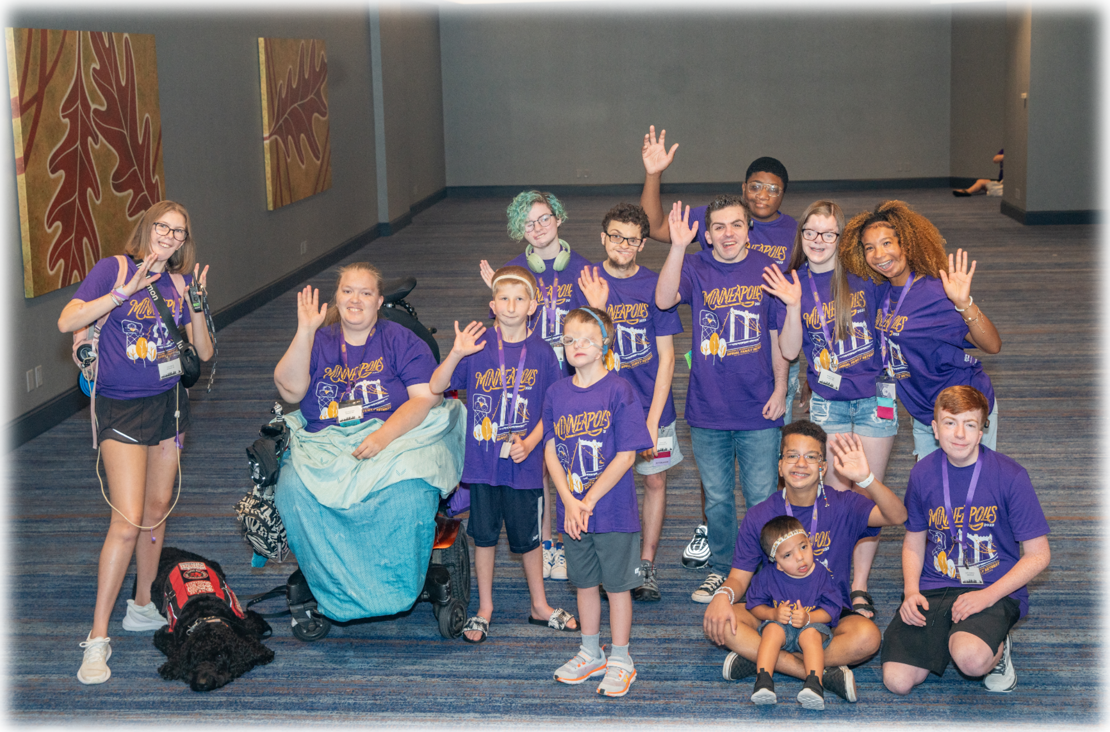
children's craniofacial association

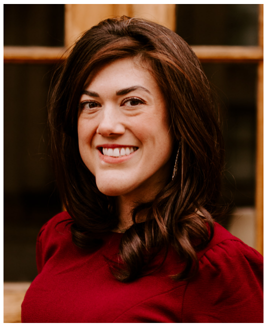
2023



"The Future is Inclusive"

CCA's 19th Annual Craniofacial Acceptance Month Them

Message from the Executive Director



There are definitely years that spark awakening to new opportunities and new obligations, and 2023 certainly fits into that category for CCA. By no accident, our Craniofacial Acceptance Month theme was, “The Future is Inclusive.” We don’t *only* mean that we see a global future of our vision “where all people are accepted for who they are, not how they look,” but also, we mean that our own organization’s future will be more inclusive.

It started a few years prior, when working with David Roche, Dr. Jaz Gray, Rasheera Dopson, and Khadija Moten, our Outreach Director, to intentionally be more inclusive in our online content. These videos, educational tools, and inspirational materials needed to be more representative of our community. Plus, we wanted people to see and hear more of our story than just the craniofacial journey. Yes, that is our foundation, but our lives include so much more than medical appointments, surgeries, and combatting stigma. They are rich in family traditions, career aspirations, and personal style. They are full of joy and triumph, and the struggles we share are not exclusive to only the craniofacial community.

We realized that to be more inclusive, we needed to share more: more people, more paths, and more advocacy efforts. We teamed up with Ear Community to advocate for Ally’s Act, and the American Cleft Palate-Craniofacial Association (ACPA) to rally for the ELSA Act (Ensuring Lasting Smiles). We continued our collaboration with ACPA in other ways, and formally announced our relationship to the craniofacial community in October. Another wonderful organization, Face Equality International (FEI), is spearheading the campaign that facial differences are a human rights issue, and we continued to support their work and join alongside them in these efforts at recognition and protection for people with facial differences. We also partnered with The Moebius Syndrome Foundation and participated in their Conference in July, which offered connections and learning that help us further advance our joint goals.

We also took an immense amount of constructive feedback on our programs and began implementing ways to make them more inclusive. For example, we learned at our 2023 Annual Family Retreat & Educational Symposium, that audio-visual needs must be addressed to make our Retreat inclusive of participation of attendees. We are excited to share that we will be offering live captioning at our Symposium in 2024 and are still exploring ways to make our events more accessible to more people. This is also true for our virtual programs. While we are still working to find tools and implement them into our content, our commitment to this inclusivity will not waiver, and we are so grateful for those who helped us understand what we need to offer and to those who are helping us locate and fund those resources.

Furthermore, the CCA Board of Directors and Staff underwent training in November of 2023 to learn about the ROI of Disability Inclusive Content and are working to implement content review standards to make sure the content we create is not produced in a vacuum, but is truly representative of the community we serve. We see the work ahead is a long-term commitment and as a small organization, we have to be creative in finding ways to change and grow with limited resources. We aim to steward donor dollars to areas of the highest need, without neglecting the imperative to grow alongside our children and families and represent their interests and insights appropriately.

The light of inclusivity led our mission in our tried-and-true programs, as well. Our Financial Assistance program for medical travel hit a record level in 2023. **This year, we supported 60 families on 80 trips, at an average of $681 per trip. While the amount of each trip varied widely, over $70,000 was awarded to families seeking care for their children and young adults.** We also mailed out **110 care packages** to kids recovering from surgeries or who needed an extra “pick me up” from their CCA friends. **Annie Reeves, our Program Director**, managed all of these efforts, along with other programs like the coordinating our quarterly newsletters, craniofacial center collaboration, special projects for news outlets and media, Craniofacial Acceptance month activities, and the ever-critical family networking opportunities. She also “donates her birthday,” to CCA each year, and this year her birthday gifts totaled **over $10,000 in donations for CCA**! She is truly a champion for our families.

Our virtual programs also hit record levels this year with **31 videos** being created, edited, and added to our video library, providing on-demand, evergreen content for people searching the web for information on craniofacial syndromes and facial differences. Our programs fall into two main groups: educational and supportive. The educational side of our virtual content is managed by our **Outreach Director, Khadija Moten**, who seeks out members from the community and directs the production of interviews, webinars, story times, and panels. She has spent the last two years collaborating with our star intern, **Aaliyah Booker**, whose personality and talent shine across our social platforms as she engages with new and veteran voices.

