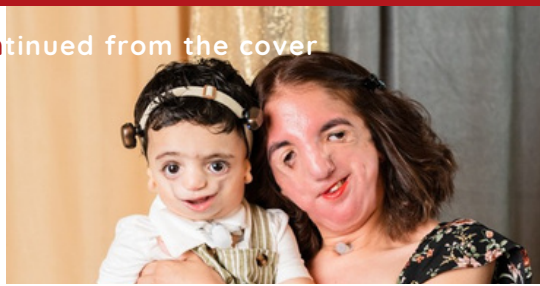
A heartfelt thank you also to our Keynote Speaker, Sarah Tompkins, Ms. Wheelchair USA. Sarah’s powerful story of living with Ehlers-Danlos Syndrome, advocating for invisible disabilities, and ultimately embracing empowerment, authenticity, and courage captivated everyone. A highlight was when a young audience member asked Sarah her age—her quick, playful response had us all laughing.



A very special thank you goes to Rita Albert, JD, and Julie Silva from ConnectMed International and Shelbie Rand and Elena-Lee Ritoli, DMD, MDS from Kenzie’s Camp, and Ashley Rhodes from FACES, who held a camp session for Parents & Teens on “Fostering Independence in Your Child.”

Roz Cornejo and Sylvia Crow from The Bellevue Youth Theatre brought joy and creativity with

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their “Theatre Games Galore!” session, and Amy Schefer from Advocate Angel shared practical wisdom in “Overcoming Medical Chaos.” Lastly, our heartfelt thanks to CCA family members Ashley Jupp, Jeremy & Eva Nicholas, and Charlee McLaughlin and the ConnectMed team for lending their voices and experiences as panelists and session hosts, including our Kintsugi Workshop, which had us all “in pieces” laughing at times.

This year, we welcomed our Platinum Sponsor — Seattle Children’s Hospital — whose support made a huge difference! Having their sponsorship and involvement made our Retreat even better! We also welcomed our wonderful Symposium exhibitors: Born a Hero, ConnectMed International, Kenzie’s Camp, and Seattle Children’s Hospital.

A special thank you to Roseann Opdyke for sponsoring The Opdyke Memorial Scholarship and to Diana Sweeney of Craniofacial Connection, for sponsoring scholarships annually.



## THANK YOU 2025 SPONSORS!

BUILT FOR THE FUTURE

## letter from the PD, continued from page 6

To our incredible volunteers, you kept things running smoothly at registration, the Symposium, and throughout the Retreat. We couldn't have done it without you. Thank you all!

- Vanessa Acero, MS, PsyD
- Sharon Allbright
- Falina Alvey
- Taylar Aumann
- CJ, Bette & Jessica Barbalaci
- Lisa & Ashley Bock
- Gloria & Aaliyah Booker
- Martha & Shelley Bradley
- Megan Brown
- Lia Burton
- Yesi Alva Castro, Joseph, Jasmine & Gabriel Pacheco-Alva
- Lindsey Condefer & Sprout
- Jason, Liz & Jasper Cox
- George, Kristine, Jeremy, Tommy, Cody Dale, Katie Favaloro, and Brooke Sumner
- Abby Daniels
- Dede & Peter Dankelson
- Mary Donatelli
- Deena Dyson
- Dr. Michael Goodman
- Brooke Hall
- Ryan & Whitney Hollingshead
- Kara Jakckman
- Ashley Jupp
- Ed, Amy, & Matthew Kern
- Bari & Hannah Klein
- Michelle, Anah & Ella Kryzanowski
- Jono Lancaster
- Stacy McAllister
- Amy & Charlee McLaughlin
- Johnny & Jessica McMahan
- Harlena Morton
- Jeremy, Eva, Cassidy & Cameron Nicholas
- Julianna & Brooklyn Nicholl
- Jennifer Oransky
- Jan Perkins
- Liz, Justin, Jessica & Daniel Prince
- Jaci Samhammer
- Mark & Laurel Sanborn
- Sabrina Seitz
- Cassandra Shanklin
- Kimmy Snow
- Carolina Sommer
- Summer Thomas
- Courtney Vysocky
- Charlee White
- Megan White
- and all of our raffle ticket sellers, those who helped during the raffle and everyone who brought raffle items/baskets



We also continued our “C.A.R.E.” Counseling program for the sixth year, thanks to Vanessa Acero, MS, PsyD, Cindy Olva Trevino, PhD, and Allyson McDonough, MSW, LSWAIC of Seattle Children’s Hospital for serving and staffing this resource.

Thursday evening, we officially kicked things off in the Grand Ballroom with a delicious dinner buffet followed by a quirky, high-energy magic show from Kameron Messmer. His humor and tricks kept us laughing, and the moment he pulled one of our CCA moms on stage was unforgettable!

Friday began with breakfast and our now-beloved Interest Groups, where families connect over shared hobbies and passions. These were followed by Group Meet-Ups, one of our most popular events which are organized by syndrome and special topics like adoption journeys, advocacy, and even lightsaber skills.

After some free time for lunch and exploring, families gathered for a lively Social Hour before pulling on neon, leg warmers, and big hair for our first-ever “Totally Radical” 80’s Party with live music from Voodoo Economics. The band generously donated their time and had everyone on their feet from the very first song. It was totally tubular, completely righteous, and an unforgettable afternoon of dancing and laughter.

Meanwhile, our CCA Kids & Teens unleashed their imaginations in a Superhero Workshop led by Jono Lancaster. The room was filled with laughter, bold ideas, and unstoppable creativity—and by the end, it was clear that every single one of them is a true real-life superhero.



