THIS ISSUE OF THE E-NETWORK IS DEDICATED IN MEMORY OF **JAMES JOHN VARA JR.**

ccanetwork

newsletter of children's craniofacial association

2025: ISSUE 1

inside

SCAN THE QR CODE TO MAKE A DONATION!

Left to Right: **Kara, Abigail,** and **Garette**

meet the christies

by Kara Christie

i believe God uses our special kids to show us the beauty and kindness in the world around us. In a large way, this has been our story: nurses, doctors, and teachers who have gone the extra mile; neighbors, friends, family, and even strangers who go out of their way to surround a child with love and encouragement. It warms my heart to look back at some of these experiences. But how did our journey start?

Once my husband, **Garette**, and I decided to have a baby, we struggled for several months. When we finally got involved with our doctor, he teased me that at my age, we'd have to be a lot more intentional about our methods. Sure enough, following his advice, we were soon celebrating the awaited pregnancy. Garette had chosen the name of his first daughter as a teenager, so we knew that if we had a girl, her name would be: **Abigail (Abi)**. At our 20-week visit, we were thrilled to discover that this was the case and to see Abi

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letter from the outreach director

We are humbled and honored to enter 2025 with you all, our CCA community! Since the start of Children's Craniofacial Association (CCA) the goal has always been rooted in supporting, empowering, and giving hope to families affected by facial differences. So much of what we do at CCA is a result of the contribution of ideas, advocacy, love, and support that you, the community, bring to the table. Thank you!

As I enter my 8th year with CCA, I am so proud of the growth that I have had the privilege of witnessing. This past year, our #ChooseKind programming has reached **3,248 students** through the distribution of complimentary curricula, book donations, and speaking engagements. This number does not even come close to our digital footprint which, in ways, is immeasurable and growing thanks to our digital educational library interviews, syndrome booklets, and overviews. Last year, we added **33**

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to support and inspire individuals and families affected by facial differences

christies, continued from the cover

for the first time. We also discovered something we were much less prepared for. Abigail was missing her right eye. The doctors didn't know why and still now, after a host of genetic tests and discussions, there's no clear syndrome or cause. This was hard news, yet I had a strong sense that this child and the circumstances surrounding her life would be for God's glory. I found out later that God had touched Garette's heart with those very same words.

As we were nearing the time of Abi's arrival, our excitement mounted, and I discovered something else. Garette was an artist. He painted a beautiful nature scene on two of her bedroom walls. While we enjoyed working together to prepare Abigail's room, quite a bit was happening medically. With the frequent tests and ultrasounds of a geriatric pregnancy, my doctor discovered that Abigail wasn't drinking the amniotic fluid as expected. I gained about 45 lbs of mostly amniotic fluid! Our doctor performed an amniotic drain to reduce the risk of premature birth. I'll always be grateful to him for all the steps he took to ensure that Abi had the best chance to thrive.

About a month before birth, our doctor noticed something unusual near the base of Abi's brain. His initial belief was that this was blood, and he brought us in to inform us that there was a significant chance our child wouldn't survive. This was a difficult time for Garette and me. Our church family surrounded us with prayer and encouragement; some came over to our home to pray with us. Thankfully, it was later determined that this was a mass in her brain rather than blood. The doctors believed she would need brain surgery shortly after birth. At this time, I was working for a doctor who was friends with the neurosurgeon, **Dr. Ben Carson**. He was able to help us get an appointment and transfer our care to **Johns Hopkins**, where Dr. Carson was on staff. At 5 days old, Abigail did have brain surgery where they removed a portion of the mass to alleviate the pressure on her brain. To everyone's relief, it wasn't cancerous. It was extra brain tissue, and despite the many possibilities, her cognitive abilities were only minimally impacted.