Speaking of Aaliyah, she was also the winner of the second Annual David Roche Award for Excellence in Advocacy. Her work has brought so many conversations to the forefront and her efforts, while she is still in college herself studying biology, is a testament to her passion and dedication to the craniofacial community.

The entire process of selecting a winner for the David Roche Award was an extremely emotional experience. **There were 71 nominations submitted, representing 29 amazing people.** What we saw was advocacy that went way beyond public speaking. Stories poured in of grassroots advocacy: organizing parent support groups; working tirelessly to connect new parents to veteran parents, patients to doctors and hospitals; and offering hours of supportive communication. We saw students broadcasting "different is cool" on TikTok and being upstanders when a classmate was being bullied. All of these types of advocacies and more spilled out of grateful hearts into an online form that I got to read. A selection of the nominations was read during the September live virtual award show, and in addition to Aaliyah, we also awarded two posthumous awards **to Paul Patrick "PJ" Reynafarje** and **R. Scott Guzzo**.

In fact, losing PJ, Scott, and our dear **Dr. Francis Smith**, was also an important defining part of 2023. These losses hurt our community so deeply. The grief was palpable and 2023 was a very heavy year. This led to the need for much more support among our community and **Kara Jackman, our Adult Programs Coordinator**, stepped up and stepped in to help offer times for her peers to come together and process not only these losses, but also the ebb and flow of daily life. Kara continued to offer her monthly support group for Adults and Alums, and added this year a monthly call for Caregivers on Zoom. She also held a few pop-up sessions for periods of intense emotions, both in person and virtually. Kara continues her professional development as a peer-mentor and excels at creating a welcome and safe space for our adults and caregivers to go to feel seen, heard, and supported. **In 2023, we held 32 support group events.**

Crystal Kouri, our new Educational Engagement Coordinator, continued as volunteer staff, despite losing her son in January. Crystal continues the #ChooseKind initiative, which distributes books and curriculum to educators across the country. Her love of PJ and wanting to continue his legacy keeps her moving forward with our organization, and for that we extended our deepest gratitude. We know that students benefit from this programming, and in 2023, we **reached 3,838 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**, produced an amazing surplus year for CCA in 2023. Her work included helping us secure a second year with the PAR Golf Event as the selected charity beneficiary. Not only did they raise $80,000 for CCA Kids, but they also helped secure a new office location for the CCA headquarters, which moved into in May 2023. This location, at 15851 Dallas Pkwy. Ste. 245, in Addison, 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 managing special events for CCA including The Meck Invitational (raising over $175,000 for CCA) and the HHI Christmas Gala (over $10,000 net), and the Pest R'Us Anniversary Auction (over $13,000 in funding), Christine continued Year 3 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 2023, 76% 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 2023. 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 2024, 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 – and helping us create this more inclusive future for all.

With gratitude,

Erica Klauber

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 2023, we host our event in Minneapolis, MN, and in 2024, we will host the event in Baltimore, MD.

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.

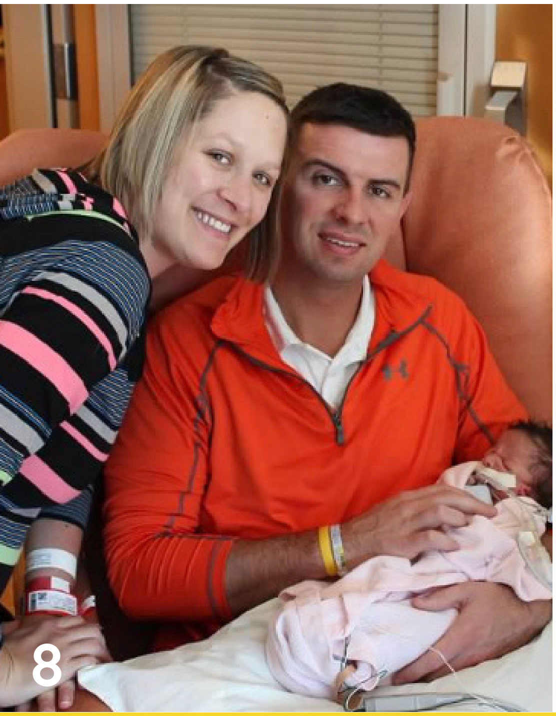
Another part of our support for families is offering care packages to children (and adults) undergoing surgeries or difficult emotional periods. Families can request these care packages via a link on our website, but we also keep an eye out for people posting on social media or contacting us, and often 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

by Whitney Wright

October 4, 2013 is a day we will never forget, for more reasons than just the fact we welcomed our first child into our lives. We were high school sweethearts, but waited many years to get married. Once we were married, we knew we wanted a family right away. There are no words to explain the feeling of finding out you are expecting a baby. It was something I had dreamt about for years and absolutely could not wait to be a mom. I felt good throughout the first few weeks of my pregnancy and everything looked good at my first doctors' appointment. When it came time for the 20-week anatomy scan, we were so excited to find out whether we were having a girl or boy. We had a gender reveal planned for that evening to share the big news with our family. Everything checked out except the sonographer could not get a good profile picture of the baby, but the doctor brushed it off as no big deal and we would try again at a later ultrasound. We celebrated that night we were having a baby GIRL!



As the pregnancy progressed, we continued to have difficulty getting a profile picture and I started measuring 2-3 weeks ahead of schedule because of extra amniotic fluid. Despite multiple ultrasounds, non-stress tests, and even a visit with the high-risk obstetrician, there was no explanation for the extra fluid and what appeared to be a small jaw. At 39 weeks pregnant I was induced due to the poly-hydramnios. I was in labor all day and our little girl just didn't want to join us. I was taken for a cesarean section at 7:00pm and at 7:29pm Harper JoLee was born. I immediately knew something was wrong because I did not hear her cry. I can still remember lying on the operating table asking the doctor what was wrong and him telling me, "Just give her a minute."

The neonatologist came over to speak to us a few minutes later and explained Harper was having trouble breathing on her own and they were attempting to intubate her, but her small jaw was making it difficult. She also explained that Harper had microtia (small or absent ears), a cleft palate, and no cheek bones. I can still hear her naming off all of the differences, but all I wanted was to hold and see my baby. My husband and I had to wait two hours before we could even be wheeled up to the NICU to see her. Seeing Harper for the first time was magical. She had dark curly hair, long dainty fingers, very long eyelashes and she was much smaller than I was expecting. I couldn't stop smiling and just wanted to hold her. That night I slept one floor away as the NICU nurses kept a close eye on our sweet girl.

The next morning was the day we got her diagnosis. I remember my obstetrician sitting on the bed next to me and explained he believed Harper had Treacher Collins syndrome. He said we would have to get genetic testing to be sure, but based on her appearance, he felt confident it was TCS. I had never heard of TCS, but I was ready to learn all I could about the syndrome. I was able to connect with families of young children with similar stories on social media, which helped with the shock of the diagnosis.

