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celebrating 35 YEARS 1989 – 2024

newsletter of children's craniofacial association

2024: ISSUE 2

inside

Left to Right: **Erin, Rivet, and Alesia**

meet the coys

by Erin Coy

i'm not sure when I first clued into the fact that I was different. Of course, it was many, many years later when I started to think about what those differences meant to me as a person and the impacts they've had on my life. I must have known there was something different in elementary school because I distinctly remember the pang of awkwardness every time a classmate would point at my ears and ask, 'What's that? My grandma/grandpa has those.' It offended my childhood sensibilities every time I was compared with old people just because I wore hearing aids. As an adult, I can see now that grandparents were often other kids' only reference point when it came to wearing hearing aids, and to see them out of that context on another child piqued their curiosity and was the most accessible way to learn. We all have to start somewhere, whether in a hospital room, a parent's lap or in a classroom. These revelations often mark journeys defined by

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max abel climbs to new heights

by Kara Jackman,
CCA's Adult Programs Coordinator

From wakeboarding and swimming with sharks to scaling African mountains, **Max Abel** has done it all. Max summited **Kilimanjaro** via the northern circuit with his family this summer. His father, **Jeffrey**, mother, **Beth**, and twin brother, **Carter,** made the ascent in July 2024. The Abel family are adventurous travelers with destinations like **South Africa, Cuba,** and **Zimbabwe** stamped in their passports.

Max and his family did not need a destination to prove their dedication and strength. Max and Carter were born in 2005. Max was born with Apert syndrome. His parents waited four days for a diagnosis from doctors. Soon after the Abels transferred Max's care to the craniofacial team headed by

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challenges and resilience for those who must walk this path.

To hear my mom tell it, she and my dad were clued in about 30 minutes after I was born on a Wednesday in 1997 by the neonatal specialist. They had whisked me away for all the usual tests and came back shortly to tell them that I had Treacher Collins syndrome (TCS).

Like most people, they had never heard of it and were quickly informed of the highlights: it's a condition that affects the growth and formation of craniofacial bones and is found in an estimated one in 50,000 people, which is to say, rare. Upon hearing that TCS can vary widely in severity and therefore need for surgical intervention, and present as cleft lips/palates, hearing loss, breathing issues, feeding issues, and visible facial differences, my mom began to cry. My dad, on the other hand, resolved that this diagnosis should change nothing. After all, the specialist also said that the physical impacts could be major, but people with TCS usually have normal intelligence.

Armed with a new baby and many, many informational leaflets, my parents went home and proceeded with the normal life of parents to a newborn. The information packets and doctors' notes were filled with the latest and greatest advice of 1997, some of which has definitely changed, some of which has remained the same. Mixed in with the deluge of medical information, were resources for parents of kids with TCS and other craniofacial issues. My parents never availed themselves of community support and our involvement with CCA would only come after I was an adult. Not getting involved and leaning on other parents with similar circumstances is something that my mom now regrets, along with a lack of family counseling. This theme of independence and self-reliance has echoed continually throughout my life.

Aside from their research, my early days and months were largely the same as any other newborn born without genetic abnormalities. Days were filled with desperate attempts to find sleep, accidental incidents like setting fire to baby bottles left on the stove due to aforementioned sleep deprivation, and trying to manage the normal demands of daily life. Three months after I was born, I was sleeping in the kitchen while my parents dried dishes when my mom dropped a metal lid to a cooking pot on the tile floor. Like most parents, they immediately turned to look at me, expecting crying. Instead, they saw me still sleeping undisturbed. The next day they called **Texas Children's Hospital in Houston** and asked for an appointment and a hearing test. Sure enough, I had moderate hearing loss and would need corrective action. After that, there was a flurry of appointments and tests. The doctors determined I had a fairly mild case of TCS but would likely need hearing aids in both ears, extensive orthodontia, and surgery once I had stopped growing.

I was given hearing aids but otherwise had very typical early years, aside from the occasional speech therapy appointment. My parents were resolute that I have a normal childhood in every way possible, despite the odds and expectations. As my parents enrolled me in public school, the school insisted that I needed special education. They justified their insistence for special education as accommodations for my loss of hearing, which, on the surface seems reasonable, but in truth, they had no idea of what TCS entailed and thought I would not be able to meet their state-mandated performance criteria. They saw that my face looked different and that I

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needed hearing aids and assumed I was like other children with developmental delays, despite being able to read, speak, and otherwise do the same things as other children my age.

Teachers were reluctant to have me in their classroom until they got to know me because they didn't know what to expect and didn't know how to classify me. My parents' efforts to explain that my genetic disorder was physical and had no effect on my cognitive abilities, while backed by numerous doctors' notes and presented research, had limited effects. For four years, my parents met with my teachers, special education staff, school therapists, and administrators to discuss my progress, despite consistently outperforming the rest of my class. While special education often provides better opportunities for people with various disabilities, the separation of children based on visible differences, without an understanding of that difference can be highly damaging.

Outside of school, I took dance classes, swam on my neighborhood swim team, and went camping with my dad. I knew I wore hearing aids and that other kids didn't but I didn't feel any different. This was challenged somewhat when I was diagnosed with sleep apnea. During one camping trip, my dad, listening to me breathe as I slept, noticed that I would stop breathing and then, after a couple of missed beats, gasp for air. Understandably, this scared him. So, in I went for a miserable night's sleep, otherwise called a sleep test, and came out with a large box capable of transforming me into a tubed, earthbound astronaut at bedtime. No amount of imagination unfortunately could spare me from the awkwardness of showing up to a sleepover with a noisy CPAP machine. While it did dampen my enthusiasm for attending sleepovers a bit, steadfast friends and parental insistence ensured I still enjoyed those formative experiences and developed a healthy resilience in explaining my various medical apparatuses.

Eventually, I grew out of needing a CPAP and into needing orthodontia which I had for about 7 years. Unlike every other accommodation in my life, orthodontic treatment felt normal and, at first, even kinda cool. Many kids in my middle school had braces and retainers, so for the first time, I didn't have to explain anything. Because of that, I never once considered my braces as a corrective action for TCS's effects. **Reflecting on it now, it demonstrates the power of community and the influence of visibility.** Instead of having to explain what my hearing aids were and giving my standard spiel that hearing aids are like glasses for the ears (corny but effective, especially with those with a sense of humor), I didn't have to explain anything and could relate to those around me. Braces and retainers were familiar to everyone, even if they didn't wear them themselves due to their prevalence. Someone noticing the colors of my braces was far less awkward for me than someone noticing my hearing aid making noise. For a long time, I thought very little of my differences. Because I've been wearing hearing aids since before I can remember, the part of TCS that impacted me most felt commonplace only drawing attention when malfunctioning or brought up by others. However, my perspective shifted upon entering college. A looming jaw reconstruction surgery my freshman year, and the encouragement to think deeply and critically that came with being in the **University of Houston Honors College (UH),** I started to think about what having TCS meant to me. Certainly, I had done well to go through my childhood social, studious, and hard working. Mainstream education did wonders for my ability to approach life with a "stick with it" attitude, preparing me for conventional adulthood where questions about my hearing aids still occasionally arise, and knowledge of TCS remains scarce. My parents' emphasis on overcoming obstacles likely fostered my deep connection to music, cultivated through a decade of participation in orchestra and choir. Yet, this resilience did not shield me from adolescent insecurities. Despite parental reassurances, the teenage years wrought their inevitable self-doubts. At eighteen, discussions with surgeons regarding my