When Abigail was born, she was immediately surrounded by professionals and whisked away to be intubated. The tube placed in her nose went down into her throat and prevented vocal sounds. The first time I saw her cry without making a sound, I went into the bathroom and cried myself. In the days prior to her surgery, I prayed that I would be able to hear her voice and hold her before the surgery. Shortly after that, for a time, the doctors tried a different device for administering oxygen, which was called a CPAP. It utilized a little cup that covered the nose in place of the tube that was inside it. For the first time, I heard Abi cry…the most beautiful sound on earth that day. Also, on one of the days leading to her surgery, there was a different nurse on duty in that part of the NICU. I don't know if she was supposed to allow it, but she brought in a rocking chair and allowed Garette and me to sit and hold Abi. In so many ways, the kindness of the NICU nurses during

christies, continued from the page 2

this time brightened our experience.

After a month and a half, Abigail had a trach & g-tube placed and was able to transfer from the NICU to a children's hospital. Again, the doctors explained that because she'd been intubated for the procedure, her vocal cords may have been damaged and she might not ever be able to speak. Initially, she learned to sign. Yet, after several months, when she was strong enough to get air around the trach, she began to talk…and talk…and talk, making up for all that lost time. Sometimes I smile when I think of those anxious moments when we didn't know if she'd ever be able to do that.

After another month and a half, Abigail was finally able to come home. She came with machines and tubes, home nurses and therapists, but we were so glad to have her with us. Our family, my parents, and my brother's family all lived on the same street, so we had plenty of company and support.

Abigail's unique facial features naturally draw attention wherever she goes — sometimes positive, sometimes not. Many adults, and even some children, pause to offer kind affirmations, often telling her, "You are beautiful." However, not everyone is so considerate. Some people stare, and children in particular, often ask, "What happened to your eye?" These questions become increasingly more frustrating for Abi. To help her navigate these moments, Garette encouraged her to use lighthearted responses to deflect the curiosity. She later grew more comfortable and self-accepting. In fact, she's chosen for the time being to forego surgery and enjoy her appearance as she is.

At present, Abi is a very bright 14-year-old who loves music, reading, singing, meeting new people and sharing her faith. As an adult, she would like to become a missionary. This has been her goal for as long as I can remember, and we've watched her grow toward it. There are still many obstacles for her to overcome, including a more recent epilepsy diagnosis, but each year brings fresh evidence that truly all things are possible.

ccaadult

meet lindsey

My name is **Lindsey Tippman** and I am 38 years old. I grew up the youngest of three children in Indiana. I have wonderful memories from my childhood despite looking different and having surgeries to repair my mid-facial cleft that included a cleft lip and palate. My biggest surgery was when I was 4 years old. It was 19 hours long! I had the best surgeon ever, **Dr. Michael Sadove**, at **Riley's Children's Hospital in Indianapolis**. He treated me with such compassion, kindness and love. I will forever be grateful God chose him to care for me through my journey as a craniofacial kid. Growing up I loved Jesus, cheerleading, shopping, makeup, being with family and friends, traveling, summertime and Christmas. I did what most other kids did but there were a couple things that I got to experience because I was a cranio-facial kid going on **Retreat** and attending **Camp About Face at Bradford Woods**. I remember the first time I went on Retreat, I was filled with awe at discovering I wasn't the only one with a facial difference! My fondest memories from Retreats and CCA were getting to cut the lines at Disney World and meeting Cher at one of her concerts!

For as long as I can remember, I have always wanted to be a wife and mother, but since you can't go to college for that, I went to nursing school. The nurses I had who cared for me during my surgeries had such a strong impact on me. Their tenderness and care aided in my successful healing and getting through difficult and sometimes painful things. I wanted to be able to care for others in that same way. I graduated from nursing school in December 2007 and have worked in a variety of areas, from ICU, to Oncology, a crisis pregnancy center, to most currently teaching CrMS fertility care (one day a week) to couples trying to achieve pregnancy. My nursing career has been so rewarding. But even more rewarding is my husband, **Blake**, and our 6 children: **Judah** (15), **William** (13), **Elsie** (12), **Violet** (10) , **Memphis** (8) and **Avila** (3.) They are my greatest joy in this life and I am forever blessed to call them mine!