## Letter from the PD, continued from page 7

Friday evening brought Family Night and our famous Hometown Basket Raffle, featuring baskets from across the country (and beyond!). The generosity in both donating and purchasing tickets was incredible. While parents tried their luck, our teens rocked the mic during Karaoke Night! Bruh, teens are hard to please, but I think Karaoke was something they all enjoyed! This night wouldn't be possible without our amazing chaperones. Thank you all so much!



Saturday began with breakfast and another round of Interest Groups, followed by our big group photo—over 400 smiling faces filling the Hyatt's stunning Grand Staircase. A huge thank you to **Eva Nicholas** for capturing the moment so beautifully, and to **Samantha Saperstein** for the amazing job of getting everyone's attention when it was time to say "cheese!"



Seeing our entire CCA family together in one spot is both powerful and deeply heartwarming. We know it takes patience to make it happen, and we're so grateful to everyone for making it work—what a moment to remember!

After lunch, we came together for "CCA's Got Talent"—our beloved Talent Show—which was once again bigger, brighter, and more inspiring than ever. From music and dance to skits and puppetry, the courage, creativity, and talent on display left us in awe. A huge thank you to our fabulous (and equally talented) emcees, **Aaliyah Booker** and **Peter Dankelson**, for keeping the show flowing with energy, humor, and heart. Another big thanks to our sound and music master, **Johnny McMahan**, who created the perfect playlist and made sure everything ran smoothly and sounded amazing, he truly nailed it, as always! And a very special thanks to Johnny's incredible and hardworking wife, **Jessica**, for helping with stage setup for each performer. We couldn't have done it without you both!

Saturday night's "Scott's Dinner & Wipeout Dance" was pure joy from start to finish. We want to especially thank **Bob** and **Paula Guzzo** for this incredibly generous named sponsorship of this hallmark event at Retreat. Their sponsorship covers all of the costs, including dinner, associated with this event, and we can't think of a better way to honor **Scott Guzzo's** legacy than with a huge, joyful dance party each year. We were also honored to present the Scott Guzzo Mayoral Scholarship to **Megan Brown**, whose leadership and positivity continue to inspire our community.

The dance floor stayed packed all night—spilling onto the carpet and even the



## letter from the PD, continued from page 8

aisles—and I'm convinced no hotel dance floor will ever be big enough for our crew.

Sunday morning always arrives too soon. Breakfast is bittersweet—filled with hugs, tears, and promises to meet again next year. The bonds formed at Retreat are unlike anything else, and while the goodbyes are hard, the countdown to our next gathering begins the moment we part ways.

I left this year's Retreat with my heart full and an overwhelming sense of peace and gratitude. Thank you to every single person who made this event so special. You are my CCA Family—always have been, always will be.

We can't wait to see you in Orlando, FL, Jun. 26-28, 2026!

- Annie Reeves

CCA's Program Director 



We are so grateful to have had such talented photographers -- who shared their time and skills to capture memories for a life time! Thank you to the following: Eva Nicholas of Eva Nicholas Photography, Christine of Entwined Photography, Stacey Feasel of Feasible Photography, Carolyn Coffee Nissen of Carolyn Coffee Photography, Bonnie Leung of Bonnie Leung Photography, and Katya Rummyantseva



# retirement announcement

After 22 incredible years as CCA's Program Director, it is with a full heart and deep gratitude that I share my decision to retire in December. But don't worry, I'm not going anywhere!

Serving you—your children and your families—has been one of the greatest honors of my life. Each of you have left an imprint on my heart. I've witnessed the courage in your children's eyes, the fierce love of parents, the strength of siblings, and the beauty of a community that lifts one another up in the face of adversity.

This work has never been just a job to me—it has been a calling. Every day has reminded me of what truly matters: compassion, connection, and the power of hope.

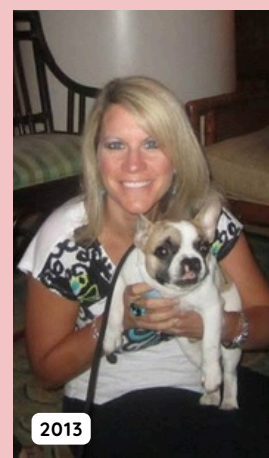
As I step into this next chapter, please know that I carry every moment we've shared with me—the hard ones, the joyful ones, and all the quiet, meaningful in-betweens. I leave this role confident that the mission will continue to grow in the hands of a team deeply committed to walking beside you on this unique and powerful journey. In case you're wondering what's next—it's family time. I'm looking forward to more trips to see my parents and sister and being more present for Tommy, Connor, Caden, and Lily.

As I mentioned earlier, please know this is not goodbye—I'm not going anywhere! You're not getting rid of me just yet! I'll still be attending the Retreats and am especially looking forward to celebrating with all of you next year in Orlando. What I'm most excited about is finally having time to sit, visit, and connect with all the families I've come to know and love over these past 22 years. And yes, I won't have to be the crazy lady running around (like a crazy lady)!

Thank you for allowing me to be part of your lives. Thank you for your trust, your stories, and your love. I love you all—and I'll see you in Orlando!

- Annie Reeves

CCA's Program Director 



Congratulation Annie on 22 years of service! Thank you for serving our families with loyalty, dedication, passion, and professionalism. Your impact on the families we serve is immeasurable. You have enriched the lives of so many and we wish you nothing but the best during your retirement! Happy Retirement!!

# financial assistance testimonial

by Shana Alford | Cedarbluff, MS

I would like to personally thank CCA for your financial assistance with Zoey Grace's surgery at Boston Children's Hospital (BCH).