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appearance, pre-, and post-surgery, resurfaced lingering insecurities, long suppressed and unaddressed. The fifteen-minute drive to **Texas Children's Hospital** from **UH** marked a pivotal shift. Throughout my first semester in college, these brief journeys were a physical transition from isolation as the sole person with TCS (to my knowledge) a community where discussions on appearance anomalies were met with normalcy. I wasn't the one doing the explaining and I didn't need to. I was learning the first time, as an adult, about this thing I had lived with my entire life and seeing pictures of other people, albeit usually at least a decade younger, who looked like me. I had no idea that TCS was the reason I had almost no lower lashes, a minor and persistent insecurity. After that surgery and its subsequent one my sophomore year, I found that I suddenly felt better about my appearance but only partially due to the physical changes.

Sure, I was twenty and for the first time in my life, was pretty well aligned with the US standard of beauty but there are still obvious signs of TCS if you know what to look for. My surgeries didn't give me more lower lashes, but knowing why my face is the way it is has largely released any anxieties I used to feel about the features.

This time also coincided with attending a CCA Retreat and transferring to **George Washington University** in Washington, DC to pursue a degree in International Affairs. While there were the typical challenges of adjusting to a new environment where I didn't know anyone, I suddenly found that the lifelong subconscious anxiety about being judged based on my hearing aids or appearance had vanished. The people I was meeting had no idea what I used to look like and often didn't notice my hearing aids until months later.

I recognize that this experience is a privilege not accessible to everyone, and I am both grateful for it and deeply reflective. In my junior year, I took an anthropology class and wrote a research paper on stigma and visible congenital differences. This exploration prompted me to think more deeply on my own experiences within the context of a broader community. Individuals with facial differences, though not necessarily functionally impaired, often face societal stigma due to their appearance, influenced by prevailing beauty standards and interpersonal communication norms. This emphasis on facial aesthetics can overshadow other aspects of identity. As children, we are taught to look someone in the face or in the eyes, and to never stare at anything we find as different, yet those of us with craniofacial differences are keenly aware that our appearance sets us apart. This awareness is compounded when others avoid acknowledging our differences, inadvertently denying us respect and reinforcing a message of concealment.

People with visible craniofacial differences and impairments due to congenital disorders are often stigmatized, devalued, and separated from others. I'm lucky to have been spared from the worst of that. The development of spaces and communities where those with craniofacial abnormalities and disabilities find positive development of self-image and reduced stigma is increasingly common, something that I'm glad to see. Perhaps even more powerful for me was the reclaiming of identity, but still, **community remains the best combatant for stigma.** The world is a scary place for kids who look different but is easier to navigate together.

Be kind and courageous!

North Carolina CAM Picnic

Michigan CAM Picnic

Colorado CAM Picnic

Texas (Dallas) CAM Picnic
Photo Credit: Jessica Mills Photography
(www.jessicamillsphotography.com)

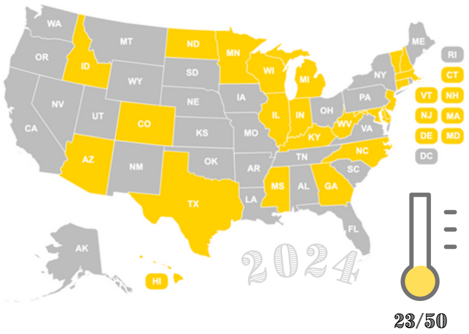
Utah CAM Picnic

craniofacial acceptance month: sept 2024

by Annie Reeves, CCA's Program Director

Craniofacial Acceptance Month (CAM) has come and gone but CCA will continue to spread the message of Acceptance and Awareness all year long! September is always such a fun-filled month full of stories of inspiration, advocating, virtual events, education, fundraisers and camaraderie. Thank you to everyone for participating! We would like to thank everyone who held a CAM Funder, participated in one of our fundraisers, logged 35 miles for 35 years or held any other type of fundraising event! Without you, none of this would be possible. And lastly, a huge thanks goes out to our Outreach Director, **Khadija Moten**, for designing all our CAM materials!

This year marked the 20th year that CCA has observed September as Craniofacial Acceptance Month. Our CAM theme was "Stronger Together." During Craniofacial Acceptance Month, CCA challenged everyone to help champion awareness as we celebrated not only our 20th year of CAM but also 35 years as an organization! We are especially proud to be "Stronger Together," built on our foundation of 35 years of serving craniofacial patients and their families. As we commemorate 35 years of service, we chose this theme because our work is done with our community as the leaders of the facial difference acceptance movement. We continued hosting our CCAVirtual programming including a Virtual Group Photo and 23 states proclaiming September as CAM. We would love to see this number increase next year and will be enlisting your help! Many states now require local families to sponsor the proclamations.



If you are interested in helping with this process, please email our Outreach Director, Khadija Moten – kmoten@ccakids.com, and you can help get that number back up to a new record in 2025.

For the 17th year, CCA held **National Picnic Day in September**. It was so nice to see everyone gathering during CAM! We even had some new locations added this year. Numerous organizations and hospitals also celebrated CAM along with us! Thank you for your continued support! We would like to thank EVERYONE who participated and send a special thank you to the following:

- **Carmen Burleigh**
- **Casey Deakins**
- **CCD Smiles**
- **Cook Children's Hospital Ft. Worth**
- **C.S. Mott Children's Hospital**
- **Kellie Dowd and Family**
- **Angela Eyer**
- **Kara Jackman**
- **Lisa Bowers**
- **Carol Ardelean**
- **DJ Joe Mir**
- **Jesanne Roden-Reynolds**
- **Ron Shover, Balloon Artist**
- **Paul Quinn and the following students from the Biomed Academy at RL Turner High School: Karishma Pilla, Addison Derrick, Anika Yalamanchili, Chelsea Major, Jaylen Jackson, Sofia Cabrera, Nawal Zafar, Mario Calzonzin, Janely Galindez, Melanie Gonsalez Lopez, Gabriela Melendez Cruz, and Aldrin Jobi**
- **Shriners Children's Texas**
- **Spring Creek Barbeque**
- **Texas Children's Hospital**
- **Utah Smiles Foundation**
- **Courtney Vysocky**
- **Jessica Mills Photography**
- **Shannon Reicherts, Photographer**
- **Those who fundraised and donated to CCA through Facebook Funders**


North Carolina CAM Picnic

We couldn't have done this without all of you. Our hearts are truly full and we thank you!

Big Hugs,
Annie Reeves
CCA's Program Director


Texas (Dallas) CAM Picnic
Photo Credit: Jessica Mills Photography
(www.jessicamillsphotography.com)


Texas (Houston) CAM Picnic


Texas (Houston) CAM Picnic

max abel climbs to new heights , continued from the cover

Dr. Fearon at **Medical City Children's Hospital in Dallas.** Max had 14 major surgeries including a Lefort I and Lefort III, multiple cranial vaults, and many minor surgeries along the way.