I would at times wonder while growing up, 'Why was I born this way?' I don't know that I'll ever know but I am certain that it has made me a better person. The obstacles I've overcome have given me strength, wisdom, kindness and love in ways I wouldn't have otherwise encountered. I thought my last surgery, at 19 years old, was the closing of that chapter in my life. However, I would come to find out it was really just the beginning in many ways. In January of 2013, I had our sweet **Elsie Lousie** who was born with a cleft lip and palate. You can read about her (pg. 5) as the CCA Kid! Being the parent to a child with a craniofacial difference has been filled with love, fear, joy, stress, enlightenment and obstacles similar and different to the ones I faced myself. I have been humbled in many ways and have come to understand every craniofacial journey is different. My journey kind of came full circle when I was blessed to have my surgeon, Dr. Sadove, be the surgeon to my own daughter. Blake and I had such peace for those trying times when your precious baby is enduring so much, knowing she was in the hands of the best. Unfortunately, due to a move and our insurance changing, we had to find her a new surgeon when she was a few years old. As the Lord would have it, He led us to Dr. Sadove's very good friend, **Dr. Gosain** in Chicago. However, we didn't know they even knew each other until we went for her first appointment and he asked who her previous surgeon was. When I told him, he said, "Oh we are good friends! I was just vacationing in Florida with him."

The journey as a child with a facial difference and the parent of a child with a facial difference has been a grace-filled journey to say the least. It certainly isn't always easy and there are unexpected twists and turns but I wouldn't have it any other way!

meet elsie

Hi, my name is **Elsie Tippman** and I am 12 years old. I was born with a cleft lip and palate and I have had a lot of surgeries. I used to be scared when I was little but as I have gotten older, I have gotten a lot more brave. But having a cleft isn't what is most important about me! I am just like any other kid that doesn't have a cleft. My favorite things to do are cheerleading, horseback riding, shopping, skin care with my friends, Starbucks, and candy.

I have practiced cheer for many years with my older friends and cousins but I actually got to be on the Team since I am in 5th grade. I got to cheer for football and basketball this year.

I also started horseback riding in the fall. I have learned how to ride Western and English, groom horses and have even gotten to dye their manes! My trainer says horses are just like big dogs. At first I was kind of nervous to get on a horse but I knew that I would eventually be brave enough and now I think it is so fun!

I have some great friends at school and we like to FaceTime and do skincare and makeup together. I love meeting new people and that was one of my favorite things when I went to my first CCA Retreat in Minneapolis in 2023. It was really nice to see that I wasn't the only one who had to have surgeries. Another favorite thing from the Retreat was the Talent Show. I didn't participate in it but I loved watching everyone who did! Lastly, can we say "Starbucks?!" The hotel where the Retreat was had a Starbucks in it! Who wouldn't want a Pink Drink or Refresher every day?? I hope to go to another Retreat really soon!

I just want other kids to know that even though surgeries and doctor appointments aren't always easy, just keep pushing through! You can do it! Slay!

ccakid

letter from the OD, continued from the cover

videos online and updated **3 syndrome booklets**. The outreach component of CCA allows us to not only serve our internal community, but to also bring awareness, education, and understanding of facial differences to the broader population in hopes of creating a world where all people are accepted for who they are, not how they look.

Not to brag, but I happen to work with some of the most amazing ladies!!! And I would be remiss to not mention their department's contributions to CCA's 2024 impact and wins!

Left to Right: **Kara Jackman** (Adult Program Coordinator), **Erica Klauber** (Executive Director), **Christine Andler** (Director of Development), **Annie Reeves** (Program Director) and **Me**

Left to Right: **Me** and **Aaliyah Booker** (CCA's Outreach Intern and Host of CCA's Outreach Series)

Last year, we were able to support **46 families** through our financial assistance program and funded **95 medical trips** making access to the healthcare they need one step closer. We topped **$60,000 in assistance**, at an average award of **$642 per trip** assisting families in **24 states** and **8 international territories/countries**. Surgeries, illnesses, and doctor appointments are rarely fun but we hope to bring smiles to the children and families we serve through our complimentary care packages, sent to over **100 kids** in 2024.