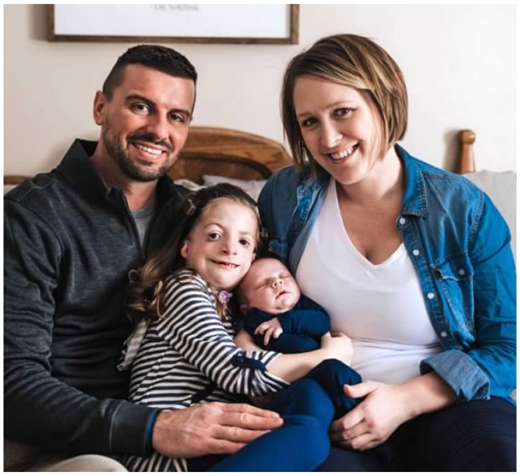
In the five weeks we spend in the NICU, Harper had a tracheostomy placed at three days old and a g-tube placed at four weeks old. We were able to go home after five weeks in the NICU. It was so good to be home, but our routine was very different than what I had expected. I remember someone shared the poem "Welcome to Holland" with me shortly after Harper was born. I could relate to the poem in many ways. I may not have expected or planned for my baby to have a tracheostomy, a feeding tube and be hard of hearing, but I was going to embrace every minute with her and make the most of it because we were chosen to be her parents for a reason and for that I will be forever grateful.

Harper had her first internal jaw distraction at six months old in hopes to move her jaw and open her airway enough to have her trach removed. At 11 months, her cleft palate was repaired. She started eating more food by mouth and gaining weight. She was thriving. She went on to have a second jaw distraction at four years

first time attendee

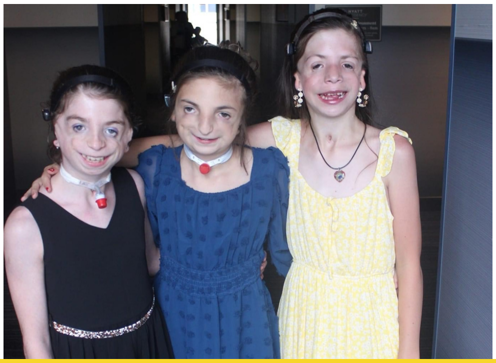
, continued from pg 8

old, again in hopes to have the trach removed. Harper has had around 12 surgeries total since she was born. Her most recent surgery was the LeFort III with Rigid External Distraction Device at **Dayton Children's Hospital** with **Dr. Christopher Gordon**. This was her most intense surgery, but it also her most successful surgery. The procedure moved her jaw enough and opened her airway enough that she was able to remove her tracheostomy on January 20, 2023 after 9 years!

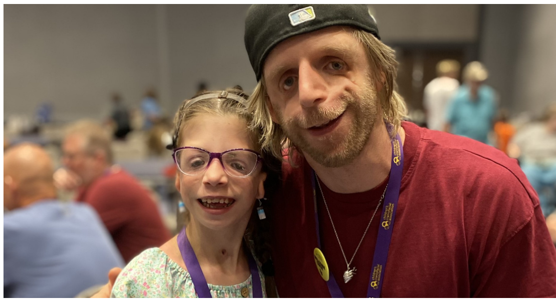


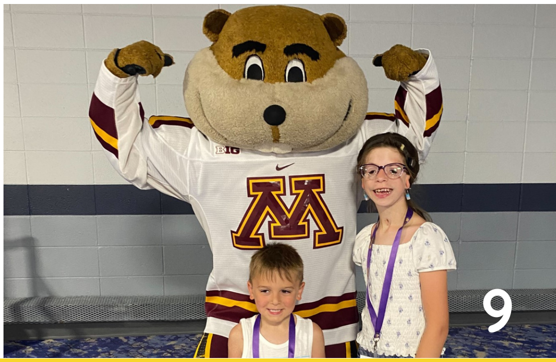
Due to the many surgeries and traveling for surgery, we were never able to make it to the CCA Retreat, until this year. Minnesota is only about four hours from our home in Iowa so we knew we were going to make it happen this year. When we pulled up to the Hyatt Regency Hotel in Minneapolis, Harper looked out the window and said, "Dad, look! They look just like me!" Harper had seen other children with TCS through social media, but she had met very few children with TCS in her 9 years. It was so heartwarming to know she was going to have a weekend to meet children and adults that looked just like her and she didn't have to worry about people staring or asking questions about her hearing aids or make comments about the way she looks. We have always had a motto since she was born and that is "BE BRAVE, BE YOU." We have always encouraged her to be herself and use the stares and questions as teaching moments rather than shying away from them. We live in a small town south of Des Moines, Iowa and our community has been so accepting since the day Harper was born. I remember going to the grocery store when she was little and people would say "hi" to her, that I didn't even know!

The Retreat Weekend was a life changing weekend that we will never forget. We cried, we laughed, we met TONS of new friends and DANCED our hearts out. Harper connected with two other girls her age with TCS from day one. You would have never known they had just met by the way they played together all weekend. They have even stayed in touch since the Retreat ended which has been great for Harper. She wants to introduce her new friends to her friends and family back home when they get the chance to video chat. Another fun thing to watch was the older teenage girls take the younger girls under their wings and include them at the dance. Harper danced all night long with the older girls and practically had to be carried up to our room she was so tired by the end of the dance. I hope someday Harper is that teenage girl making the younger girls feel special and seen at the Retreat. I know it is something Harper will never forget.



As parents it was so nice to talk to other parents of children with TCS to hear their experiences and compare experiences. It was nice to know we aren't alone and there is a whole group of parents out there going through the same highs and lows that we have. I cannot put into words how life changing this experience was for our entire family, but most of all for Harper. I hope going to the Retreats will give her the confidence to be her authentic self and love who God made her to be. I hope she makes lifelong friends and gains a whole other family through these experiences. She's counting down the days until Baltimore!