The Abel family may have climbed a medical Mount Everest, but they were not done yet. Jeffrey wanted to see if Max could accomplish something during his senior trip that Max could look back on and be proud of. Something - some achievement - that proved nothing could hold him back when he reflected upon it. So despite Beth's disdain for camping, and not showering, the family decided to travel to the border of Tanzania and Kenya to climb the northern circuit of Mount Kilimanjaro over nine days in July. Jeffrey says of his wife's commitment, **"She understood that it was important for Max to look back on this experience and know that because he was able to summit Kilimanjaro, that he could do anything."** Kilimanjaro is the tallest free-standing mountain in the world standing proudly at 19,341 feet above sea level. For scale, the tallest mountain in the Rocky Mountain range located in the U.S. is 14,500 feet above sea level. Jeffrey knew his son was capable of the climb because Max had repelled off Table Mountain and swam with sharks while in South Africa.

Max did not have extensive hiking experience, but he did enjoy participating in hapkido, water surfing, wakeboarding, and water skiing. In spite of his lack of experience, and only being able to breathe out of one nostril, Max stayed ahead of the family on the final day of the climb by approximately 15 to 20 minutes. The family climbed with eight other people, and were assisted by 50 guides and porters. Jeffrey said, "these guides were essential to Max's success and they stood by to make sure he did it on his own." Max made fast friends with the other adults and even swapped phone numbers with some of them.

Climbing Mount Kilimanjaro was not only special to Max, but also to his parents. Jeffrey said, "Seeing him summit really gave me comfort and strength that when I drop him off at college, he can do it with no problem." Max began his freshman year at the **University of Denver** this August after being accepted to 11 colleges and universities. He will pursue a creative calling like his parents with schooling in digital practices. All of Max's achievements remind us, as his father puts it, that we can **"achieve difficult goals, and also inspire parents to allow their children to reach for the stars" because the sky is truly the limit…**And Max was blessed enough to touch it with his family by his side if just for one brief, shining moment.

ccaadult

meet linda

hi my name is **Linda Flores Alcantara** and I'm 32 years old. I am the youngest of two siblings. I have an older brother and an older sister. I was born July 19, 1991 in the beautiful city of San Francisco, California. I was born with Apert syndrome. When I was born, the doctors told my mom that I wasn't going to be able to talk or walk.

BUT thankfully, my mom made me learn to walk with the help of an aunt that lived in Mexico. My aunt gave her the idea of cutting thin blankets round my hips. My mom and my older sister would wrap sheets of thin blankets around my waist to help me walk. The social worker told my mom and sister they should ask where we could get speech therapy for me to talk. As I grew up, I learned that I shouldn't give up. That phrase doesn't exist in my head. Thanks to my mom and sister, and with the help of the therapist, they taught me how to talk. I would point to the object and they would say "Oh do you want juice?", "Can you say juice?" and I would repeat it. I had my first surgery a few days after I was born. I now have had about 22 surgeries and counting.

From preschool to high school, I was in special day classes. At the age of 20, my mom suggested I should go to college for early childhood education. By 27, I graduated with an associates degree in early childhood education. I learned to take the bus to school. I got my first job in the same district where I did my hours for college. And a year later, a principal from the same school asked me if I would be interested in working as a teacher assistant for special day classes. I'm still working with them! Some students get attached to me because I have the love and patience for them. One of the parents saw that I had so much care for her son and asked if I could take care of him when she needed me. Besides going to work, in my free time, I love going dancing with my friends and going shopping. The states I have visited include Minnesota, that's where my cousins live. I have moved to Tennessee two times. And I travel to Arkansas where my sister lives.

3cheers for volunteers! and interns

by Khadija Moten, CCA's Outreach Director

We are so grateful for the amazing support we received this past summer from our interns and volunteers! It was filled with so many helping hands! Thank you to all our interns and volunteers for their kindness and generosity in sharing their time, skill, and heart with us. Your efforts make a long lasting impact to the CCA community!

In the office, we had college intern, **Mackenzie Grant**, who worked closely with the Outreach Department by assembling educator materials for schools, creating graphics for social media, reaching out to volunteers to assist at our Annual Retreat, prepping and organizing Retreat resources, writing proclamations to governors in honor of Craniofacial Acceptance Month and so much more! **Thank you Mackenzie!** Also in office, we had two high school interns from the **Ursuline Academy of Dallas**: **Saira Francis** and **Michelle Rodriguez**. They both worked closely with **Christine**, CCA's Director of Development, on organizing and recording donor files and requesting in-kind donations from businesses for future fundraising events. **Thank you Saira and Michelle, we are so grateful!**

Hi I'm Mackenzie or Mack Grant. I'm in college studying to be a speech pathologist. This summer I interned with CCA! Over the few months I was there, I focused on outreach. I helped set up supplies, volunteer photographers, and plans for the yearly Retreat. Every week I was greeted by the smiling faces of the CCA staff. It made coming in each time even more worth it. Reaching out to many families and individuals gave me a greater appreciation for what nonprofits and small groups can achieve. The most impactful project for me was reaching out to state governors to ask them to recognize September as Craniofacial Acceptance Month. The process showed me how much I have overlooked what impacts the lives of millions of people. Overall, the summer was a wonderful experience that taught me about how to help, regardless of experience and skill. Everyone, in and out of the office, worked with kindness and patience in a way I hadn't ever experienced before. Thank you for such a great internship!

- Mackenzie Grant, CCA Intern

Additionally we had one more in office high school volunteer: **Zoya Moten**. Zoya spearheaded a major organization revamp in our office! Thanks to her hard work, our storage room is now easily accessible and efficient, making our day-to-day in office operations smoother. **Thank you, Zoya, for your hard work and dedication!**

We are humbled by the many individuals who reach out virtually to offer their time, assistance, and skills for CCA's mission and purpose!

We would like to recognize our virtual volunteer, **Jeremy Dale**. Jeremy and his family have been long-time supporters and advocates for individuals with facial differences. Now, he's bringing his talents to CCA by helping with video editing and graphic design for our CCA Outreach series. We are so grateful for his assistance. **Thank you Jeremy!**

I'm a newer Volunteer, having edited two videos so far, but my degree in New Media has helped me a lot while working. Every year me and my mom go into local schools and beyond to speak about the book Wonder and the Importance of choosing kind. I enjoy the work I do and am always eager to help.

- Jeremy Dale, CCA Volunteer

● ●

I'm Saira Francis, a high school junior at Ursuline Academy of Dallas, TX, and this summer I interned with CCA. During my internship, I focused on tasks such as filing, recording checks in an online database, and soliciting donations. These tasks were new to me, so I developed many new and valuable skills and gained insight into the various roles within CCA. During my time with CCA, I also came to understand all the ways they help kids with facial differences, and the supportive and vast community they foster with the kids and their families! -Saira Francis, CCA Intern

My name is Michelle Rodriguez, and I am a current junior at Ursuline Academy of Dallas. This summer, I worked with CCA as a Development intern. I helped with an in-kind donation project by sending out emails to corporations asking for donations for our upcoming Meck Invitational Golf Tournament benefitting CCA Kids and PAR Premier Golf Tournament. I focused more on the Meck Invitational Golf Tournaments and sent over 1,400 emails to different wineries and hotels to gather donations. I learned a lot about the development world and am so grateful for this experience! I can't thank my mentor, Mrs. Andler, enough! -Michelle Rodriguez, CCA Intern

3 cheers for volunteers,

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As many of you may know from our previous newsletter and YouTube page, **Aaliyah Booker**, is our virtual CCA intern who leads the CCA Outreach Series. We thank her for her dedication in amplifying diverse voices through her CCA interviews by featuring various professions and passions. We are grateful for the impact she has made and excited to see how she continues her work with CCA and the broader facial difference community. Thank you Aaliyah!