The journey of navigating a facial difference can be complex but we believe what makes things a bit easier is knowing you are not alone. Many of our CCA adults went through their entire childhood not knowing that there was an entire community out there that could relate to their journey. We at CCA pride ourselves on having an annual program that brings families together across the globe to mingle, connect, share resources and so much more. **CCA's Annual Retreat and Educational Symposium** allows for children and families to find a sense of belonging and connection that does not have to wait till adulthood. Last year, we hosted **479 people** in Baltimore, MD and this year we are looking forward to hosting **500 people** in Bellevue, WA -- **celebrating 35 years of Retreats!** We understand there is a need for connection outside just the Retreat alone. Not everyone has the privilege to place life on pause to attend a Retreat across the nation; therefore, we have virtual support groups that meet every month to help fill the gap. Last year we added a third support group, "Siblings Support Call," hosted by **Abbey Merrill of Sibling Strong**, on top of our two existing groups: "Adults and Alumni" and "Caregiver Support Call." **25 support group** meetings were held in 2024.

Of course, none of the work we do at CCA would be possible without the support of donors, like you. **Thank you!** We are grateful to have been awarded **27 grants** in 2024 totaling over **$130,000**.

We are excited to see what this year has in store for CCA! I hope 2025 has been kind to you so far!

* * * * * *

I often feel the newness of the year until about April. During those first four months the excitement and hope for change is still fresh! The list of possible to-dos endless: creative projects, home organization, fitness goals, advocacy events, volunteering in the community, learning a new skill, a new language… oh the options! Once the flowers start blooming, I often feel that time is up for any goals that have not yet been started. It is almost as if I am comparing my growth to that of the foliage around me.

This year that will not be the case! Just as nature has its seasons, I will too. The goal for this year is to treat the entire year and each season as brand new with the hope for growth and a belief in change. Just as we grant grace to the trees when they lose their leaves in the fall, I hope you too grant yourself and humanity grace in its flaws and shortcomings, with the hope that truth and love always win- just as we welcome those same trees with their new growth of leaves, flowers and seeds.

Thank you for walking this journey with us! We are excited to hear about all your dreams and goals for 2025. What new thing will you try this year?

- Khadija Moten
CCA's Outreach Director

Me trying these cute custard buns shaped like sheep at the Dallas Thai Market this year!

chi omega christmas market

by Christine Andler, CCA's Director of Development

We're honored to be a first-time grant recipient of the **Chi Omega Education & Charity Fund of Dallas** thanks to the generosity of the Chi Omega Alumnae of Dallas volunteers and chairs!

We had a fantastic time at the **Chi Omega Christmas Market** that took place on September 26-28, 2024 at the **Dallas Market Hall**! This market was in its 47th year and brings in thousands of people to shop and support DFW charities and small businesses.

Pictured: Emily Thorsen Blair, COCM Liason; Christine Andler, CCA's Director of Development ; and Sally Larroca, Office Manager
Photo Credit 📸: George Fiala Photography

This year marks our first year to receive this grant of $25,000 and which will be used to provide assistance to more families in our local DFW community and for families attending our Annual Retreat in 2025! A big thanks to the entire Chi Omega Alumnae of Dallas volunteers and chairs for this opportunity!

marathon recap

by Erica Klauber, CCA's Executive Director

Many of you followed along with me and my marathon journey last year. I want to thank you all for the most amazing support and encouragement I felt as you all cheered me along the way.

The miles of training were the best part, scooping up all that social media goodness and using it as fuel as I ran through my neighborhood, sending love and light to every one of you who came into my thoughts as I ran. The second best part was all the snacks I got to eat when running 25 miles a week.

The race was a wonderful success - thanks to all of you - and I'm happy to say not only did I beat my goal time, with a time of 4:19, I also exceed my financial goal, raising $26,400 for CCA! I couldn't have done it without your support.

And to anyone out there thinking, "Can I do the crazy thing on my bucket list?" I want to assure you that you absolutely can. You'll need time to train/prepare and dedication and sacrifice to things that stand in your way, but NEVER let your facial difference or any perceived inadequacy convince you that you are not worthy of pursuing your wildest dreams. Keep chasing your goals, friends. Achieving your goal is just the icing on the cake of the journey of self-discovery.