Zoey was born with a rare diagnosis called frontal encephalocele and partial cleft. Before Zoey's arrival, I was informed of her diagnosis when I was 20 weeks into my pregnancy. Local doctors here in Mississippi (MS) strongly suggested that I shouldn't continue with the pregnancy. I was often told by doctors that life would be challenging for me and for Zoey. I was once told that I was being selfish and would have to endure a lot financially.

Even with all the backlash, I decided to continue with the pregnancy, so on April 20, 2015 I was blessed to have Miss Zoey Grace.

Zoey has exceeded all the doctor's expectations and to be honest she's exceeded mine as well.

Zoey has thrived with all of life challenges thrown her way. Challenges that include constant stares and whispers, being picked on, to having to transition to just a single parent household.

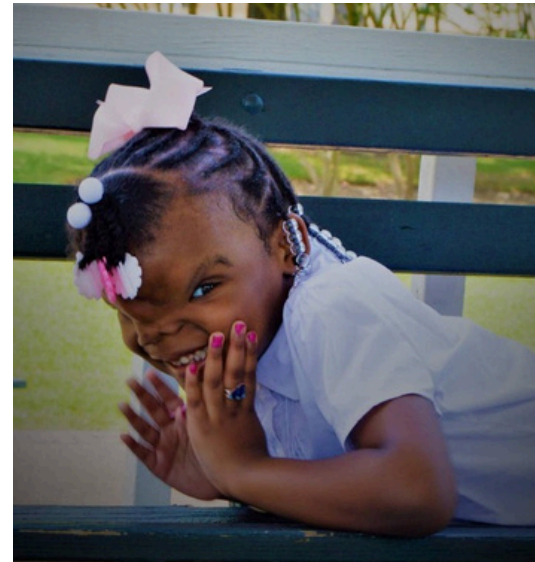
One challenge I never wanted Zoey to worry about was finances. As parents we worry! We worry when our little ones scrape their knees. We worry when they fall. We worry when they must have major surgery. So, the last worry I wanted to have was "how do I get Zoey there?"

For my family, Boston Children's Hospital is where Zoey receives her care, but with that comes a financial burden. In MS hotels average \$65 a night so roughly \$2k for a month. But on our first trip to Boston, we spent over \$15,000 on just the hotel alone. The plane tickets were not included in that. This is why I am thankful for organizations like CCA. I no longer have to worry about financially how to get Zoey to her doctors for medical treatment. I simply get to focus on her care and recovery.

Since the last operation Zoey has been doing well. She has to see her local pediatrician (who works closely with BCH) weekly for bloodwork. She takes her antibiotics daily and typically has a Zoom call once a week with BCH.

CCA has taken one less worry from this mommy and for that I will be forever grateful!!

A thankful mommy,  
Shana Alford



# first time retreat attendee

by Eliza Bahneman | Concord, CA

As a little girl I have always been in love with the idea of life; making friends and meeting new people. The world inspired me. I always wondered about cultures, languages, people's habits, and lifestyles. As an immigrant, I have had the privilege to experience the good and the bad. Most of what I've experienced has taught me life lessons I use today. The biggest one is acceptance. After being excluded throughout my adolescence years, I knew that I would always be the one to include those that were not.

Fast forward to 2018, after almost a year we finally got pregnant with our first child. My pregnancy was a breeze. Aside from the beginning stages of exhaustion which I felt mostly in the evening, I had no other symptoms. My energy during the day was through the roof which helped in running my clothing business. Erik and I were thrilled and kept guessing what the baby's personality would be like. After our first ultrasound, I was informed I needed follow up ultrasounds due to the shape of my uterus. They were concerned that the baby may not have enough room to go full term. After months of ultrasounds at about 6 months I was cleared. At my 7-month appointment I was sent down for an immediate more detailed ultrasound as the blood flow through the umbilical cord didn't seem like it was going to the baby, however, after several ultrasounds and monitoring that, too, was ruled out.

My water broke on October 24, 2018 and we rushed to the hospital. I recall being slightly nervous over the early arrival of our baby but not once did I think about what lay ahead. It was a little passed midnight. We called our

12 parents to inform them of the

news. My parents came within 20 minutes of my call and Erik's were already on the road as it was a little over an hour drive. When we arrived to the hospital I was quickly rushed in. At that point, I was 3.5 cm dilated. Unfortunately, I learned the hard way to not eat prior to giving birth. My cravings of In-N-Out burger did not settle well once I was in my room. Aside from being nauseous during birth and Bella having a hard time coming out, I did not have other complications. My labor all in all was 12 hours. After pushing for less than 45 minutes, our rare diamond made her grand entrance 5 weeks early. I recall looking at Bella and thinking she looked different. She was swiftly taken. The room filled with the loudest silence I had ever heard. My delivery doctor stepped out, confusion on everyone's face, and no congratulations. The NICU staff was already there and immediately took Bella for evaluation. Doctors and nurses were coming in and out, the machines were beeping, Bella was crying under the heat lamp with 5 doctors around her, and the bright lights in the room all of a sudden felt like an interrogation room. I was confused, broken and crying. I looked up to my mom and husband for comfort only to find them just as concerned and confused. My mom walked over to me to hold my hand. I remember asking her if I ever can have a normal birth, and she said everything was going to work out. Unbeknownst to us Isabella was born with a rare syndrome.