BIO: Aaliyah is a facial difference + disability advocate. She is a recent graduate from Saint Peter's University in Jersey City, NJ, with a bachelors in biology aspiring to work in the medical field. Aaliyah's mission in life is to forever share her story in different aspects to inspire young kids & teens out there who physically look different that we are more than just our differences! She recently ran for Miss NJ USA beauty pageant by making history by being the first woman ever with a facial difference to perform. Aaliyah started her own business: "Born to Stand Out" that focuses on self love and acceptance. You can find her on all social media platforms celebrating her uniqueness!

Another virtual intern you may be familiar with from our Sibling's Panel on YouTube is **Abbey Merrill**. Abbey is the founder of **Sibling Strong** and has assisted in providing platforms and community for siblings of those with facial differences! Check out the Panel on our YouTube page!

Since winter 2023, I've been working as an intern with the CCA, where I focus on supporting siblings, or super sibs, of individuals with craniofacial differences. I've helped with various projects aimed at addressing the unique challenges super sibs face. I contributed to creating and distributing a survey to better understand the needs of this community, which informed several new initiatives. Additionally, I played a role in facilitating sibling support groups during CCA's Retreat, offering a space for super sibs to connect and share their experiences. In addition to my work with CCA, I lead my nonprofit, Sibling Strong, to empower and connect super sibs. We provide emotional and practical support to siblings navigating life alongside their siblings - Abbey Merrill, CCA Intern

Lastly, we are grateful to for our virtual intern, **Jaimik Patel**, from the **UT CONNECT Program**! The program seeks to activate learning from data and build both capacity and interest in greater data, measurement, and evaluation capacity within community organizations. Learn more about the program at: tinyurl.com/utconnectprogram .

Have you ever gotten one of these newsletters twice? Or maybe you missed one of our emails that you look forward to each month. Well, these are technology issues.

So, in an exciting collaboration, CCA worked with Jaimik Patel, UT Graduate Student in Information Sciences, to assist us with database cleanup and mailing list segmentation. Jaimik was able to deduplicate our mailing lists and generate reports for us to run - with better parameters - that will hopefully streamline and improve our mailing list process.

I'm Jaimik, an MSIS student at UT, and I had the amazing opportunity to be an intern with the Children's Craniofacial Association (CCA) through the CONNECT Fellowship. This summer, I dived into data management, cleaned up records, and worked on generating reports to help the team make informed decisions I also explored CRM systems to recommend the best fit for CCA. Working with Erica and the entire CCA team was a highlight for me. I'm incredibly grateful for the chance to contribute to such a meaningful cause and for the warm welcome I received. Thank you to everyone at CCA for making this experience so rewarding! - Jaimik Patel, CCA Intern

WE ASK YOU TO JOIN US IN GIVING THREE CHEERS FOR ALL OUR INCREDIBLE INTERNS AND VOLUNTEERS!

letter from the program director: retreat 2024

by Annie Reeves, CCA's Program Director

Get out your portable speaker, because Take Me Out to the Ball game, Motownphilly, We Are Family and Time of our Lives are just a few of the MANY songs that come to mind when I think of this year's Retreat! So many wonderful memories were made over the course of four days and we loved having our first Maryland-based Retreat.

The Retreat took place at the beautiful **Hyatt Regency Inner Harbor Hotel in Baltimore.** The hotel had so much to offer within walking distance and we loved knowing that many of our families were able to go out exploring together before the Retreat even started! We ended up having **139 families from 34 states attend as well as families from Canada and the United Kingdom. Of the 139 families, 17 of them were first-time attendees.**

The Retreat started on Thursday morning and I feel like I say this yearly, but I'm going to say it again: it's always so heartwarming to see the new families instantly bonding with families they have connected with through social media, those who haven't been in years seeing each other for the first time in a long time, hugs, laughter and so much love in one space. It's truly special to witness and hard to put into words.

Once again, this year we had professional speakers in the field of craniofacial research and medicine hold sessions for our families during the **16th Annual Educational Symposium**. We would like to thank the following speakers:

- **Kensi Saia, AuD, PhD** and **Grace Smith, AuD CCC-A** of **MED-EL**
- **Vanessa Acero, PsyD M.S.**
- **Stephanie Boblooch, MSW, LCSW-C & Liz Mull** of **GBMC**
- **Lisa Miller** of **MTF Biologics**

We would also like to thank our Keynote Speaker, **Evan Wolkenstein**, who is a high school teacher and the author of 'Turtle Boy,' which is a powerful young adult novel about hope and friendship. His session explored the way in which we can use our abilities as story tellers to understand and make sense out of our lives—building resilience in the face of adversity, and sometimes emerging as families of heroes. Evan also hosted a talk show during Retreat, featuring three of our teens: **Jasper Cox, Shane Vysocky** and **Abby McGowan.** Their stories were so relatable, funny, inspiring, and helped us all realize that we have what it takes to knock a few things off our "bucket list," even when we're scared to try. Evan brought his own story of living with a facial difference to our community, and it is incredible to see the diverse lives our community embodies.

A very special thank you also goes out to **Rita Albert, JD,** and **Julie**

Photo Credit: Matthew David of That Baltimore Photographer

Photo Credit: Olga Gurton of Olga Gurton Photography

Photo Credit: Olga Gurton of Olga Gurton Photography

Photo Credit: Eva Nicholas of Eva Nicholas Photography

letter from program director: retreat 2024

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Silva from **ConnectMed International**, who held a session for our CCA Kids and Teens; **Dani Doughty**, who we met at the **Moebius Syndrome Foundation Conference** in 2023, who held a session on “Adventure Is Out There: Navigating Travel with Kids with Disabilities,” **Cashel Gaffey, MSW**, for moderating our Parent Panel Discussion, and last but certainly not least, CCA family members **Aaliyah, Justyn & Julian Booker, Josey Daley, Paul, Carrie & Jack Greer, Jennifer Kilmer, Amy & Charlee McLaughlin, Hunter McMahan, Abbey Merrill, Anthony Seelig** and **Dominika Tamley.** We had a variety of topics covered that included hearing aid technologies, managing bullying, advocacy, parenting, and new technologies in costal cartilage, as well as a Siblings Panel and a Parent Panel.

A special thanks goes out to **Roseann Opdyke** and the **Opdyke Memorial Scholarship, Lindsay Condefer** and **The Lentil Bean Memorial Scholarship, SmileTrain, Children’s Hospital of Philadelphia (CHOP)** and **Diana Sweeney** from **Craniofacial Connection** for being scholarship sponsors.