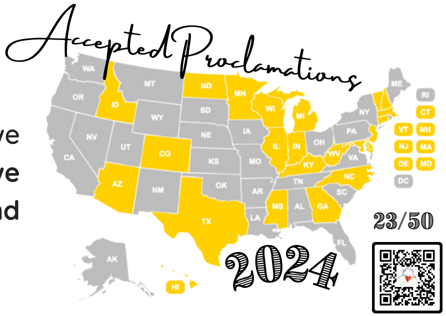
requesting proclamations

Every September, we advocate for **Craniofacial Acceptance Month (CAM)** by contacting Governors' Offices across the nation to proclaim September as Craniofacial Acceptance Month! Last year, 23 states officially recognized CAM—let's get that number even higher this year!

Can you help us get your state to proclaim September as Craniofacial Acceptance Month?

Fill out the google form and we will do the rest! **Together, we can promote acceptance and awareness of facial differences!**

https://qrco.de/ccaproclamation



SCAN FOR GOOGLE FORM

200 muslim women who care

by Christine Andler, CCA's Director of Development

CCA has been awarded as a recipient of a **$10,000** grant from the DFW chapter of **200 Muslim Women Who Care (200MWWC).** The Dallas Chapter of 200 Muslim Women Who Care® was formed in 2024 and its mission is to embody the principles of Islamic faith by serving and supporting their neighbors throughout the Dallas-Fort Worth Metroplex.

On February 13, 2025, **Erica Klauber**, Executive Director competed with two other nonprofits to pitch for a grant voted on by 200MWWC members. This format was new to us and truly showcased some great work being done in our community. Erica was able to clearly identify our goals of this grant and explain to the members the importance of CCA and our critical programming. She specifically spoke to our Annual Retreat and the local impact to our DFW families for 2025.

After a review of all three organizations, including an on-the-spot Q&A, the members voted and we were announced the winner of this amazing grant! It was such a special night and such an impactful chance to speak about our work in front of a group of talented and generous women who truly care about the community. We were connected to this organization from our Outreach Director, **Khadija Moten** and then nominated by her mentor, **Nosayba Mahmoud**, who cheered us on from the audience. Thank you to all these wonder women who believe in our work!

upcoming events

MONTHLY AT 7:00PM CST
MAR. 5TH, APR. 2ND, MAY 7TH, JUN 4TH
VIRTUAL

CAREGIVER SUPPORT GROUP

REGISTER: HTTPS://QRCO.DE/CCACAREGIVERGROUP

SCAN TO REGISTER

MONTHLY AT 7:30PM CST
MAR. 17, APR. 17, MAY 19TH, JUN. 23RD
VIRTUAL

ADULTS AND ALUMN GROUP

REGISTER: HTTPS://QRCO.DE/CCAADULTS

SCAN TO REGISTER

MONTHLY AT 7:30PM CST
MAR. 18TH, APR. 15TH, MAY 20TH, JUN 17TH
VIRTUAL

SIBLING SUPPORT GROUP

REGISTER: HTTPS://QRCO.DE/CCASIBLINGGROUP

SCAN TO REGISTER

MARCH 22ND AT 11AM - 1:30PM CST
VIRTUAL

THE PEACE PORTAL

WITH VANESSA ACERO, PSYD, MS, RVT-200, CLINICIAN AND YOGA INSTRUCTOR

THE PEACE PORTAL WILL BE A SPACE FOR JOURNALING, SOMATIC RELEASE, REFLECTIVE DIALOGUE, AND ADAPTABLE GENTLE YOGA.THE FOCUS WILL BE ON PROCESSING FEARS, CHALLENGES, AND TRANSITIONAL OR ANTICIPATORY ANXIETY RELATED TO EVOLVING CHANGES IN A SUPPORTIVE, SAFE ENVIRONMENT FOR HEALING.