As the team was preparing to head out, I asked if I could hold my baby. I looked at Isabella and she looked into my eyes and I said whatever it is you have- I will always protect you and give you the best life. After what felt like hours I was reunited with Erik and Bella. It was the sweetest skin to



skin I had ever witness. Our baby girl looked so vulnerable and little. My husband looked up at me and said, "honey I think I diagnosed our daughter, she might have Treacher Collins or Goldenhar syndrome." Within a day, with the help of my best friend, we were transferred to Oakland Children's Hospital where her amazing care began. The stars aligned. The craniofacial surgeon happened to be great friends with one of my really good friends. He ended up repairing Bella's palate. My uncle, a gastrologist, ended up saving us couple times with Bella's gtube. Within two weeks of being in the NICU, Erik's boss's daughter was hired as Isabella's night nurse. They say it takes a village to raise children and our village kept growing! With the help of our parents, families, and friends, we were able to overcome the hardest times. As you all know it



takes time to process everything. Just like most of you, we were in survival mode. Extended family and friends heard we had Bella and that things did not go as planned, but we hadn't had time to inform them about the details of her care and our birth. One evening, as I was sitting bedside and reading Bella a book I had a moment. I thought to myself, if my daughter has to endure this much, she has to be supported and celebrated by everyone. I went public with my birth and slowly called family and friends to share with them our story and new normal. I think the most challenging part of motherhood for me was the beginning. I learned that life can't always go as planned. I learned that the path you want for yourself sometimes is not the path that you will get and that the challenges you face you will learn to overcome them.

Bella's love for life and her energy is so contagious that she affects everyone she meets. Watching her interact with the world is the most rewarding thus far.

The outpouring love we received was warm and overwhelming. With everyone's help we built the foundation to educate, spread kindness, and overcome difficulties. As I shared our story via social media, I started to connect with

families all over the world. We became part of the Treacher Collins Facebook community and started to learn about events that support children and families that share a similar story. We had learned about CCA and had been invited to come to Retreat several years in a row. Honestly speaking, we weren't ready. I knew the Retreat would be an overwhelming but beautiful experience. After receiving the dates for the 2025 Retreat, we immediately put the dates in our calendar and made accommodations to attend. Leading up to the trip we were excited and nervous. Our concern was mainly how Bella would process the experience. We knew we would be emotional, we knew our youngest would be excited to play with everyone his age, and we knew Bella would enjoy making new friends. But what we didn't expect is to leave the event with a bigger family!

The first day was the most overwhelming. Many of you probably would say the same. What makes it overwhelming is seeing how vulnerable we all were. How we all have a story to tell. I remember telling my husband I needed a moment to myself in the room after we had met everyone. I was processing. I sat in the room, cried, and thought about everything everyone had been through.

Watching our daughter interact within the room with grace and curiosity made me emotional. Shortly after, Bella joined me. I asked her if she had any questions. She was teary eyed and said no. She just hugged me and laid with me. The following day we really enjoyed the symposiums. The information we received was insightful. The kids loved everything they did that day and all the new friends they made. At lunch break, we went back upstairs and I once again approached Bella on how she felt and if she had any questions. She said, "mommy I know what you're going to say, that we are all different in our own way." I said Bella, "Ask mommy your question and I will do my best to explain." Bella surprised me with real questions. Just like me she was taking it all in. Fast forward to a month later, as we were getting in the car Bella said, "mommy thank you for taking me to Bellevue, I now know there are people like me with hearing aids and I don't care what other people think about me." In that moment, I knew that the trip was really a success. We left Retreat feeling so wholesome and happy. We shared laughs, tears, anger, and stories. We made memories and created new ones. **Our village grew bigger and together we are stronger!** 🌈💖



# ccakid

## meet cooper

by Allison Aro | Baltimore, MD

God's presence in our lives often shows up in unexpected ways. When we found out we were pregnant with Cooper, we were overjoyed. He was the missing piece of the puzzle, and we couldn't wait for his arrival. When we went for our mid-pregnancy ultrasound, they noticed that the hands of our baby boy looked a little different than was expected. This abnormality sparked some concern, so genetic testing was recommended. Through this process we learned that Cooper would be born with a rare genetic condition called Apert syndrome.

This news was shocking and unsettling as we had no idea what to expect. Our team of doctors tried their best to help prepare us, but there were so many uncertainties. They presented us with all the worst-case scenarios, and it was discouraging to say the least. We did our best to prepare for the unknown with hopeful hearts and a lot of prayer. On March 19, 2022, Cooper was born via C-section. It was love at first sight. The baby boy we had anxiously anticipated was finally here, and he couldn't have been more perfect in our eyes. The first few days after he was born was a blur. While we were overjoyed with this miraculous little person, we were also very aware of the challenges he would have to overcome. So many questions raced through our minds and the gravity of each

decision weighed heavily on our hearts. We relied on our families and on the expertise of our medical team. Cooper's airways were tiny and his breathing and eating were our first concerns. He has undergone several surgeries and procedures including one for craniosynostosis, and two different syndactyl surgeries. We are currently preparing for his next round of surgery on his fingers. These will help him be able to use his hands more functionally.

As Cooper grew, we were able to work with a team of Early Childhood professionals to help him with his physical and cognitive needs. Weekly therapy sessions and lots of practice helped Cooper learn the things that most kids take for granted. At three years old, you wouldn't know how much progress he has made because he is thriving despite the obstacles he must face. Cooper loves to watch Ms. Rachel and play with his big sister, Rylee. He loves playing peekaboo and blowing kisses. He loves his cars, especially the school bus and his mischievous little grin will melt your heart. Cooper has truly changed our lives and watching him grow has been nothing short of miraculous. We have learned that blessings come in unexpected forms. The fear and uncertainty that once consumed us has slowly but surely been replaced by the certainty that God is using Cooper to bless our lives in unexplainable ways. This past June we had the opportunity to attend the Annual CCA Retreat. Meeting so many other people with similar

stories has been a true inspiration and an experience that we will never forget. Finding this community has not only provided us with so much support and encouragement, but also with the understanding that we are not in this alone. Each of the individuals we have met has touched our hearts and inspired us.

