



children's craniofacial association

2022



"I am Enough!"

CCA's 18th Annual Craniofacial Acceptance Month Theme

Message from the Executive Director



Wow, we returned to the “real world” this year...And it is so good to be back! Clearly, the highlight of the year was the ability to host our in-person Annual Family Retreat and Educational Symposium in Dallas, TX!

The amount of love and friendship and quite frankly pent-up joy was palpable and thankfully, the Sheraton Dallas was an enormous hotel, so it we had room to let the energy abound! Thanks to everyone who joined us in-person and to the many donors and volunteers who supported this event in numbers worthy of a comeback! Some say the Retreat is our signature program, and while I agree, it is certainly not the only way CCA drives impact.

In addition to Retreat, we were thrilled to offer our Financial Assistance program for medical travel at record levels. So many of our children had their scheduled surgeries delayed or canceled during the pandemic years and surgeons are just starting to work through backlog of patients. This has meant more families are needing to travel for their care and we are standing by to meet those needs so they can focus on their child, and not the cost of traveling to get care. **In 2022, we supported 41 families on 72 trips, average per trip \$770.53.** We also mailed out **125 care packages** to kids recovering from surgeries or who needed an extra “pick me up” from their CCA friends. Annie Reeves, our Program Director, is extremely passionate about serving our families and these programs we offer. Each year, I see her dedication to advocating for new ways to serve our families deepen and I am thrilled to congratulate her on 20 years of service this year. We are so proud of the way she has led CCA's programs over the past two decades and excited to continue our mission of empowering and giving hope to families affected by facial differences.

We also continued our virtual programs, which have become second nature to us all! We offered many different kinds of programs, with them falling into two main groups: educational and supportive. Our support calls featured panels of parents and adults with facial differences and included our robust and growing monthly “Adults and Alums” calls for our adult population. I myself attend these calls as often as I can (tho having a baby has really shaken up that 7:00PM time slot!) and I truly gain so much from them. Our facilitator, Kara Jackman, CCA's Adult Programs Coordinator, has developed a format that opens up time for fun, personal shares, and mindfulness. I am pleased to announce she will add another monthly virtual group to our offerings in 2023, the Caregivers Support Call. Please check that out if you are a caregiver and share both of these programs with your loved ones.

The other arm of our virtual programs focuses on education, with a catalog of webinars and interviews that showcase our medical professionals and individuals' lived experiences. Khadija Moten, our Outreach Director, invests her time into recording, editing, uploading, and curating this content for our audience. We know that millennial parents are less likely to call an 800 number and much more likely to seek out “infotainment” when they have a need. Hosting a library of on-demand content, ranging from advice on jaw distraction to an interview with an adult with Goldenhar syndrome, these videos educate and inspire people right where they are – holding their phone in a delivery room or waiting in an airport to meet a new grandbaby. **In 2022, we created 29 videos and held 15 support calls.**

Not only did Khadija spearhead our virtual programs, but she also continues to run and grow our Speakers' Bureau programming, and she onboarded Crystal Kouri, our new Educational Engagement Coordinator, as volunteer staff. Crystal will continue the #ChooseKind initiative, as we continue to distribute books and curriculum to educators across the country. We know that students benefit from this programming, and

in 2022, we reached 8,462 students with our curriculum, speakers, pen-pals, and book donations. We are so grateful to Crystal for volunteering her time to help us accomplish this mission as we continue to grow the programs and services we offer. She is building our capacity in a real and meaningful way, that stewards donor dollars to programs of high impact without increasing those programs' costs.

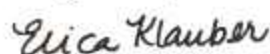
Our Director of Development, Christine Andler, worked extremely hard in 2022 to help us reach our budget goals and raise funds for the work we do. We are immeasurably grateful to her for helping us secure the PAR Golf Event as the selected charity beneficiary. Her connection to this corporate sponsor is close, as her husband is the VP of Sales for PAR, and they certainly showed up for CCA. Not only did they raise \$80,000 for CCA Kids, but they also helped secure a new office location for the CCA headquarters, which we will move into in 2023. Securing this new location not only helps us save money, but also is increasing our visibility and protecting our assets. We are grateful to the PAR team for making this happen for us!