REGISTER: HTTPS://QRCO.DE/PEACEPORTAL

SCAN TO REGISTER

JUNE 26-29, 2025
HYATT REGENCY BELLEVUE
BELLEVUE, WA

35TH ANNUAL FAMILY RETREAT & EDUCATIONAL SYMPOSIUM

REGISTRATION CLOSED

CELEBRATING 35 AMAZING YEARS OF CCA'S ANNUAL RETREAT AND EDUCATIONAL SYMPOSIUM

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gingertown 2024 raises $35,330 for ccakids

by Christine Andler, CCA's Director of Development

On December 10th 2024, hundreds of people from DFW's Design, Construction, Roofing and Architecture firms teamed together for the **15th Annual Gingertown Dallas!** This impressive build continues to be one of the biggest gingerbread house events in the nation. We are so lucky to again be the beneficiary of this amazing event at **NorthPark Center** in Dallas, Texas. On the night of this event, teams compete in a live gingerbread building exhibition to help spread joy and hope during the holidays! Millions of people nationally and internationally visit the Center each year. The theme for 2024 was "Paris" and showcased the beautiful sights of this enchanting city! We were tasked with the **Oreo Opera House** and it turned out to be one of the CCA's kid's best builds yet!

In total, the event raised $35,300 that will go directly to CCA.

We are so grateful for all those that came out to support us and wanted to especially thank **Nancy Nasher** and her children for attending the build, **RJ Ressig** and his staff for all they do to make this a huge success each year, and last but not least, the **Kimberlin family** and the **Alvey family** for participating in the build and building the CCA kid's Oreo Opera House as seen on this page. We love this event each year and truly are so grateful to be the beneficiary of this each year.

NorthPark Center is celebrating their 60th this year in 2025!

meet nico

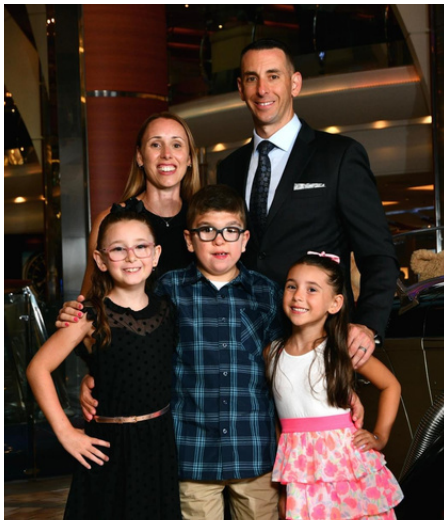
My name is **Nicholas Palmieri** and I'm 13 years old. My nickname is Nico and I live in Hamilton, NJ. I was born with Apert syndrome and a rare heart defect called Tetralogy of Fallot.

My surgical journey began with an open-heart procedure when I was just six weeks old, followed by several more procedures over the years. At the age of five, I underwent mid-face advancement surgery, which significantly improved my ability to breathe at night and allowed me to finally say goodbye to my CPAP machine.

I have a variety of interests that keep me active and entertained. I love spending time with my sisters, whether we're swimming, sledding, or hanging out with our cousins. Going to the beach is one of my favorite things to do, and we often make the most of the sun and sand. I love playing baseball and getting to be a part of the **Miracle League of Mercer County**. This is a baseball league for kids with disabilities and is so much fun to participate in. I love to get my adrenaline pumping on roller coasters and if I can't be outdoors, you'll find me playing video games.

I am currently in 7th grade and part of a life skills classroom. What I love the most is our special classroom has a kitchen inside of it and we get to run a cafe every Friday. This cafe is open to the staff, students, and public. My family gets to come visit me and support our class. I get to be in charge of the sign-in sheet and welcome all our guests.

Last June, my family and I went to Baltimore to attend our second CCA Retreat. My sisters and I had so much fun dancing, swimming, and playing bingo. I got to meet other kids just like me.



ccateen

meet giuliana

My name is **Giuliana Palmieri**, and I'm **Nico's** younger sister. I'm 10 years old and in the fourth grade. I have a passion for arts and crafts, where I love to express my creativity. I also enjoy dancing and take classes in ballet, hip hop, and jazz. Additionally, I'm proud to be a part of the Girl Scouts, where I learn new skills and make great friends. Being Nico's sister is one of my favorite things in the world! We have so much fun together! Some of our favorite activities include swimming in our pool, going to the movies, and playing with our little sister, **Aria**. Our family vacations to the beach are always something we look forward to, filled with laughter and adventure. On rainy days, you can usually find us lounging around and playing Roblox on our iPads. I also love watching Nico play baseball. My sister and I have a blast cheering him on from the sidelines. I'm really proud of my brother. Even when things are tough, he never gives up, never complains, and always manages to keep a smile on his face.