Throughout this experience my mother frequently reminded me of verse that has become truth in our lives. "I praise you because I am fearfully and wonderfully made; your works are wonderful, I know that full well," Psalm 139:14. Cooper is fearfully and wonderfully made, and we will continue to praise God for the blessing that he is in our lives.



# ccasupersib

## meet rylee

by Rylee Aro | Baltimore, MD

**m**y name is Rylee, and I am Cooper's big sister. I am nine years old and I am in the fourth grade. My favorite subject is Math and I like hanging out with my friends.



Some things I enjoy are playing with Legos and Barbies, swimming in the pool, camping with my family, dancing in my living room, having sleepovers with my friends and doing arts and crafts. Most of all, I love playing with my baby brother. I like to help him learn new things and to show him the ropes.

When I was little, I was born early and had to spend the first few months in the hospital. I had to have a few surgeries of my own, so I know how my baby brother feels when he has to do the tough stuff. I know it's hard for him, but I try my best to make him smile.

Recently, I attended the CCA Retreat in Bellevue, Washington and had a blast! I loved making new friends and attending different events. Bellevue was really far away but I made a lot of great memories. It was cool to be able to meet so many new people and be a part of all the fun! 🎉



# meck invitational 2025 raises \$215,000 for cca

On September 10th and 11th, the Mecklenburg family hosted the 14th Annual Meck Invitational benefitting the Children's Craniofacial Association. There were 47 golfers from across the country and one international participant. Several others attended dinners and participated in a significant way. We are so grateful for our committed friends and neighbors who joined us for this two-day event, that continues to raise the bar each year.

We were especially honored to have three incredible speakers at the event. Vanessa Acero and Lia Burton did an incredible job of representing the CCA community and its impact on their lives. Several participants commented on how wonderful it was to hear from Lia who is an accomplished young woman who grew up in the CCA family. Lia shared how her mentors positively influenced her life and gave her the confidence to pursue a career in the entertainment industry, including being nominated for a Daytime Emmy Award for Outstanding Art Direction and winning Art Directors Guild Award for Everything Everywhere All At Once.

We also had the honor of hearing from Dr. Erin Wolfe, who is in the final years of her medical residency with a focus on craniofacial surgery. Dr. Erin Wolfe is the daughter of Dr. Anthony Wolfe, who was one of the true pioneers in the craniofacial

surgical field. Her stories of her father's journey and her journey were both moving and remarkable.

Dan Beaudette and Glenn Sudol were the low medalists and our 2025 champions. There was a tie for the runner up honors with the team of Miles Anderson and Jason Jones and The Fairgrove Property Management team. Colleen Hart captured the Ladies Championship. Several teams got into Bill Mecklenburg's wallet by beating him in the Greg Bonnell Memorial Challenge which generated an additional \$1,000 for CCA in Greg's memory.



## meck inviational , continued from page 16

The true champions of the tournament were our CCA Kids who inspired this small group of friends, corporate sponsors and auction participants to contribute over **\$215,000** to benefit the Children's Craniofacial Association. A special thank you goes out to our Sponsors:

### HOST SPONSORS:

- Bill Mecklenburg & Christine Condino-Mecklenburg

### PREMIER EVENT SPONSORS:

- Alliant Underwriting Solutions
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- Julian Shearer
- Christian Shearer
- Travelers
- Property Advisers Realty (PAR)

A special thank you is also deserved for **Shawn Craig** and **Holly Jaenichen** of Invited Clubs for providing incredible golf

experiences for the auction. **Coto de Caza Golf and Racquet Club** was the host venue and all out-of-town participants stayed at the **Balboa Bay Resort** in Newport Beach, California. Private dinners were held at **Hanna's Restaurant and Bar** in Rancho Santa Margarita and at **Coto de Caza**.

CCA and the Mecklenburg family would like to thank all of the volunteers, participants, contributors and auction item donors who made this a memorable and meaningful event. 🥂



Dr. Susarla shares Dani's progress during a recent visit.



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Dani, with Dr. Meikle and Dr. Susarla

## upcoming events

**MONTHLY AT 7:00PM CST**  
NOV. 5<sup>TH</sup>, DEC. 3<sup>RD</sup>  
VIRTUAL  
**CAREGIVER SUPPORT GROUP**



REGISTER: [HTTPS://QRCO.DE/CCACAREGIVERGROUP](https://qrc0.de/ccacaregivergroup)

**MONTHLY AT 7:30PM CST**  
NOV. 17<sup>TH</sup>, DEC. 22<sup>ND</sup>  
VIRTUAL  
**ADULTS AND ALUMN GROUP**



REGISTER: [HTTPS://QRCO.DE/CCAADULTS](https://qrc0.de/ccadults)

**MONTHLY AT 7:30PM CST**  
NOV. 18<sup>TH</sup>, DEC. 16<sup>TH</sup>  
VIRTUAL  
**SIBLING SUPPORT GROUP**



REGISTER: [HTTPS://QRCO.DE/CCASIBLINGGROUP](https://qrc0.de/ccasiblinggroup)

**OCTOBER 25TH AT 8:00AM CST**  
DALLAS, TX

### MICROTIA ARTESIA CONFERENCE WITH DR. TAHIRI

THE CONFERENCE IS FOR CHILDREN AND ADULTS AFFECTED WITH MICROTIA ATRESIA. THIS EXCLUSIVE EVENT IS COMPLETELY COMPLIMENTARY AS PART OF DR. TAHIRI'S COMMITMENT TO SUPPORTING MICROTIA FAMILIES.