Photo Credit: Matthew David of That Baltimore Photographer

And last but not least, a HUGE thanks goes out to all of our amazing families and friends who volunteered their time during the symposium, registration and Retreat: **Vanessa Acero, Rita & Angie Albert, Sharon Allbright, Lisa Bock, Aree, Gloria, Aaliyah, Justyn & Julian Booker, Josh Boucher & Allison Mitchell, Lisa Bowers, Martha Bradley, Cheryl Papciak-Brooks, Jerry & Joe Brooks, Diana & Megan Brown, Jessica Prince Bucholz, Chelsea Buyalos, Lindsay Condefer, Jason, Liz & Jasper Cox, Josey Daley, LaDarius Davis, Dani Doughty, Jeff & Whitney Dunn, Edward Edwards, Katie Favaloro, Marjorie Foxon, Cashel Gaffey, Paul, Carrie & Jack Greer, Olga Gurton, Justin Haddock, Tiffany Kerchner, Ed & Amy Kern, Jennifer Kilmer & Anthony Seelig, Sandy Klinger, Michelle, Anah & Ella Kryzanowski, Jono Lancaster, Matthew Mahlstedt, Janis Macut, Stacy McAllister, Abby McGowan, Amy & Charlee McLaughlin, Johnny, Jessica & Hunter McMahan, Abbey Merrill, Harlena Morton, Eva Nicholas, Roseann Opdyke & Shannon Sesa, Kevin & Erin Richmond, Jaci Samhammer, Mark & Laurel Sanborn, Rose Seitz, Julie Silva & Amy White, Dominika Tamley, Summer Thomas, Shaun, Courtney & Shane Vysocky, Albert & Connie Williams, Scott Williams & Ashley Jupp, Anne Zaengle and all of our raffle ticket sellers, those who helped during the raffle and everyone who brought raffle items/baskets.**

For the fifth year in a row, CCA held **“C.A.R.E” Counseling** which is a counseling opportunity that takes place during the Retreat. We would like to thank ConnectMed International and **Cashel Gaffey, MSW**, for offering this important service to our families.

Thursday night we all gathered as a group for the official Retreat Kick-off where families enjoyed a delicious dinner buffet while announcements and welcomes were being made. Following the announcements, we had a very entertaining and fun magic show, which was performed by **George Ripley of Ripley’s Magic**. He kept the crowd engaged and had quite

Photo Credit: Eva Nicholas of Eva Nicholas Photography

THANK YOU 2024 SPONSORS!

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letter from program director: retreat 2024

, continued from page 11

an audience sitting in front of the stage. He also had quite a few tricks up his sleeve, no pun intended!

Friday morning started with breakfast and a new addition to our Retreat: Interest Groups. We pulled in volunteers to host special interests group tables at breakfast so our families could meet people with similar interests.

Following this, the families gathered for Group Meet-Ups, which continues to be one of our most popular events of the Retreat. These groups give our families the opportunity to meet others and learn in a smaller group setting. This year we offered groups by syndrome and topics. Some of the group topics included "Journeys in Adoption," "Grandparents Are Great," "Dating with a Difference" and more!

Photo Credit: Eva Nicholas of Eva Nicholas Photography

Another new event we held this year was Baseball & Bingo! It was quite apparent to the audience that my "calling" skills were a bit … amateur. **Erica** and I gave it our best shot and we had a blast, along with some good laughs! Thankfully, there were plenty of bingo aficionados in the audience to keep us on track. We even had a special guest appearance by **The Bird** from **The Baltimore Orioles!** He greeted our families and took photos with everyone. It was a nice surprise! We had some amazing baseball themed baskets and prizes for the winners and would like to thank our donors who made those baskets such desirable prizes.

Friday is always capped off with Family Night. One component of Family Night is our Hometown Basket Raffle which is where our families from across the United States and beyond bring items or baskets of goodies from their local areas (or special interests) for CCA to raffle. These baskets always amaze me and get bigger and better year after year! Some of these baskets weighed 20 pounds this year! They blew us all away! Our families so generously donate these baskets and then buy raffle tickets to win them, which **raised $3,840 for next year's Retreat! Thank you all!**

Saturday morning started with breakfast and more Interest Groups which was followed by "THE Group Photo." It's a huge task and job to gather nearly 500 people for a group photo and this year we came up with a few extra steps to help ensure things went smoothly. The true hero of the group photo is our amazing volunteer photographer, **Eva Nicholas,** for getting so many amazing shots. A special "shout out" for **Samantha Saperstein** who got everyone's attention with her amazing auctioneer chops. Seeing everyone together in one spot is so powerful and heartwarming. Thank you all for being so understanding and patient and making this year's group photo the best and easiest it's ever been.

Back for another year, the

Back for another year, the amazing "CCA's Got Talent" Talent Show was a smash hit. We had a variety of performances this year which included singing, dancing, instru-mental performances, juggling, and more. You have to be brave and courageous to stand on a stage and perform in front of an audience and you all did such an incredible job. A huge thanks goes out to our fabulous and talented emcee, **Chelsea Buyalos** and her bows. She kept things on track, had perfect openers for each act, and kept us all laughing with her antics. Another huge thank you goes out to the sound and music extraordinaire, **Johnny McMahan,** who created the

Photo Credit: Eva Nicholas of Eva Nicholas Photography

Photo Credit: Eva Nicholas of Eva Nicholas Photography

Photo Credit: LaDarius Davis of A Capture in Time Photography

letter from program director: retreat 2024

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Photo Credit: Justin Haddock of JCH Images

Photo Credit: Eva Nicholas of Eva Nicholas Photography

playlist and made sure everything ran smoothly and sounded great. As always, he nailed it! A special thanks goes out to Johnny's kindhearted and hardworking wife, **Jessica**, for helping with the stage setup for each performer. We couldn't do it without you all! Saturday evening, everyone got dressed up for a night of food, fun and dancing! But, before the dancing kicked off, we presented a very special award, the **Scott Guzzo Mayorial Scholarship,** to a well-deserved recipient. Congratulations **Ashley Jupp,** the 2024 winner. Thank you for being an upstander within the craniofacial community. The Dinner/Dance, a signature event of the weekend, took place that Saturday evening. You know it's a fun time when the dance floor is packed and people are dancing at their tables as well!

Sunday morning always seems to show up in the blink of an eye. Bringing a box of tissues to breakfast is a must, because tears will be shed, hugs will be shared and the countdown to next year's Retreat begins in that moment. The bonds made at our Retreat are like nothing else. The goodbyes are never easy but knowing we will be reunited next year makes them a bit better. I always leave the Retreat with an overwhelming sense of peace and happiness. I have the best job on the planet, thanks to all of YOU! Thank you for making my life even better!

We look forward to seeing everyone next year in yet another new location for CCA: Bellevue, WA, June 26-29, 2025.