meet aria

My name is **Aria Palmieri** and I'm 7 years old. I am the youngest sister of **Nico** and **Giuliana**. I am in the first grade at the same school as my sister. I have a lot of fun activities that I love to do. I play soccer, take dance classes, swim, and I'm also a proud member of the Girl Scouts. Some of my favorite things to do are riding scooters with Giuliana, splashing around in our pool, and having fun at the beach. My absolute favorite thing is when the three of us get to relax and play Roblox on our iPads together. We always have the best time! I really enjoy our family vacations and weekend visits with our cousins. We have a big family, and we're all really close, which makes every gathering special. Last summer, I was so excited to go to Baltimore for my first Retreat. I had a blast playing Bingo and dancing at the dinner on the last night. I love that Nico gets to be a part of something so special. I love being his little sister!

christmas gala for cca from sherwood tax solutions

by Cari Morse, Sherwood Tax Solutions

Alamo City Charity Partners (ACCP) held their **4th Annual Christmas Gala for Children's Craniofacial Association** in December. Due to our amazing friends and families, it was again extremely successful and as always, a ton of fun!

There are multiple ways ACCP raises funds for CCA. We start with pre-event monetary sponsors and then continue raising money throughout the event. There are raffle baskets, silent auctions and 50/50 ticket sales with all proceeds going to CCA.

This year we had a band, a food truck and a costume contest. The theme was **"Redneck Christmas Gala"** and the costumes did not disappoint. Our winners were chosen by crowd participation and it was awesome. We also team up with **Toys for Tots** for a toy drive. We had a great turn out from our military friends!

It is a huge honor that CCA works with us on this amazing event. It takes a team of us to plan, set up and keep the event moving throughout the night. Without everyone involved we would not be able to pull it off. We are excited about working with CCA Kids for many years to come and we thank you for your continued support!

financial assistance testimonial

by Luis Carlos

From the depths of our hearts, we want to express our profound gratitude for the kindness and generosity you, CCA, showed our family during one of the most difficult moments of our lives. When we were struggling to see the light, you extended a helping hand and reminded us that we were not alone. Your support with our lodging expenses was not just financial assistance—it was a gift of comfort, hope, and stability when we needed it most.

We especially want to recognize **Annie** and **Erica**, who welcomed us with such warmth and treated us with the utmost kindness. Their compassion, patience, and professionalism truly touched our hearts. They were not only incredibly helpful but also so politely educated, making us feel respected and cared for in a way that words can hardly describe. Their presence was a reminder that genuine kindness still exists in this world, and we are so grateful to have crossed paths with them.

Additionally, we feel incredibly lucky to have found **Dr. Yates** and his team. They are truly extraordinary human beings who radiate kindness, empathy, and an unwavering dedication to their work. Their care and commitment to their patients resonate at such a high frequency that it is impossible not to feel their sincerity. They are not just medical professionals; they are healers in every sense of the word, bringing both medical expertise and emotional support to those in need.

The work you do at CCA is invaluable. You provide more than just assistance; you restore hope and bring light to families who are going through their darkest hours. We will never forget your generosity, and we will always carry the warmth of your kindness in our hearts.

Thank you for everything you have done for us and for so many other families in need. May your organization continue to be a source of love and support for those who need it most.

With heartfelt appreciation.

Lujan Family
Lucca, Ivonne and Luis Carlos

sensory bag overview

Erica Klauber, MBA
Children’s Craniofacial Association’s Executive Director

Many of you have expressed to us that Retreat can be a wonderful kaleidoscope of sights, sounds and emotions. However, this can also be overwhelming to kids and adults. Retreat is not the only situation in which you may encounter this type of sensory stimulation, thus CCA suggests you might consider creating and packing a "sensory bag" for your family and keeping it handy in your diaper bag or car.

We compiled some ideas what you might include below.

For folks who are interested in doing donation drives for CCA, we also welcome these items to be sent to us (new products only, please) so we can create and distribute sensory bags at our events!