REGISTER: [TAHIRIPLASTICSURGERY.COM/DALLAS-MICROTIA-CONFERENCE/](https://tahiriplasticsurgery.com/dallas-microtia-conference/)

**DECEMBER 2ND**  
NATIONAL

### GIVING TUESDAY

[TINYURL.COM/CCAGIVINGTUESDAY2025](https://tinyurl.com/ccagivingtuesday2025)

**DECEMBER TBA**  
NORTH PARK CENTER | DALLAS, TX

**GINGERTOWN BENEFITING CCA**  
MORE INFO TO COME

**JUNE 26-28, 2026**  
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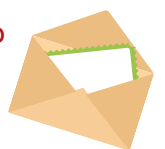
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# warriors

by Deb Breslow | Wycoff, NJ

Parents of children born with craniofacial conditions undergo a myriad of challenges. First, unless the child's condition is obvious at birth, they must endure the laborious process of finding a specialist



to correctly determine just what is wrong with their child's face. Second, once a correct diagnosis has been made, and this can be a lengthy process, particularly if the craniofacial condition is exacerbated by or coupled with other medical conditions, they need to be prepared to learn about the various methods of treatment (if there are any) for the condition. Then they need to ask if these treatments are curative, and if they're not, whether they are successful, successive, and how invasive they are. Third, if treatments are available, what type of specialist or specialists are best suited to perform them? Then the endless details: Is that specialist local or do they need to travel with their child to get to him or her? How many treatments or surgeries might be required to attain a reasonable result? Does insurance cover them, and if they're not medically necessary, are they considered cosmetic? Are there clinical trials available if the treatments or medications recommended are just too expensive? Are supportive outlets or trained professionals available and accessible to counsel parents who may be experiencing a range of emotions?

For many of us, much of the above (with variation) describes our journey in caring for our children. For the past 28 years, my husband and I have never stopped advocating for our son. From gathering clinical information to educate ourselves on his disease, to managing emergencies, to dealing with ignorant onlookers, to painstakingly negotiating with insurance companies to collaborating with various specialists and their office personnel to schedule testing, surgeries and follow-up appointments, to balancing our time and attention amongst our three boys, we've tried to stay strong and keep the lines of communication open with all who are involved in our son's care. We try hard not to

dive into maudlin self-pity or guilt, deflecting the unanswerable question we've likely all asked ourselves: "Could we have prevented this?"

Caring for a child with a craniofacial condition requires patience, empathy, resourcefulness, open-mindedness and grit. Doing it right all the time, being your best self all the time is a tall order. Overseeing the care of my son's facial anomaly has been THE most profound challenge of parenting. Thankfully, I've learned the value of caring for the caregiver.

In 2020, I found the missing link. It came in the form of support, camaraderie, compassion, understanding and friendship freely offered by the **Foundation for Faces of Children Virtual Parent Support Group** affiliated with **Boston Children's Hospital**. On the second Tuesday of each month, I open my heart to sharing my deepest fears and worries, my traumatic memories and vulnerabilities, my steadfast commitment to persevering. I share feelings I've bottled up for years with other parents who wear my shoes; parents whose experiences with their children may differ from mine, but who know inherently what it's like to be the parent of a child with a facial difference. What binds us is knowing, above all else, what it's like to be thinking about and caring for the physical and emotional well-being of that child 24/7.

I look forward to our monthly Zoom meeting and consider these strong, insightful, generous, smart, funny, kindhearted women, many of whom I've never met, to be my closest allies and beacons of hope. We call ourselves warriors because we work hard to raise our kids to be

confident, secure and comfortable in their skin. We count on each other to bring us up when we're down, to share in the good and the bad, to offer comfort during an hours-long surgery and breathe a collective sigh of relief when it's over. We care about each other as much as we care about each of our kids.

Last year, I nominated our group's facilitator, who is also the mother of a daughter with a craniofacial condition, a volunteer and a FFC board member, **Monir Sakha**, for **CCA's David Roche Award for Excellence in Advocacy**. She was shocked and humbled by my nomination. People who give unconditionally and selflessly often don't recognize the enormity of their impact on others. That's what organizations like the **Children's Craniofacial Association** aim to do — to support those who need guidance, education, funding, summer retreats and programming without expectation of anything in return. They, like the **Foundation for Faces of Children** in Boston, and countless other craniofacial support organizations throughout the world, are committed to paying it forward — giving back generously to insure that kids with facial differences and the parents who raise them have the tools to thrive in all aspects of their lives. By contributing to this issue of the **CCAKids Newsletter**, I hope that in some small way, I am paying it forward to a parent who may be struggling. Perhaps that parent will feel the load he or she carries is that much lighter because someone across the country is wearing his proverbial shoes.

I know I can't wave a magic wand and wish away my child's craniofacial condition, but I can make the effort to seek the support I need and deserve to manage his care with skill, confidence, gumption and grace.



# craniofacial acceptance month gatherings 2025

by Annie Reeves,  
CCA's Program Director

September marked the 21st year that CCA observed Craniofacial Acceptance Month (CAM), and we are so proud to continue this important tradition. Each year, CAM brings our community together to share stories of inspiration, raise awareness, advocate, and celebrate the power of acceptance. This year's theme, **Celebrate Our Differences**, we encouraged our community to take the opportunity to reflect, appreciate, and celebrate our own uniqueness and those differences we see in others.