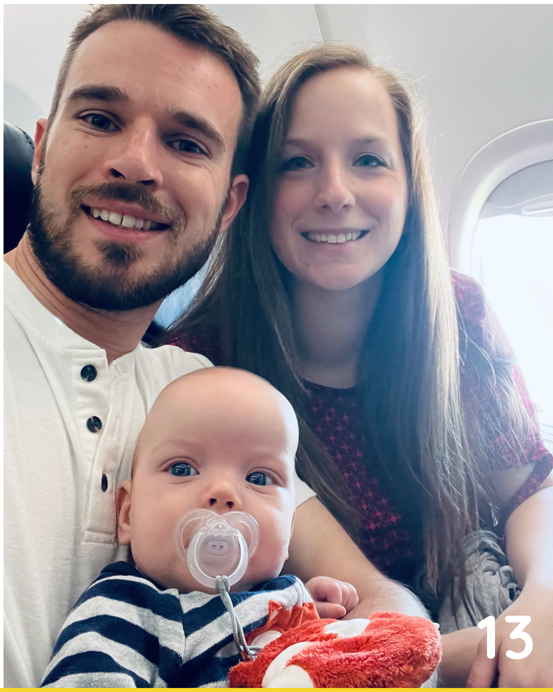


financial assistance testimonial

by Stephanie Swanson

On December 30th around 3:00 pm, my husband Ryan and I welcomed our first child into the world, **Parker James Swanson**- weighing 8 pounds 4 ounces. It was a rough 36-hour labor ending up in a C-section, but God protected me and so many people were praying for our little guy! After such a rough birth, Parker was a breath of fresh air, sleeping well, eating well, and allowing me to recover without a problem. When he reached one month we began to notice his head was developing in an unusual way. His forehead was bulging forward and the back of his head was very elongated. After an extensive online search and feeling the telltale ridge on the top of his head, I was pretty convinced that he had sagittal craniosynostosis (a condition where the top skull suture fuses early and if not corrected - by removing a portion of the skull or reshaping the skull entirely- it can lead to many brain issues). As the reality of the potential diagnosis began to set in, I was a wreck! It seemed like he was facing such a huge surgery, which I didn't know the least about! He was such a perfect and sweet baby. I couldn't stand the thought of him suffering from any pain. I was a new mom, still getting over the trauma of my birthing experience and feeling so inexperienced with everything. So, I began researching like crazy and joined as many parent groups on Facebook as I could. Through the Facebook groups I learned of key doctors around the US that were pioneers in the craniosynostosis field, had such amazing results (minimal scarring, blood loss, and minimal anesthesia time) and rarely had patients that required follow-up surgery (which the thought of a second surgery terrified me). At first, I wrote those possibilities off as I did not think there was any way we would be able to travel such distances for that amazing care. I was in a predicament, not having a local neurosurgeon that understood Parker's condition adequately and knowing there was better care available, but having no means to get that care for my son. I was so torn and emotionally in pieces! At just the right time I came across several posts on Facebook that mentioned CCA and I began to see a light shine through all the crazy fog I was working through! The realization that there were people that cared so much about my little boy and him getting the best care that they provided funds for us to do that not only blew my mind, but touched my heart deeply! After he was officially diagnosed by the neurosurgeon, I contacted **Annie** and she responded very quickly, calmed my fears and helped me work through the application process.

Because of the generosity of CCA covering travel, lodging, and food, we were able to travel to El Paso, Texas, at the end of April to be under the care of **Dr. Jimenez**. I cannot explain the relief that there is of knowing your child is in the hands of the best of the best. Yes, it was tremendously hard to hand him over for surgery and sit in the waiting room for what felt like forever! However, knowing such an experienced surgeon was operating on him gave so much peace through the whole process! When Dr. Jimenez finished surgery and let us know how it went, he informed us that Parker's brain pressure was at 24 when they measured it before surgery (normal is 3-4)! At that point we realized to a fuller degree how important it was that we went to Dr. Jimenez. Our local neurosurgeon said that Parker's skull issue was purely cosmetic and would cause no brain pressure, and it is crazy how wrong he was! It was so vital that Parker have the surgery done this early, and with Dr. Jimenez, who understands the brain pressure situation like none other.



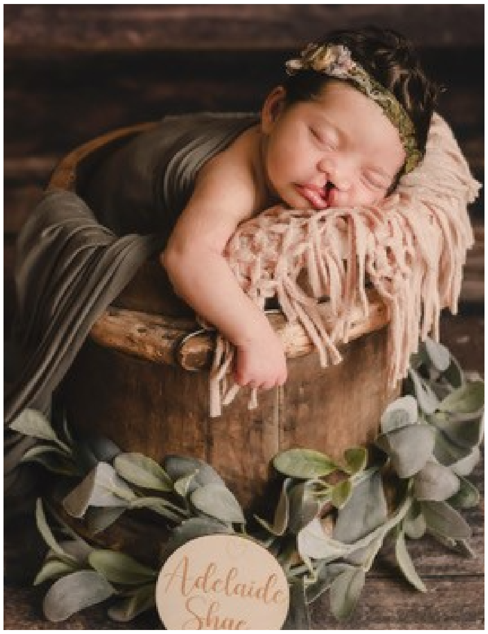
financial assistance testimonial

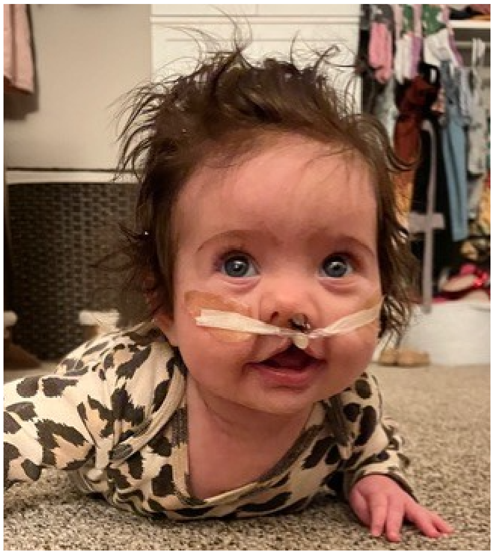
by Jessica Puccetti-Hoffman

My happy, resilient little girl, **Adelaide Shae**, was born on July 23rd, 2022 in Oregon. We found out she would be born with a left-sided cleft lip and palate on my 20-week ultrasound. Addy may need around 10-20 surgeries before she is 18. She has the potential for having hearing issues (she has failed both hearing tests so far, but her team is hopeful she will have normal hearing after palatal surgery and ear tubes), speech and language delays, potential chronic ear infections, and misaligned/missing teeth.

We live about 3 1/2 hours away from Adelaide's Craniofacial team, we make this drive for all of her cleft-related appointments. We are lucky enough to have a pediatric orthodontist on her team, **Dr. Judah Garfinkle**. Dr. Garfinkle created a device for Adelaide called nasoalveolar molding (NAM), which is a pre-surgical therapy that reduces the size of the lip, gums and nose before her first surgery. We drive to Portland every week to every other week to have Dr. Garfinkle adjust this device. Not only is this drive long, but usually includes dangerous conditions during the winter, between freezing fog, black ice, and snow storms. Oftentimes, we drive up the day before the appointment, stay the night, and then drive home the next day. This quickly became hard on us financially.