Annie Reeves
CCA's Program Director

Be sure to read about a first-time retreat attendee, Deana Ziev, and her family's experience on page 14

Photo Credit: LaDarius Davis of A Capture in Time Photography

We are so grateful to have had such talented photographers -- who volunteered their time and skills to capture memories for a life time! Thank you to the following: Eva Nicholas of Eva Nicholas Photography, LaDarius Davis of A Capture in Time Photography, Olga Gurton of Gurton Photography, Justin Haddock of JCH Images, Matthew Mahlstedt of That Baltimore Photographer and Marjorie Foxon!

chi omega christmas market

by Christine Andler, CCA's Director of Development

We're honored to be a beneficiary of this year's **Chi Omega Christmas Market** that took place on September 26-28, 2024 at the **Dallas Market Hall!** This market is in its 47th year and brings in thousands of people to shop and support DFW charities and small businesses. **This year marks our first year to receive this grant of $18,750 and will be used to extend outreach and provide assistance to more individuals and families in our community to attend our Annual Retreat in 2025 from the DFW area!** Together with Dallas-area Chi Omegas, we had a lovely time spreading joy and hope this holiday season!

first time retreat family

by Deana Ziev

The path that led me to the Children's Craniofacial Association began on November 16, 2016.

After a typical, complication free pregnancy I welcomed my second daughter, **Josephine (Joey)** into the world via cesarean section. My husband, **Matt**, and I were eager to expand our family, but no one was more excited than our first born, **Annabel**, who was five years old when her baby sister arrived.

Following delivery, the doctor pulled Matt aside while my surgery was finishing up, and told him that he could see there was a difference with her ear. When I was brought to recovery, Matt relayed the information told to him by the doctors.

I held my sweet girl for the first time, she is my "rainbow" baby, and I had waited for what felt like forever to have a second child. I took off her hat, touched her ears, one with obvious type 3 microtia, and one with a more subtle type 1 microtia. While she slept peacefully in my arms, I could see the downward slant of her eyes, and a uniqueness to her facial structure. However, what stood out the most to me was her peaceful demeanor and calming energy.

The hours passed in a blur of doctors in and out, getting us settled in our hospital room, and tests to get a clearer picture of the future.

Day turned to night, and her big sister finally arrived to meet her. She walked over to her bassinet and proudly said **"I've waited my whole life for you."** That was the beginning of a powerful bond built on mutual adoration. In the days that followed, Josephine had her first newborn hearing screening.

The nurse came into our room to take her, and said she'd seen newborns with microtia before, and told us "as long as she 'passes' on one side she'll be fine." I believe I was still on too much pain medication to fully comprehend that statement, but almost eight years later, it's one that still makes me angry. She "failed" the hearing screening on both sides, at least twice while we were in the hospital. I still think about how I'd love to run into that nurse, take out a picture of my girl, and let her know **"she never did pass on one side, and she's MORE than fine -- she's spectacular."**

After five days in the hospital together, we were discharged just in time to enjoy Thanksgiving as a family of four. At that time there were more questions than answers, but above all we were beyond thankful for the newest addition to our family. Upon discharge we were immediately referred to **Boston Children's** for her care, and our questions were finally starting to get some answers. After an appointment with our geneticist and blood work, Josephine was officially diagnosed with Treacher Collins syndrome. She is missing a sequence on her TCOF1 gene. Following her results, Matt and I both underwent genetic testing, and it was found that neither of us have Treacher Collins syndrome. Josephine was a spontaneous gene mutation.

Joey's Treacher Collins syndrome presents mild-moderately, and she has bilateral moderate to severe conductive hearing loss. She has not required any surgery beyond her tonsil and adenoid removal, which did land her in the pediatric ICU at Boston Children's due to massive swelling in her very narrow airways. She will require jaw and dental surgery down the line, and we are considering alternative options for her hearing devices on the soft band. At this time, we are not going forward with ear reconstruction. Day to day she faces difficulties with her hearing and speech, sensory challenges while eating, and extreme discomfort breathing through her nose when experiencing allergies or sickness. When Joey was about 3 months old, I reached out to **Eva Nicholas, Cassidy's** mom. I was able to go over and meet their family with Joey. Their love for her, and kindness toward me is something I will never forget. We were able to attend a gathering at their home later that year, and had the opportunity to make valuable connections with friends of theirs

first time

, continued from page 14

that also had Treacher Collins syndrome.

The Nicholas family attended their first CCA Retreat a few years later, and since then Eva's been telling me we need to go. As Joey has gotten older, she has been more aware of her differences, and we decided last year that we really needed to make it happen in 2024.

Leading up to the Retreat we were all excited, but no more so than Joey. As a parent I was nervous, but that was quelled almost immediately upon arrival.

The time at the Retreat was incredibly fulfilling. Simply put, in a world where typically day to day our children's differences separate us, during the Retreat their similarities bring us together. I see how isolating it can feel to be the only person in your family with a craniofacial syndrome, and not being exposed to role models and people in your life that you share that unique bond with. Joey was able to see thriving kids and adults that also have Treacher Collins syndrome. Matt and I were able to make connections with parents that faced the same scenarios we have faced. Annabel made friends with peers that "get" what her life is like. That didn't pepper her with questions about her sister. The staff and volunteers that spend time to make this event a reality deserve all the credit in the world for that dedication and commitment.

Our family left Baltimore incredibly grateful for the days we spent there. We made friendships that we treasure. This is more than a gathering of people who share in some way a common bond of craniofacial syndromes. It is an invaluable gift of time spent with those that share a rare and important connection. **As human beings, we all travel unique paths in our journey of life. The Retreat is an opportunity to bring a specific group of people together, whose paths are certainly not identical, but that have been on the same terrain.** We've seen similar sights and faced similar obstacles. These intertwining paths are what make this group of people feel like family. While this was the Ziev's first Retreat, it certainly won't be the last.

david roche award of excellence in advocacy

by Khadija Moten, CCA's Outreach Director

On September 12, 2024, the Children's Craniofacial Association (CCA) presented the David Roche Award for Excellence in Advocacy for the third 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 CCA and the committee were honored to award **Sora J. Kasuga** as the recipient of the **2024 David Roche Award of Excellence in Advocacy.** Sora founded **"The FaceOut Project,"** which is about two things: Community and Activism. Her vision is a hope to create a living, breathing entity where members of the Facial Difference community will come together and collectively face out toward the world. She has started with a weekly Activism Cohort which meets to discuss different topics and celebrate one another's work.

> I didn't grow up in the Facial Difference (FD) community. In fact, I didn't look for it until my mid-30's. When I found all of you, I knew I could never go back. This year, I created **The FaceOut Project** (www.faceoutproject.com), a grassroots activism hub made *by* people with facial differences *for* people with facial differences.
>
> We don't need to be fixed. We are inextricably woven into the gorgeous tapestry of human variation. I know change will come when we love us for who we are and empower ourselves and each other to call for widespread societal change. From my own journey, and the diverse array of stories from FD community members around the world, I know what being "shut out" looks like and the humanitarian crisis that ensues. But I also know the wisdom and strength we each possess, personal assets forged through our lived experiences. I know this is a fight for our lives, a fight that we are more than capable of winning... and it starts right here with love.
>
> Thank you, CCA Kids and David Roche for this incredible honor. The Facial Difference community is stronger because of the support and empowerment you continue to generously give.
>
> **-Sora J. Kasuga**
> Recipient of the 2024 David Roche Award of Excellence in Advocacy

upcoming events

MONTHLY AT 7:00PM CST
NOV. 6TH, DEC. 4TH
VIRTUAL

CAREGIVER SUPPORT GROUP
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MONTHLY AT 7:30PM CST
OCT. 21ST, NOV. 25TH, DEC. 23RD
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acpa recap | denver, co

CCA is proud to have attended the **2024 ACPA Annual Meeting** with all of our full time staff team and our intern, **Aaliyah Booker**. This conference is an important time for CCA to connect with craniofacial teams across the country in one place.