Throughout the month, families gathered together, shared stories in their classrooms, advocated online and on social media, and made the important effort to keep the bonds of this special community strong. We also participated in outreach efforts, educating the public about facial differences. This year we broke a record and had **34 states** officially proclaim September as Craniofacial Acceptance Month. Many of you assisted with serving as local sponsors for the proclamations and that helped us make huge strides across the country. Thank you all for helping CCA blanket the country in awareness!

September also marked the 18th year of National CAM Picnics.

This year, we were excited to welcome new locations, giving families the opportunity to connect in person, share stories, and celebrate in a spirit of togetherness. We had picnics in Colorado, New England, Michigan, Mississippi Gulf Coast, the Carolinas, Dallas and Houston, Texas, hosted by: Courtney Vysocky, Kara Jackman, Kellie Dowd, Casey Deakins, and Jesanne Roden-Reynolds.

Hospitals, nonprofits, and organizations also joined us in celebrating CAM, amplifying our message of acceptance and awareness, which CCA got to participate in California and Tennessee, sharing CCA's message of acceptance and celebration with new friends and familiar collaborators. We want to extend a very special thank you to ConnectMed International and Monroe Carell Jr. Children's Hospital at Vanderbilt for inviting us to be a part of your family events.

A particular delight was getting to meet the puppies of Cleft Rescue Unit at the Monroe Carell Jr. Children's Hospital at

Vanderbilt Family Fun Day at the Nashville Zoo. Cleft Rescue Unit (CRU) is a volunteer nonprofit rescue for neonatal puppies with cleft palates and medical needs, and part of their mission is connecting children with facial differences with these adorable, lovable puppies. Stay tuned to find out how CRU and CCA will work together in the future, bringing wet noses and warm bellies to our CCA families to snuggle!

Craniofacial Acceptance Month would not be possible without the



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## cam gatherings , continued from page 20

dedication of our families, friends, and partners. We are deeply grateful to everyone who hosted fundraisers, events, donated, and supported CCA in other ways. A very special thanks goes to our Outreach Director, Khadija Moten, who designed this year's CAM materials and brought the theme to life for us to share across social media. We also extend heartfelt appreciation to the many individuals and organizations who helped make this year such a success, including Children's Hospital Dallas, Shriners Children's Texas, Texas Children's Hospital, University of Mississippi Medical Center, DFW Avengers, DN, DJ Joe Mir, Balloon

Artist: Ron Shover, Spring Creek BBQ, and so many more.

Though September has ended, our mission continues all year long. Together, we will keep spreading the message of acceptance, awareness, and love—because every difference deserves to be celebrated. 🌈

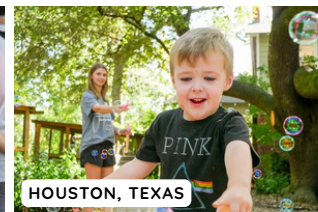
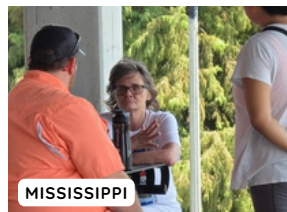


Photo Credit: Jessica Mills Photography



## gerry's cca legacy

by *Tonya Fischer & Family | Elizabeth, CO*  
forward by *Christine Andler, CCA's Director of Development*

Since I began working with CCA in 2018, one donor's loyal monthly donation has stuck with me -Mrs. Geraldine (Gerry) Brill. It was a check that I knew came monthly and she was a long-time loyal donor... Unfortunately, I did not get to speak to her in-person other than through my thank notes and her monthly checks. I always felt comfort in seeing her donations knowing our work was supported continuously. Once Gerry moved into assisted living, her daughter caught up with us and recently, we received a formal notice of a really incredible Bequest gift she has designated in our honor. The total legacy gift came to about **\$30,000!** I was able to speak to Gerry's daughter, **Tonya**, and she gave me more insight on her loyal giving to us all these years. It has meant so much to know Gerry's reason why. I hope we continue to move the needle with donors to feel our appreciation when they support us each month and with their legacy.

being such a bright spot to our organization and we truly will honor Gerry through her thoughtful gift and support of our kids and programs.

**"We are grateful that we found your organization to donate to. The story about our family and finding your organization started after my twin brother,**

**Tobyn (Tob), passed away in 2014. Tob was born with treacher Collins syndrome and he had many surgeries earlier in life, and all were very successful! He worked for AT&T and Alcatel Lucent in financial accounting where he had a successful career until his passing.**



**We found your organization through my daughter-in-law, Chelsey Fischer, who is pictured here. She helped to identify a charity to celebrate Tob's memorial at**



**his service. As time went on, my mother, Gerry Brill, continued monthly donations till she went in to a nursing home in 2022. From there, I continued her gifts for her till her passing earlier this year.**

**I believe if your organization had been around in 1961 when Tob was born and my parents would have been able to "google" it back then they would have loved being a part of the CCA community. We thank the Lord for our close Christian family, and wish the best for your organization and all you come in contact with."**

**- Tonya Fischer 🌈**

Thank you to the Brill Family for

# David Roche Award of Excellence in Advocacy

by Adele Capitella-Liu, 2025 David Roche Award Recipient | New Smyrna Beach, FL



by Khadija Moten, CCA's Outreach Director

On September 29, 2025, the Children's Craniofacial Association (CCA) presented the David Roche Award for Excellence in Advocacy for the fourth time. The award is named in honor of David Roche, C.M., a lifelong advocate for people with facial differences and a mentor to the CCA staff. This award is given to an individual who has gone above and beyond to advance the status of people with facial differences, promote acceptance and appreciation of appearance diversity, and challenge the stigma that surrounds physical differences.