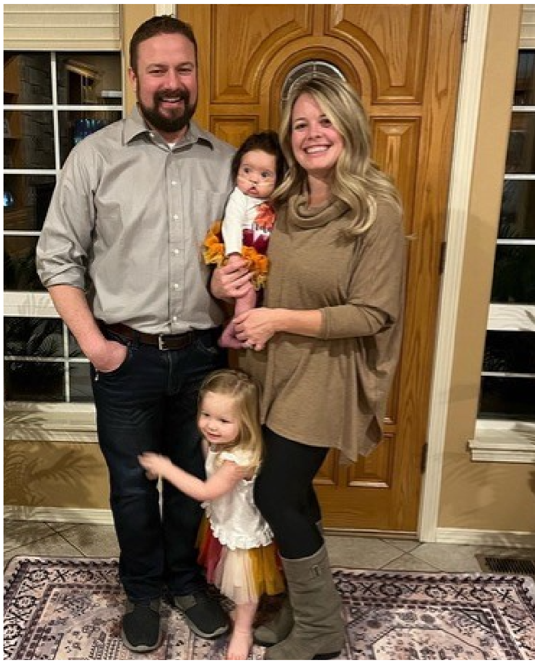
The costs of travel, accommodations, additional time away from work needed for her appointments, and medical costs that haven't been covered by insurance began piling up. We were lucky to run into a family at one of Addy's NAM appointments, whom had been through the same procedures with their son two years prior. They had done the NAM device through Dr. Garfinkle and just happened to live in the town right next to us. They had done the same drives to and from Portland and found the extra costs to be a strain. This family found Children's Craniofacial Association and had only amazing things to say about this organization as well as all the help they received through them.

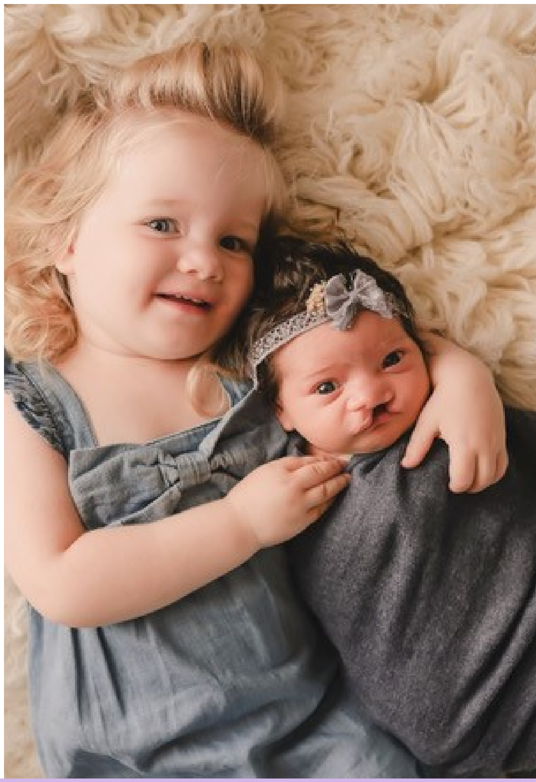




I contacted CCA the next week and was directed to **Annie**, the Program Director. Annie is such a blessing and has been so incredible for us through this journey. Thank you CCA for the financial assistance and helping us give our Adelaide the best care possible. We appreciate you all and the amazing work you do!

- Jessica, Beau, Seodna & Adelaide





ccateen

meet jace

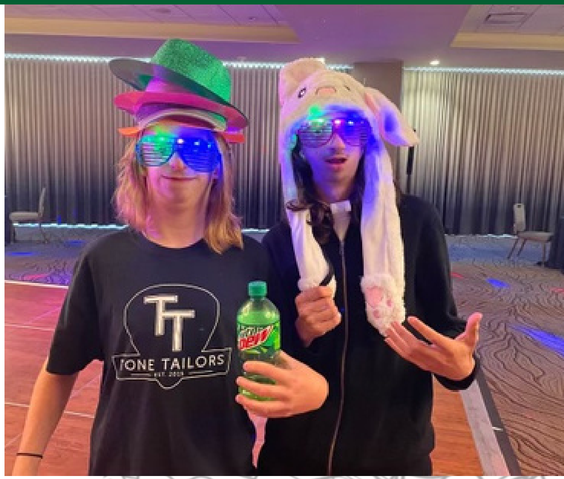
We all have a story to be told and mine goes a little something like this:

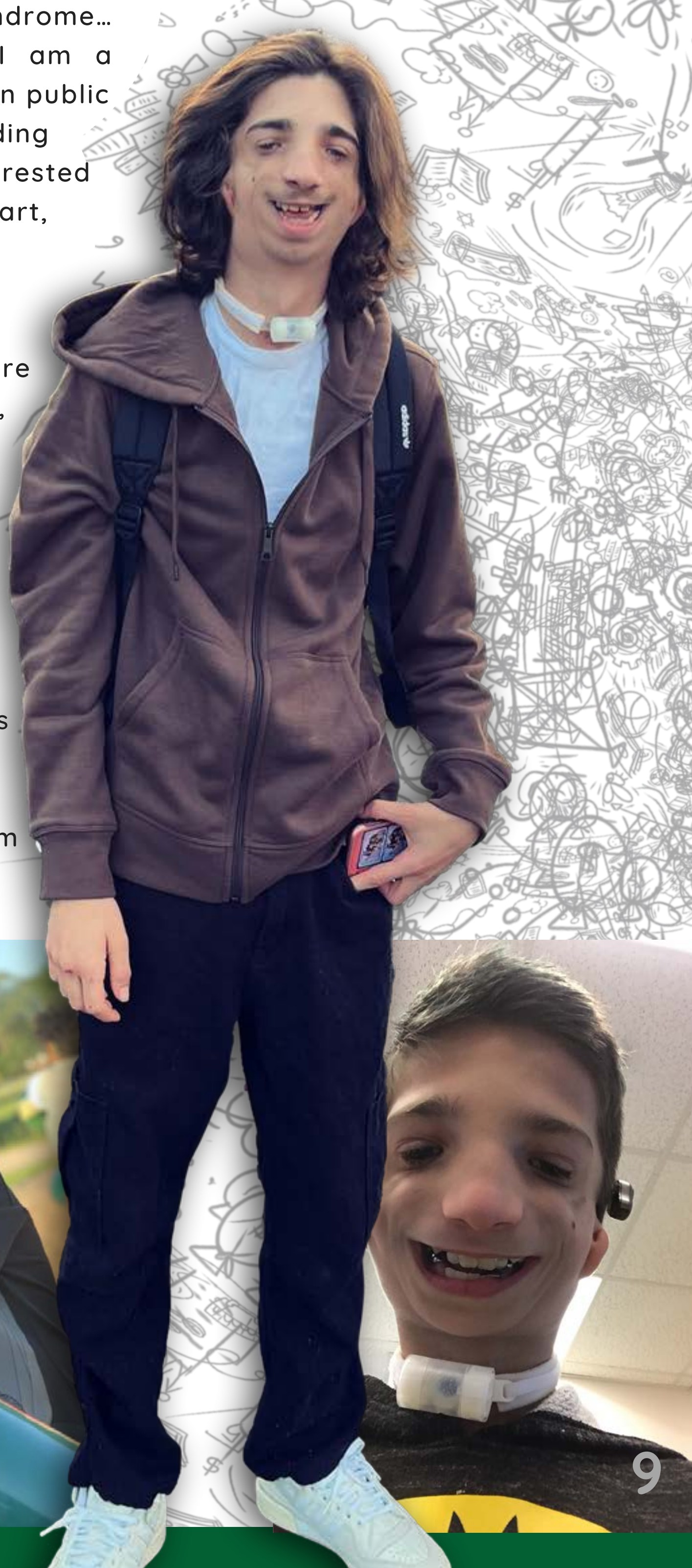
I was named Jace on July 14 of 2008. I was born with Treacher Collins syndrome. In my case, it affects my ears, eyes, jaw, breathing and eating. My condition was unknown to us therefore like many others with the same condition, the birth can be very life threatening. The next couple of years were difficult for me, but just like most things I battled through. For the next 13 years, the same three nurses helped my family care for and raise me. I can't count between my fingers and toes how many surgeries I've had. Each one I always had so much support and so many supporters. It took a village of people to keep me alive and get me to where I am today.