Each year, we host an exhibit booth during the conference and also volunteer during the event. This year was an especially powerful year, because the focus was on lived experience. We are so grateful to **Adam Levy**, CEO of the **American Cleft Palate – Craniofacial Association (ACPA)**, and their board and staff, for purposefully creating a program that featured people with facial differences as both keynote addresses and also throughout the event. It was an incredible moment during the "The Power of Lived Experience: Facing Cleft and Craniofacial Care Forward," to see nine advocates, all with facial differences, boldly assert that now is the time to put people with lived experience of having a facial difference in decision-making places to improve the models, and subsequently outcomes, of craniofacial medicine. Our utmost respect and appreciation goes out to the members of that panel: **Bieke L. Kreps, Dina Zuckerberg, Kathleen Bogart, Kariym C. Joachim, Jackson Doane, Iva Ballou, Kenny Ardouin, Phyllida Swift,** and **Gareth Davies**. Likewise, our appreciation and respect goes out to the receptive and engaged medical professionals without facial differences who understood the message deeply and took to heart how they can improve and grow their allyship with their patients.

We also had the great pleasure of talking with so many medical providers sharing our programs with them and handing out hundreds of syndrome booklets, newsletters, and curriculum packets. Each year, we bring our materials to distribute to the teams onsite, but we also give them access to our resource request form, which anyone who wants to order CCA literature can do so – for free – here: bit.ly/CCAResources (case-sensitive)

And, our good friend **Dr. Kelly Wosnik, CEO of CCD Smiles**, gave a touching keynote, and also brought in superstar, **Gaten Matarazzo**, of **Stranger Things** and **CCD Smiles**, to share his heartfelt journey – complete with his signature humor and wit. We are so thankful we all got to snap this photo (see above) with him and we are grateful for how gracious he was to take photos with everyone who wanted one, long into the afternoon.

We also appreciate everyone who attended our Lunch & Learn session, "Fun-Fueled Impact," where **Erica Klauber, Executive Director of CCA**, explained how the work we do changes lives, but looks and feels a lot like fun. As she often quotes, "the antidote to trauma is connection," and by bringing our families together, we accomplish the mission of empowering and giving hope to people affected by facial differences because they can form lifelong bonds of empathy, invest in their own mental health and wellbeing, and find a forum to launch, share, and continue their advocacy.

We look forward to our continued partnership with ACPA and thank them sincerely for putting on one of the best conferences for the facial difference community we could ever imagine.

ACPAAM24

meck invitational 2024 raises $175,000 for cca

On September 4th and September 5th the Mecklenburg family hosted the 13th annual **Meck Invitational benefitting the Children's Craniofacial Association**. There were 48 golfers from across the country and several others who attended dinners and participated in a significant way. The temperature was over 100F both days, so it was a test of endurance that only the Texas native couldn't handle!

We are so grateful for our committed friends and neighbors who join us for this two-day event, that continues to raise the bar each year.

Shaun Shenouda and **Todd Klosterman** were the low medalists both days to take home the championship. There was a tie for the runner up honors with **Brad Shofran, Lance O'Rourke, Maria Amelio** and **Jerry Farrell. Maria Amelio** also captured the Ladies Championship. Seven teams also got into **Bill Mecklenburg's** wallet by beating him in the **Greg Bonnell Memorial Challenge**.

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 **$175,000** to benefit the Children's Craniofacial Association.

- *Left to Right: Ron Guerena, Kent Penwell, Vince Foley and Bill Mecklenburg*

Left to Right: Tyler Hamilton, Darin Dankelson, Eric Klauber, and Chris Andler

Left to Right: Jerry Farrell, Mario Amelio, Joe Davies

Left to Right: Maria Amelio and Christine Condino- Mecklenburg

Left to Right: Kahtleen Philippi Betsey Robinson and Marta Bannigan

Left to Right: Todd Klosterman and Shaun Shenouda

meck invitational, continued from page 18

A special thank you goes out to our Sponsors:

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A special thank you is also deserved for **Shawn Craig**, **Holly Jaenichen, Jay Walkinshaw and Tom Jaronski 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, especially **Kathleen Philippi** who flew out from Wisconsin to volunteer for the cause and **Michael Sprague** who braved the heat for three hours to deliver iced towels to the players.

Left to Right: Tim Ayala and Ryan Njotowidjojo

Left to Right: Darin Dankelson and Robert Kacer

Left to Right: Chris Andler, Christine Andler, Eric Klauber, and Erica Klauber

Left to Right: John and Anne Mahoney

Brad Shofran, Dave Corby and Dave Leventhal

Left to Right: Jeff Patty, Christine Condino-Mecklenburg, and Tatiane Patty

meet colin

hi, my name is **Colin** and I am 7 years old. I live in Chicago, IL but was born in Austin, TX which is also my middle name. I have Nager syndrome, but there is so much more to me than that. A few activities I enjoy are soccer, bowling, art class, cub scouts, reading books by Dav Pilkey, and eating whipped cream. But my favorite activity is hip hop dancing. I danced in my school's variety show with my friend, Christian this past winter. I even did a hip hop dance at the CCA Retreat talent show. I love school so much that I get upset during winter and spring breaks because I love being in class with my friends, teachers, and therapists. My favorite subject is math and I love solving math mysteries. I also really enjoy technology and love when we use iPads and learn coding at school. I use an iPad every day to communicate with my friends, family, and teachers. I also talk a lot and my two siblings are experts in understanding my speech and translating for others. I love how they can understand me. My family travels often, and my favorite place I have been so far is Minneapolis because I got to go to the CCA Retreat for the first time and meet new friends who have the same syndrome as me. I also loved **Nickelodeon Universe** at **Mall of America**. I attended my second Retreat this summer in Baltimore and made some friends.

ccakid

meet owen

Hi, my name is **Owen** and I am 9 years old. I am Colin's older brother. We are 18 months apart and we love taking art classes together. We also enjoy reading and playing video games together. We both love Dav Pilkey books and Roblox. Both of us are in the same cub scout troop at our school. My other hobbies are soccer, swimming, water polo, and basketball. I love sports. I enjoy going to school and my favorite part is the specials: music, art, PE, and library. Every time I see Colin at school, we give each other a big hug. We play together at recess when our classes go out at the same time. Students at school ask me what's wrong with Colin often. This upsets me, but I try my best to explain all of Colin's medical equipment so that kids can understand and be more accepting. My favorite place to travel to is Austin because we used to live there. I love going to all the places Colin and I used to explore when we were little. I was excited to attend our family's second CCA Retreat in Baltimore and to make a raffle basket because that is my favorite part.