We met as a committee to read through the beautiful nominations of people advocating in their communities and across the globe. It was a difficult decision, but ultimately the committee voted unanimously to award Adele Capitella-Liu as the recipient of the 2025 David Roche Award of Excellence in Advocacy.



Rejection is a catalyst; it moves us to new levels of understanding the human heart. For all the times I've endured unkind rejection in one form or another, I promised myself all the pain encountered would be turned into something positive and productive. What do I do with the pain of rejection that broke my heart into a million pieces? First and foremost, I was to forgive those who hurt me. Practicing forgiveness opens the heart and lessens the endless power struggle; it allows you to step forward towards healing. Through trauma and trials, I learned to push my way up back towards the surface, regroup and carry-on with everyday life challenges. The thing with having a facial difference is that you anticipate new traumas and new situations that will test your patience. So, what else should I do to overcome my uncomfortable reality? I needed something to fulfill a longing. With all the overthinking, self-blame, self-sabotage and blaming the physical difference for all the unnecessary hardship, it occurred to me what was missing was a community to share unique experiences within the facial difference realm. Literally, changing the course of my life and filling the emptiness with power and promise for better days for our beloved members of this community. I wanted to transform lives and link people who can relate and identify with one another. I wanted to create a community of persons who understand the meaning of having a facial difference in a beauty centered world. We too are beautiful with our support, kindness, and goodness we have for each other. So, my creative light established a place on Facebook where persons with facial differences can uphold one another in their sorrows and more importantly in their joy!

In this spirit, I created an all-inclusive community of persons with facial differences. For the longest

time we supported a total of 5 members. With steadfast persistence and determination, the group remained until others discovered this group to belong to. Slowly, slowly we began to thrive. Many members in the group were ready and willing to share their story. We were listening and giving support. We acknowledged their experiences, gave space that was safe and sacred. We validated and never judged. We gave confirmation to deeply moving stories. Many times, members within the group are seeking solutions for complicated issues that only our members who can understand unusual dilemmas. We were growing, transforming, pushing the boundaries, enclosing in on something special. We began to discuss relevant issues that were specific to our community. We grapple with discussions on mental health, conquering chronic isolation and loneliness, breaking the long-held stigma of what is expected of a person with a facial difference and changing how we are perceived, discussion on the language used to describe us, especially in the medical world, and how that language can be harmful to our people. We moved away from the pressure to "medically fix us" to acceptance of who we are. Conversations of how we are portrayed in the media and how it lessens our value and how we are often defined as villainous characters. More importantly, how will we address these issues beyond our closed discussions. Here we are lifting the veil of ignorance, we want the world to see our humanity.

The facial difference community has found its voice, and we are no longer on the sidelines. I am in true awe of the younger members who are fierce and vocal. The adults gather to offer support, give encouragement and we hold a place to share our lived experiences with the younger generation. I myself am a late bloomer, many of us grew up

## david roche award, continued from pg 22

a world where we kept our heart aches bottled up with the ferocity of a lion, not allowing anyone into our very private world. It was a generational thing. We were uncomplaining, tight-lipped, incidentally courageous and brave.

Last year, a long-held dream was realized by hosting an all-adult weekend retreat. We gathered together to break bread and embrace one another in a common bond that only few can share. For the first time this year, I had to accept the word disability as it relates to me. Having a facial difference is a disability. Hard pill to swallow. It was difficult for me as I lived my life by example. It took me a while to understand that this is a social disability. How members are at times treated less than, including me. I've always tried to forge ahead in a tough world. But I have to remember I am tough too, I'm a kid from Brooklyn, NY.



At keeping with the idea of belonging, inclusion and service to others, each of us need to be held accountable to one another - we have a moral obligation to uplift and assist when we can and never forget who we lovingly are. As each of us blaze through the cosmos, remember the power you hold in your existence and truth.

heart of our stories is this longing, a desire and a deep yearning to be loved. To be loved is deeply human and the threshold to our very existence. This love experience sometimes misses the members of the facial difference community. It challenges our mental health, our well-being and the very ordinary need to belong to someone who is gentle, kind, understanding. Yearning for a hug of affection. This is at the core of our struggles. To know when your heart grieves, and someone is there to cushion the heartache. I want to express my deep love to all of you. I see you, I hear you, and I love you beyond measure.

In conclusion, taking the painful rejection to form a reality of forgiveness, love, understanding and acceptance. We embrace this community with its strong voice that tells the world we are here. We are part of this intricate fabric we call life. 🌈

# 3 cheers for interns!



We are so grateful for the amazing support we received this past summer from our intern, Kate Doise, from the Ursuline Academy of Dallas.

She worked closely with Christine, CCA's Director of Development. During her time she assisted with organizing and recording donor files and requesting in-kind donations from businesses for future fundraising events. Thank you Kate, we are so grateful! 🌈

Dear Christine and all of CCA,

I just wanted to reach out one last time this summer and give you all a very warm thank you for everything that I learned and got to do with you all. Working with you guys taught me how rigorous it is to run a nonprofit and all the work that goes on behind the scenes. I'm so grateful for my experience at CCA and I hope that I was able to help you guys with your upcoming events! 🌈

- Kate Doise  
CCA Summer Intern  
Ursuline Academy Dallas

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-Erica, 41

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