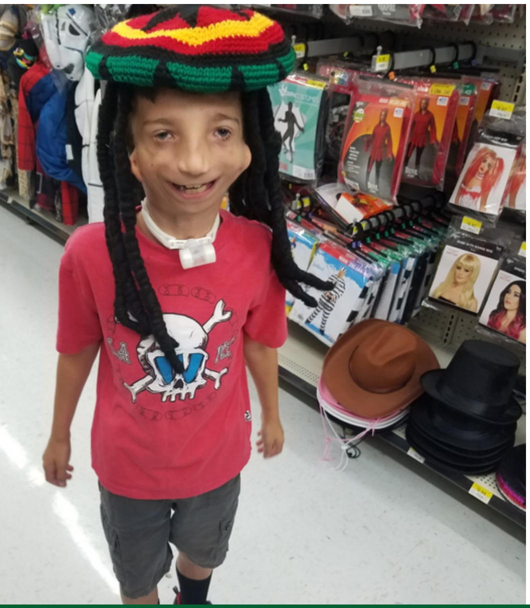
I'm an average 15-year-old boy. I have two siblings. An older brother and a younger sister. My mom always jokes about me having middle child syndrome… like it's a bad thing. I am a freshman in my hometown public high school. I enjoy spending time with friends. I'm interested in various things such as art, video games and creating music.

As I mature, I become more independent, more social, and more confident. I'm starting to make more friends going more places and trying new things.

Emotionally I go through good times and bad times but I feel like there's always a brighter side to things. As of right now, I'm doing bigger and better things with my life.







children's craniofacial association
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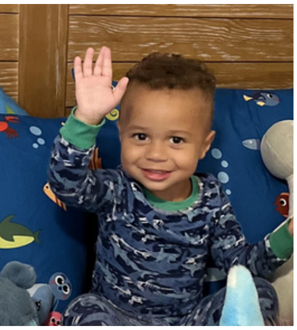
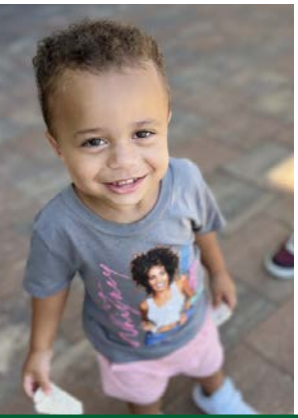
leave us a review! on Great NonProfits @ greatnonprofits.org/org/childrens-craniofacial-association

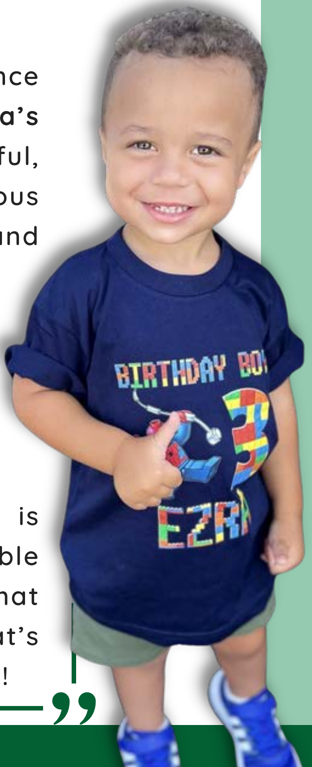
financial assistance testimonial

by Brittany Williams





> CCA has provided financial assistance for our lodging during my son **Ezra's** surgery. To say that we are grateful, is an understatement. CCA's generous assistance has givenmy husband and I the ability to focus on my son's surgery and recovery, rather than worrying about any money related issue. **Annie Reeves** has been our point of contact from the start and has been nothing but wonderfully helpful. When my son is done with treatment and we are able - we will be donating to CCA, so that another family can focus on what's important. Thank you so much CCA!!



voice **214. 570.9099**
toll-free **800.535.3643**
url **ccakids.org**

CHILDREN'S CRANIOFACIAL ASSOCIATION

FINANCIAL STATEMENTS
AND
INDEPENDENT AUDITORS' REPORT

DECEMBER 31, 2023

Children's Craniofacial Association
Table of Contents
December 31, 2023

SST
ACCOUNTANTS & CONSULTANTS

INDEPENDENT AUDITORS' REPORT

To the Board of Directors
Children's Craniofacial Association

Report on the Audit of the Financial Statements

Opinion

We have audited the accompanying financial statements of Children's Craniofacial Association, which comprise the statement of financial position as of December 31, 2023, and the related statements of activities and changes in net assets, functional expenses, and cash flows for the year then ended, and the related notes to the financial statements.

In our opinion, the accompanying financial statements present fairly, in all material respects, the financial position of Children's Craniofacial Association as of December 31, 2023, and the changes in its net assets and its cash flows for the year then ended in accordance with accounting principles generally accepted in the United States of America.

Basis for Opinion

We conducted our audit in accordance with auditing standards generally accepted in the United States of America (GAAS). Our responsibilities under those standards are further described in the Auditors' Responsibilities for the Audit of the Financial Statements section of our report. We are required to be independent of Children's Craniofacial Association and to meet our other ethical responsibilities, in accordance with the relevant ethical requirements relating to our audit. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Responsibilities of Management for the Financial Statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with accounting principles generally accepted in the United States of America, and for the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, management is required to evaluate whether there are conditions or events, considered in the aggregate, that raise substantial doubt about Children's Craniofacial Association's ability to continue as a going concern for one year after the date that the financial statements are issued.

Auditors' Responsibilities for the Audit of the Financial Statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditors' report that includes our opinion. Reasonable assurance is a high level of assurance but is not absolute assurance and therefore is not a guarantee that an audit conducted in accordance with GAAS will always detect a material misstatement when it exists. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control. Misstatements are considered material if there is a substantial likelihood that, individually or in the aggregate, they would influence the judgment made by a reasonable user based on the financial statements.

In performing an audit in accordance with GAAS, we:

- Exercise professional judgment and maintain professional skepticism throughout the audit.
- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, and design and perform audit procedures responsive to those risks. Such procedures include examining, on a test basis, evidence regarding the amounts and disclosures in the financial statements.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of Children's Craniofacial Association's internal control. Accordingly, no such opinion is expressed.
- Evaluate the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluate the overall presentation of the financial statements.
- Conclude whether, in our judgment, there are conditions or events, considered in the aggregate, that raise substantial doubt about Children's Craniofacial Association's ability to continue as a going concern for a reasonable period of time.