In addition to this event, Christine continued Year 2 of our Development Plan, authored by M. Gale and Associates, for CCA. We focused on five areas of growth: Investing in Fundraising, Approaching Fundraising Regionally, Growing the CCA Board and Connections, Elevating Data Management and Reporting, and Developing Donor Centered Communication. As we endeavor to sustain our programs for the long term, these guiding principles help us steward donor dollars and maintain a low overhead. **In 2022, 81% of our expenses went directly to funding our programs.**

In conclusion, I want to thank you for reading our annual report and engaging with our organization. This summary is just a small portion of the activities of 2022. The CCA staff is an incredibly dedicated team who love our organization and the members who make it up. We could not do this work without your love and support, too. Our deepest appreciation is given to our donors, fundraisers, and sponsors.

We have big goals for 2023, and we know you will be a part of our progress on developing a world where people are accepted for who they are, not how they look.

With gratitude,



Erica A. Klauber, Executive Director

Mission & Vision

The mission of Children's Craniofacial Association is to empower and give hope to individuals and families affected by facial differences.

We envision a world where people are accepted for who they are, not how they look.

Programs & Services

Information and Support – CCA disseminates information to educate craniofacial patients and their families, health care providers, and the general public regarding craniofacial conditions. CCA also promotes public awareness of craniofacial conditions and social acceptance of individuals with facial differences. Craniofacial patient families often contact CCA to seek emotional support, discuss problems, and identify resources. Through our database and volunteer network, we are able to connect families with support groups and/or others who have similar conditions and experiences. We also keep a list of helpful resources and are always willing to listen and offer emotional support to family members who need a shoulder to lean on.

Physician Listing – Children's Craniofacial Association refers to the full members of the American Cleft Palate-Craniofacial Association (ACPA) Approved Teams listing. These surgeons head teams of specialists specifically trained in the surgical management of problems involving the face and head. Centers with craniofacial teams working together have the advantage of a greater experience to provide comprehensive, quality care, which leads to better results and fewer complications. In addition, ongoing research at these centers offers patients the latest breakthroughs in treatment. As there are relatively few experienced teams, it is quite common for families to travel long distance to get the best care.

Financial Assistance – Since there are relatively few quality craniofacial centers, many families must travel to receive this quality care. The treatment of craniofacial patients may require from one to as many as twenty or more surgeries. Even families with insurance are often unable to meet the financial requirements to travel to receive quality care for their children. CCA offers funds for food, travel, and lodging through its financial assistance program. CCA also helps families find discounted hotel rates and donated airfare.

Website and Social Networks – www.ccakids.org offers another entry point for both parents and the public to learn about craniofacial conditions. More than one million families, healthcare professional, and others have visited this site this year from 176 countries. The website offers up-to-date information about craniofacial conditions, issues related to having a craniofacial condition, esteem-building articles and interactions and information aimed to educate the public and families with a new diagnosis. Our social media presence is often the first way families find one another. Our Facebook page has reached over 12,000 followers and our Instagram has over 6,000 followers. We distribute content on these channels that ranges from personal stories to educational information about specific syndromes, from event announcements to uplifting quotes and graphics. This daily feed from CCA bonds our community and gives them encouragement and connection to one another. We also maintain a YouTube channel where we post on-demand content that is educational and inspirational.

ChooseKind Educational Initiative – In addition to providing curriculum and books related to social/emotional learning and bullying prevention, we also provide a Speakers' Bureau of trained individuals who can give talks of varying lengths and formats from their own lived experiences. Our speakers visit and video chat with classrooms, libraries, students as well as corporations and professional groups. This program continues to evolve as our participants bring new ideas to the table and the current administrator of this program is a volunteer. We continue to add books to our ChooseKind Library and feature authors on our virtual platforms, as we seek out and curate their works.