Deciding what to Pack

Pack a small zipper tote or drawstring pouch with these items designed to help individuals with sensory sensitivities manage overstimulation, including:

- **Noise-reducing headphones**
- **Sunglasses, Light Sensitivity Glasses, and/or Visors**
- **Communication cards:** Printed or hand written cards with common phrases to communicate needs to others (Thirsty, Hungry, Bathroom, etc.)
- **Fidget toys**
- **Chewable toys / Chewable jewelry**
- **Weighted Blankets, Shoulder Wraps, Eye Masks, or Lap Pads**
- **Stress balls, Koosh balls, etc.**
- **Painters’ Tape**
- **Two cardstock handprints cut-outs that can be placed on a wall as a deep pressure "push place" (use with painters’ tape)**
- **Two cardstock footprint cut-outs for jumping or stomping on (use with painters’ tape)**
- **Travel-size Lotions or Balms (calming scents, such as lavender or eucalyptus)**
- **Small write-on, wipe-off board and dry erase markers**
- **Unbreakable mirror (so your child can see their emotions)**
- **Emotion chart or pictures to help your child begin to identify these emotions**
- **Therapy putty, silly putty or other ‘slime’ or ‘goop’ to shape**
- **Mouthing toys such as blow toys, harmonicas, kazoos, etc.** (*NOTE: Parents, make sure this noise won’t overstimulate you if you intend to provide it!)
- **Fidget items like hair bands, key rings, bracelets**
- **Fabric swatches**

Be Kind to Yourself

Remember, we want you to be able to enjoy your outings and we support how you support yourself! Everyone is welcome. Be kind to yourself!

in memory of james john vara, jr.

We want to thank the friends and family of **James John Vara, Jr.**, who took up a memorial collection of donations in James's memory, after his passing on November 3, 2024. Together, they donated **$6,615** in his memory.

James was known for being a hard worker, always willing to do what was necessary to provide for those he loved. His dedication to providing for his family was matched only by his vibrant personality, making him the life of the party and a social butterfly who never met a stranger. James John Vara, Jr. will be deeply missed by all who knew and loved him.

His spirit, kindness, and laughter will forever remain in the hearts of his family and friends.

We appreciate them deeply for this loving tribute to further the mission of CCA.

cca mission statement update

by Erica Klauber, CCA's Executive Director

We are excited to announce that we have updated our mission statement in 2025! Previously, since 2008, our mission statement read **"CCA's Mission is to empower and give hope to individuals and families affected by facial differences."**

After careful reflection, CCA leadership has taken the stance that it is hard (if not impossible) to "give" someone hope or empowerment. Hope and being empowered are intrinsic states. We certainly want individuals to find, access, and embody hope and find empowerment, but we believe it has to come from within.

Therefore, we slightly altered our mission statement to read:

The mission of the Children's Craniofacial Association is to support and inspire individuals and families affected by facial differences.

We believe this more fully recognizes what we do with our programs and services.

First, we "support"… we foster an atmosphere and community that helps people develop confidence and wellbeing; a place from which they can learn, grow, and heal that will allow them greater agency in their own lives. From financial assistance for medical travel to storytelling workshops; from donating curriculum to students' schools to hosting monthly support groups; from our lived experience communities to our public advocacy, all of CCA's activities create support for people with facial differences.

Secondly, we want to "inspire" people. With the content we create and the resources we provide, we believe we can inspire new patients and parents, longtime community members, our medical professionals who surround our lives, the general public, and even media and governments to understand and accept facial differences. We do not believe we are the givers of hope or empowerment, but we certainly inspire that resolve with the work that we do.

Thank you for celebrating this new, revised version of our mission that we will approach with the same dedication and passion with which we've served for 36 years.

"stronger together" limited edition cca t-shirt

We are so excited that CCA Family, **The Cronins**, wore their "Stronger Together" CCA shirts to Mexico and snapped a photo on the beach! They also handed out CCA wristbands at the music festival they went to and worked to spread a lot of awareness for facial differences and CCA! **Thank you, Cronin Family!**

GET YOUR OWN SHIRT:
https://qrco.de/ccashirtst

SCAN TO PURCHASE

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or visit:
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Erica Klauber, MBA

PROGRAM DIRECTOR:
Annie Reeves

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