We are required to communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit, significant audit findings, and certain internal control–related matters that we identified during the audit.

SST Accountants & Consultants

SST Accountants & Consultants PLLC

August 29, 2024

Children's Craniofacial Association
Statement of Financial Position
December 31, 2023

ASSETS

Cash and cash equivalents	$ 757,559
Investments	838,558
Prepaid expenses	30,797
Cash surrender value of life insurance policies	33,031
Deposit	2,334
Operating lease right-of-use assets	211,688
TOTAL ASSETS	$ 1,873,967

LIABILITIES AND NET ASSETS

Liabilities	
Accounts payable and accrued expenses	24,333
Deferred revenue	6,307
Operating lease liabilities	216,285
Total Liabilities	246,925
Net Assets	
Without donor restrictions	1,613,934
With donor restrictions	13,108
Total Net Assets	1,627,042
TOTAL LIABILITIES AND NET ASSETS	$ 1,873,967

The accompanying notes are an integral part of this financial statement.

Children's Craniofacial Association
Statement of Activities and Changes in Net Assets
For the Year Ended December 31, 2023

	Without Donor Restrictions	With Donor Restrictions	Total
Revenues and Support			
Contributions and grants	$ 397,467	$ 68,000	$ 465,467
Special events, net of direct donor benefit of $77,231	299,014	-	299,014
Program service fees	19,301	-	19,301
Other income	3,748	-	3,748
Investment return, net	110,387	-	110,387
Change in cash surrender value of life insurance policies	11,252	-	11,252
	841,169	68,000	909,169
Net assets released from restrictions	64,892	(64,892)	-
Total Revenues and Support	906,061	3,108	909,169
Expenses			
Program services	577,190	-	577,190
Supporting services	76,221	-	76,221
Fundraising	110,512	-	110,512
Total Expenses	763,923	-	763,923
Change in Net Assets	142,138	3,108	145,246
Net Assets, Beginning of year	1,471,796	10,000	1,481,796
Net Assets, End of year	$ 1,613,934	$ 13,108	$ 1,627,042

The accompanying notes are an integral part of this financial statement.

Children's Craniofacial Association
Statement of Functional Expenses
For the Year Ended December 31, 2023

	Program Services	Supporting Services		
	Education and Assistance	Management and General	Fundraising	Total
Salaries and related expenses	$ 240,790	$ 15,610	$ 78,049	$ 334,449
Bank charges	-	1,244	9,350	10,594
Dues and subscriptions	1,710	7,254	8,246	17,210
Equipment rental	1,251	95	-	1,346
Events	198,902	-	1,000	199,902
Individual assistance	67,201	-	-	67,201
Insurance	-	3,997	-	3,997
Office expenses	13,727	2,298	-	16,025
Postage	8,887	382	2,612	11,881
Printing	7,124	-	2,793	9,917
Professional fees	10,074	24,909	764	35,747
Public awareness	-	-	429	429
Rent	19,047	4,725	2,586	26,358
Telephone	1,124	-	-	1,124
Travel and entertainment	7,353	15,707	4,683	27,743
	$ 577,190	$ 76,221	$ 110,512	$ 763,923

The accompanying notes are an integral part of this financial statement.

Children's Craniofacial Association
Statement of Cash Flows
For the Year Ended December 31, 2023

Cash Flows From Operating Activities	
Change in Net Assets	$ 145,246
Adjustments to reconcile change in net assets to net cash provided by (used in) operating activities:	
Amortization of operating lease right-of-use assets	20,573
Unrealized gains on investments	(65,634)
Realized gains on investments	(12,385)
Change in cash surrender value of life insurance policies	(11,252)
Change in operating assets and liabilities:	
Contributions receivable	12,303
Prepaid expenses	(25,472)
Deposit	(607)
Accounts payable and accrued expenses	7,010
Deferred revenue	(23,653)
Operating lease liabilities	(16,668)
Net Cash Provided by Operating Activities	29,461
Cash Flows From Investing Activities	
Proceeds from sale of investments	608,696
Purchases of investments	(929,020)
Net Cash Used in Investing Activities	(320,324)
Change in Cash and Cash Equivalents	(290,863)
Cash and Cash Equivalents, Beginning of Year	1,048,422
Cash and Cash Equivalents, End of Year	$ 757,559
Supplemental Disclosure of Cash Flow Information	
Right-of-use assets obtained in exchange for lease liabilities	$ 223,900

The accompanying notes are an integral part of this financial statement.

Note 1: Summary of Accounting Polices

The summary of significant accounting policies of Children's Craniofacial Association (Association) is presented to assist in understanding the financial statements. The financial statements and notes are representations of the Association's management, who is responsible for the fairness and objectivity embodied in the financial statements. These accounting policies conform to accounting principles generally accepted in the United States of America (U.S. GAAP) and have been consistently applied in the preparation of the financial statements.

Organization

The Association is a 501(c)(3) nonprofit organization which was incorporated in 1989 under the laws of the State of Texas. The Association is organized exclusively to assist facially disfigured individuals and their families to live positive, enriched lives. The Association addresses medical, financial, psychosocial, emotional, and educational concerns on a national and international basis. The Association promotes education, treatment, and emotional support on behalf of persons with craniofacial deformities. The Association is supported primarily through donor contributions, grants, and fundraising activities.

Financial Statement Presentation

Net assets and revenues, expenses, gains, and losses are classified based on the existence or absence of donor-imposed restrictions. Accordingly, net assets and changes therein are classified as follows:

> Net Assets Without Donor Restrictions - Net assets not subject to donor-imposed stipulations. Net assets without donor restrictions may be designated for specific purposes by action of the board of directors.
>
> Net Assets With Donor Restrictions - Net assets subject to donor-imposed stipulations that may or will be met by actions of the Association and/or the passage of time.

Some net assets with donor restrictions include a stipulation that assets provided be maintained permanently (perpetual in nature) while permitting the Association to expend the income generated by the assets in accordance with the provisions of additional donor-imposed stipulations or a board of directors approved spending policy. As of December 31, 2023, no such net assets restrictions existed.

Revenues are reported as increases in net assets without donor restrictions unless use of the related asset is limited by donor-imposed restrictions. Expenses are reported as decreases in net assets without donor restrictions. Gains and losses are reported as increases or decreases in net assets without donor restrictions, unless their use is restricted by explicit donor stipulation or by law. Expirations of net assets with donor restrictions (i.e., the donor-stipulated purpose has been fulfilled and/or the stipulated time period has elapsed) are reported as reclassifications between the applicable classes of net assets.