Education Booklets – CCA has a comprehensive library of publications that focus on educating families about craniofacial conditions and associated issues. To date a series of 14 syndrome booklets have been published (and are reviewed regularly) that explain various craniofacial conditions and their treatment. Many have been translated into Spanish. The booklets are in question/answer format, and are written in easy-to-understand text. In addition, 28 information papers have been published covering issues families dealing with craniofacial conditions experience.

Newsletter – A newsletter is published three times a year to inform more than 8,000 readers of CCA activities, as well as educate families, donors, and interested parties of the latest in craniofacial treatment. The newsletter also addresses issues affecting not only the craniofacial patients but their siblings and parents as well. Subjects such as teasing, grieving, and other psychosocial issues are addressed.

Annual Family Retreat & Educational Symposium & Virtual Programs – Often considered our signature program, the Annual Family Retreat & Educational Symposium is held each June and is what the CCA families describe as a life changing experience. Each year nearly 500 people including patients, parents, siblings, grandparents, and family friends gather in together for a four-day conference-style program that features educational symposiums, inspirational speeches, group meetups, a talent show, a dance, mental health workshops, and offsite visits to local attractions. Families pay a nominal registration fee to attend and all of the activities during the weekend are provided free of charge. We move the Retreat around the country each year, to give everyone a chance to attend when it visits their region. Furthermore, we offer travel scholarships for approximately 30% of attendees who would otherwise not be able to attend without financial support. In 2022, we had our Retreat in Dallas, TX, our national headquarters. In 2023, we will host our event in Minneapolis, MN.

Public Awareness – One of the most important goals of CCA is to promote social acceptance of children and adults with facial differences. We believe that in order for the general public to accept these and any differences, they must see and understand them. We accomplish this mission in various ways, but we are always looking to "widen the circle of acceptance" for people with facial and physical differences by centering our people and stories in front of audiences, large and small.

One of the main ways we promote public awareness is our Craniofacial Acceptance Month, which we promote every September.

Family Networking & Support – CCA has a list of qualified families who are willing to communicate with families new to CCA. Being able to communicate with other parents, siblings, or patients can help family

members feel part of a larger community with others who are ready to help them through rough times, work through decisions and just "be there" for one another.

Another part of our support for families is offering care packages to children (and adults) undergoing surgeries or difficult emotional periods. Families can request these care packages via a link on our website, but we also keep an eye out for people posting on social media or contacting us, and often proactively send surprises their way, to reaffirm that they have a community who loves them and sees what they are going through. While this is a relatively small program, it often is one that receives the most feedback and the items (exclusively donated to our Care Package Closet) are small reminders of the large community rooting for our CCA Kids and Adults.

Please read on to see testimonials of program participants and CCA's financial statements.

first time retreat attendee family testimonial

by Carol Smith

Hello to our CCA family! We are the Smith family, Gary, Carol, and Savannah. We live in Statesville, North Carolina and our daughter, Savannah is 12 years old. Savannah has Pfeiffer syndrome and Turner syndrome.

This summer, we attended our first-ever CCA Family Retreat & Educational Symposium! We were so amazed at all the love that was immediately shown to our family. For the very first time, we were able to connect with other Pfeiffer families and had the opportunity to meet others who shared similar medical journeys like ours. It was so heartwarming to be able to be in a place among people who are truly understanding, accepting, and inclusive to each other.

We had so much fun making new friends and sharing our life experiences. Our family immediately felt at home and in a place where we belong! It's an amazing and comforting feeling to know that we now have all the love and support from our CCA family. We can't wait to be part of future retreats!

We are so thankful to have experienced such an amazing event. We had the time of our lives! 🥰



financial assistance testimonial

by Victoria Shay

Our son, James, was born with a rare genetic condition called **Treacher Collins syndrome (TCS)**. TCS exists on a spectrum and James is considered to have a mild case of TCS. He was born with a smaller jaw, malformed ears, hearing loss, and underdeveloped bone in his cheeks and jaw. James was diagnosed after he was born. Like so many parents before us, we experienced the overwhelming joy, love, and triumph of birth only to have it taken from us in a moment as our eyes landed on our son's face, knowing something was wrong. It's a moment you don't forget. It was that moment that catapulted onto this medical journey we are on now.