meet ryan

Hi, my name is **Ryan** and I am 5 years old. I am Colin's younger sister. I am 2 years younger than Colin Colin and cannot wait to go to the same school as him next year. The activities I love are gymnastics, swim lessons, hip hop, and riding my 2-wheel bike. Colin and I love competing in the Just Dance video game. Colin is a great brother because he plays princesses and dress up with me. He is always up for playing pretend with me and I love that about him. I love preschool and my favorite activity is doing art projects with my teachers. My favorite place to be is the beaches of Lake Michigan and collecting rocks and shells. I was excited to go to our 2nd CCA Retreat this summer, my favorite part is the kids' activities like the magic show and last year, the carnival where I got my face painted. I love to help Colin by laying out Colin's coat at the proper height so he can put it on, getting Colin his talker and telling people that it isn't a play tablet, it is what he uses to communicate.

cellie review

by Erica Klauber,
CCA's Executive Director

We learned about this cool product from **Marissa Koven March, PhD, Pediatric Psychologist** at **Monroe Carell Jr. Children's Hospital** at **Vanderbilt**, at ACPA 2024. She was showcasing her work where she developed the **Cellie Coping Kit** for Craniofacial Conditions as a psychology extern at the **UI Health Craniofacial Center**, with her supervisor **Janine Rosenberg, PhD; DePaul University graduate school advisor, Susan Tran, PhD;** and **Cellie Creator, Meghan Marsac, PhD.** Creating this new version of Cellie was her dissertation project. We are very excited about Marissa's work and CCA wants to make our community aware of this cool resource that could help you, your child, their siblings, and your whole family cope with surgeries and frequent medical interventions, and emotional and social challenges that may come up over the course of childhood.

From the website: "The mission of the Cellie Coping Company is to make medical care better for kids and families. We do this by empowering kids and families to live life to its fullest, even in times of a crisis such as a diagnosis of a medical condition. In other words, we are here to support families!"

To learn more and to find Cellie, visit online at: celliecopingcompany.com

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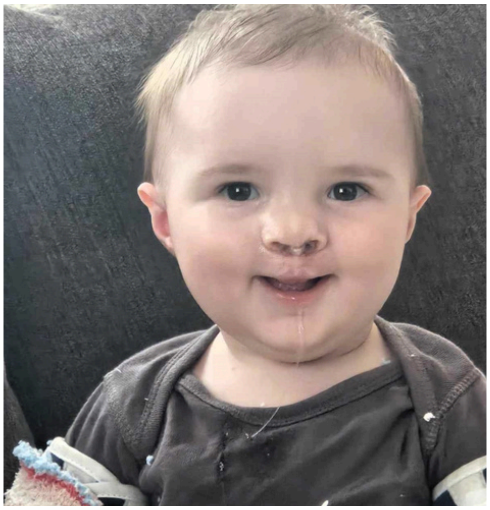
financial assistance testimonial

by Katelyn Lyman



Our sweet **Charley** was born in November 2023 in Maine. At our 20-week anatomy scan we learned Charley would be born with a bilateral cleft lip and palate, with the severity of the cleft palate to be determined after birth. Charley is our first child so we were overcome with varying emotions. Truly, all we wanted was a healthy baby, and that he is!

You don't realize the additional costs associated with caring for and raising a child with special needs until you're in it yourself. Of course there are medical bills and the cost of medical supplies. But what you don't think about, or at least I didn't, are travel costs to specialty doctors, the cost of specialty equipment (clothing, bottles, etc.), or the work missed for the appointments and recoveries.

We were hesitant at first to complete the financial assistance application from the **Children's Craniofacial Association** as there's always the feeling of 'someone else could use this resource more than us'. But we're so glad we did!

Knowing that some of our travel costs would be covered was a huge relief as we'd be traveling to Boston, MA for most of Charley's appointments the first few months, sometimes weekly.

Annie at CCA has been nothing but incredibly helpful and kind. We can't thank the organization enough for what they've done for our family and all of the other families!

-Katelyn, Ryan & Charley

road to 26.2 mile marathon for CCA

Have you heard? Our Executive Director, Erica, is running a marathon for CCA for her 40th Birthday! You can help by chipping in $26 to her campaign or even sponsoring a whole mile! She's halfway to her goal!

tinyurl.com/ccamarathon
(case-sensitive)

The journey started years ago, around the time of my last big surgery in 2010. I had to have jaw and ear surgery, at the same time, and the recovery was brutal. When the swelling finally went down a little and I could walk around, I took a little walk outside. It had snowed – a rarity in Alabama – and everything just seemed so fresh, so new in that cold, winter light.

I made a promise to myself right then, that I would never disrespect my body again. My fitness journey began with that walk, but has morphed over the years into a way of life for me; a way to stay connected to the world around me and myself.

I started walking at first and then I remember one day, I pondered, "What if I ran? What if I just ran to that tree?" So, I did.

It was awful. But the next walk I took, I thought, "Maybe you could run to the end of the greenway… I mean, everyone on Facebook is running 5Ks these days… surely you can, too."

So, with a little bit of envy and a little bit of enlightenment, I ran to the end of the path. It was still brutal, but it was also invigorating, empowering, and freeing.

From that moment on, I was just like Forrest Gump, who said, "I just kept running."

So, why I am writing to you? Because even though Forrest Gump claimed he wasn't running for anything, we all know you don't run this far for nothing. And I am running to support the organization that has been with me since 2008: Children's Craniofacial Association.

When I found CCA, I had less than 2mm of opening in my mouth. I literally talked and ate through clenched teeth.

Tony Davis, a board member of CCA, was the first person who ever said to me, "What craniofacial condition do you have? You need to know about CCA!"

When I was introduced to the staff and subsequently, the board, I was met with radical acceptance, instant understanding, true empathy, a surgical recommendation, and a lot of pure fun. CCA has become my extended family and an organization I credit with changing my life.

The past couple of years, we have faced challenges in rising costs and serving all the new families finding us for the same support I needed when I was younger.

Upon much reflection, I decided my marathon mission had to be dedicated to CCA.

Sure, I'd like to do it quietly, just in case I don't finish, to save myself the added vulnerability on top of rigorous training. But, hey, I will probably only do this once, so I want to do it *BIG* and I want to make it count.

My goal is to raise $1,000 for every mile, and $200 for that pesky 0.2 that you have to complete to call it a marathon. $26,200 in total. At the time of printing, I've already raised $12,160.

I have only come this far in life with your support and that is what I will carry with me across the finish line.

With all the love and light in my heart,

Erica Klauber

Erica Klauber,
CCA Executive Director

do you want to host a CCA fundraiser?

CCA relies on the charitable donations and contributions of individuals and grant-making foundations. We receive no government funding. All of our programs and services exist because of generous donors and fundraisers!

To learn more about supporting CCA Kids and Families, visit
ccakids.org/fundraising-ideas.html
or email Christine at:
candler@ccakids.com

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celebrating 35 years of CCA

Join us in celebrating 35 incredible years of Children's Craniofacial Association!

Consider making a meaningful impact by giving a gift of $35 or more to support CCA's mission.

www.ccakids.org/donate

donate@ccakids.com donate@ccakids.com

YEAR ANNIVERSARY
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