As I reflect on the first few months of James' life, I remember it as a



rollercoaster. James was able to go home a few days after he was born, and for a brief period, we thought maybe James would not need any major medical intervention. However, within a couple of months his medical team became concerned about an upper airway obstruction. As is common with so many children with TCS, James's airway is smaller than is typical. Our lives seemed to shift again as we navigated the medical world to figure out what this smaller airway would mean for James. One of the frustrating things about a rare disease is navigating a medical system that isn't familiar, or well experienced, with your syndrome. Medicine is referred to as a "practice," but having a rare disease makes it clear how much of medicine comes down to experience and opinion. There are no evidence-based treatment pathways for TCS, so having the opportunity to see an experienced and respected craniofacial team is invaluable. CCA's financial assistance helped us travel to receive a second opinion from **Seattle Children's Hospital**. Now we know we have the right resources and a team that

is on our side. James is now one year old, and his medical journey is far from over. We're still navigating the waters with his new team. Soon we will learn if it will be necessary to perform a tracheostomy on James. While the thought of that fills us with anxiety and fear, we trust our medical team. We know that if the procedure is needed, it will be the best decision because we have a team that is ready to support us through that transition. In the meantime, we can spend more of our time and mental energy focused on our little guy, who is very active, rambunctious, and curious. We hold on tight to the moments that fill our hearts with joy and refill our cup. **Thank you CCA for giving us these gifts!**



financial assistance testimonial

by Cindy Avila

We were taken by surprise when we found out we were expecting our fourth child, to know that we were going to be starting all over again with a little one. We were blessed by our family and friends that provided all the essentials we needed to start our new journey.

Zion was born one week past due and a healthy baby boy was the surprise we were hoping for. But unknown to us, this new transition in our family would come with another surprise at his one month checkup. My husband and I were excited to see how much he had grown in just one month; it was supposed to be a regular check-up with his pediatrician but our lives were forever changed at that appointment. At the end of the visit the doctor asked if we had any concerns. I mentioned I was concerned about the shape of his head and he seemed to not be able to lie on the back of his head. She proceeds to do head measurements and physically examined his head then stated she had to step out of the room to consult with her colleague. My heart sank at that moment. I knew this had to be serious. She came back in the room and it felt like she dropped a bomb on us, she diagnosed him with **cranial stenosis** (craniosynostosis). She proceeds to explain she is sending us to a specialist and the only way to fix this would be surgery on his head. We left that appointment in tears and I couldn't share the news with the rest of my family without



crying. I was devastated, scared, sad, anxious but most importantly I felt helpless. I decided to do some research on his diagnosis because up until this point in my life I had never heard of it. That's when I came across CCA's website. I was beyond excited to find such resources with first hand testimony of families that have been through the same problem with their babies. So we began to start the process of doctors' appointments and meeting with his surgical team. We were sent to his specialist which was 90 miles from our home, but were determined to do whatever it took to get the best care possible. His surgery would only be a few days after he turned three months. This was consuming all my emotions and attention. We then realized we would have to make a trip and stay nearby to take turns during his hospitalization. His specialist was in Los Angeles and the cost of this trip was beyond what we could afford. So a few weeks before his surgery I found myself back on the CCA



website reading and came across a financial assistance application to help offset the cost of travel for his surgery. CCA was quick to respond and approved our application, I don't know how to put into words what this meant for our family. The financial stress was relieved and we were able to put all our attention on caring for our baby. His surgery was a success and he is now 5 months old and has adjusted to wearing his helmet full time. CCA has been a true blessing to our family. 🌸



legacy giving

Simply put, planned giving enables you to make a meaningful gift to CCA that reflects your beliefs and values. Your gift will create an enduring legacy by supporting CCA Kids during your lifetime and beyond. We are happy to help you choose the program or services that mean the most to you, as you make your estate plans.

To learn more about how to leave your mark on the world through supporting CCA Kids and Families, visit:



ccakids.org/legacy-planned-giving/
or email **Christine** at candler@ccakids.com