Note 1: Summary of Accounting Polices (Continued)

Cash and Cash Equivalents

For purposes of the statement of cash flows, the Association considers all highly liquid investments with original maturity dates of three months or less to be cash equivalents. Highly liquid investments held within an investment broker account are considered cash equivalents. The Association had cash equivalents of $425,994 as of December 31, 2023. The Association places its cash and cash equivalents, which, at times, may exceed federally insured limits, with high-credit quality financial institutions. The Association has not experienced any losses on such amounts.

Contributions Receivables

Contributions receivable consist of unconditional promises to give from various donors. Management evaluates the contributions receivable for collectability based on dues dates and provides an allowance for estimated uncollectible accounts.

Investments

The Association's investments consist of mutual funds and exchange traded funds held at a brokerage firm. The mutual funds and exchange traded funds are carried at fair value. Investments are exposed to various risks such as interest rate, market and credit risks. Due to the level of risk associated with certain investments, it is at least reasonably possible that changes in the values of investment securities will occur in the near term and that such changes could materially affect the amounts reported in the accompanying statement of financial position.

Investment return includes dividend, interest and other investment income; realized and unrealized gains and losses on investments carried at fair value; and realized gains and losses on other investments, less external and direct internal investment expenses.

Cash Surrender Value of Life Insurance Policies

Cash surrender value of life insurance policies is recorded at fair value and is based on the Association's share of cash surrender value of the respective life insurance policies as presented by the insurance company. Changes in the cash surrender value of life insurance policies are recognized in the statement of activities and changes in net assets in the period in which the change occurs.

The Association does not intend to surrender these policies in the near term and expects to maintain them for their insurance coverage and investment potential.

Note 1: Summary of Accounting Polices (Continued)

Property and Equipment

Property and equipment are stated at cost when purchased or fair value at the date of donation, less accumulated depreciation and amortization. Property and equipment in excess of $2,500 is capitalized at cost or estimated fair market value of donated assets at date of donation. Major expenditures which substantially increase useful lives are capitalized. Maintenance and repairs which do not improve or extend the lives of the respective assets, are expensed when incurred. When property and equipment are sold or otherwise disposed of, the asset and related accumulated depreciation and amortization are removed, and any gain or loss is included in the statement of activities and changes in net assets. There was no property and equipment as of December 31, 2023.

Revenue Recognition

The Association recognizes contributions and grants when cash, securities or other assets, or an unconditional promise to give is received. Unconditional promises to give that are expected to be collected in future years are recorded at the present value of the amount expected to be collected. All contributions are considered available for unrestricted use unless specifically restricted by the donor. Conditional promises to give – that is, those with a measurable performance or other barrier and a right of return – are not recognized until the conditions on which they depend have been substantially met.

Program service fees are recognized as the Association satisfies its performance obligations. Revenue is reported at the amount of consideration to which the Associations expects to be entitled in exchange for providing program services under *Revenue from Contracts with Customers Accounting Standards Codification* (ASC) Topic 606. The Association determines the transaction price based on standard charges for services provided. Program services paid in advance are classified as deferred revenue until the services have been provided.

Revenues from special events are recognized when the events are held.

Contributed Nonfinancial Assets

Contributions of nonfinancial assets are recognized as revenue and expenses on the accompanying statement of activities and changes in net assets at their estimated fair value at the date of receipt.

Donated services are recognized as contributions if the services (a) create or enhance non-financial assets or (b) require specialized skills, are performed by people with those skills, and would otherwise be purchased by the Association. There was no revenue recognized from donated services for the year ended December 31, 2023. However, many individuals volunteer their time and perform a variety of tasks that help the Association. The value of this contributed time is not reflected in the Association's financial statements because it does not meet the above criteria.

For the year ended December 31, 2023, there were no contributed nonfinancial assets.

Note 1: Summary of Accounting Polices (Continued)

Functional Allocation of Expenses

The financial statements report certain categories of expenses that are attributable to more than one program or supporting function. Therefore, these expenses require allocation on a reasonable basis that is consistently applied. The expenses which are allocated on the basis of estimates of time and effort include salaries and related expenses, and rent expenses. All other natural expense categories using the key concept of direct conduct or direct supervision are charged to the benefiting program or supporting service.

Fair Value Measurements

Financial Accounting Standards Board (FASB) ASC Topic 820, *Fair Value Measurements and Disclosures*, provides the framework for measuring fair value. That framework provides a fair value hierarchy that prioritizes the inputs to valuation techniques used to measure fair value. The hierarchy gives the highest priority to unadjusted quoted prices in active markets for identical assets or liabilities (level 1 measurements) and the lowest priority to unobservable inputs (level 3 measurements).

The three levels of the fair value hierarchy under FASB ASC Topic 820 are described as follows:

Level 1 Inputs to the valuation methodology are unadjusted quoted prices for identical assets or liabilities in active markets that the fund has the ability to access.

Level 2 Inputs to the valuation methodology include

- Quoted prices for similar assets or liabilities in active markets;
- Quoted prices for identical assets or liabilities in inactive markets;
- Inputs other than quoted prices that are observable for the asset or liability;
- Inputs that are derived principally from or corroborated by observable market data by correlation or other means.

If the asset or liability has a specified (contractual) term, the level 2 input must be observable for substantially the full term of the asset or liability.

Level 3 Inputs to the valuation methodology are unobservable and significant to the fair value measurement.

The asset's or liability's fair value measurement level within the fair value hierarchy is based on the lowest level of any input that is significant to the fair value measurement. Valuation techniques maximize the use of relevant observable inputs and minimize the use of unobservable inputs.

Following is a description of the valuation methodology used for assets measured at fair value. There was no change in the methodology used at December 31, 2023.

Mutual funds and exchange traded funds: Valued at the closing price reported in an active market in which the individual securities are traded.

Note 1: Summary of Accounting Polices (Continued)

Fair Value Measurements (Continued)

The preceding method described may produce a fair value calculation that may not be indicative of net realizable value or reflective of future fair values. Furthermore, although the Association believes its valuation method is appropriate and consistent with other market participants, the use of different methodologies or assumptions to determine the fair value of certain financial instruments could result in a different fair value measurement at the reporting date.

The provisions of FASB ASC Topic 820 did not have an impact on the Association's nonfinancial assets and nonfinancial liabilities that are not permitted or required to be measured at fair value on a recurring basis.

Leases

The Association determines if a contract is classified as a lease at the contract's inception. Lease agreements are evaluated to determine whether the lease is a finance or operating lease. Right-of-use (ROU) assets and lease liabilities are recognized at the commencement date based on the net present value of lease payments over the remaining lease term. The Association's lease does not provide an implicit rate; therefore, the Association has elected to use a risk-free rate as its incremental borrowing rate, based on the information available at the commencement date to determine the present value of the lease payments over the lease term. Leases with an initial term of 12 months or less are not recorded on the accompanying statement of financial position and are recognized as lease expense on a straight-line basis over the lease term.

Income Taxes

The Association is exempt from federal income taxes under Section 501(a) of the Internal Revenue Code (IRC) of 1986, as amended, as an organization described in Section 501(c)(3) of the IRC. The Association has been classified as an organization that is not a private foundation under IRC Section 509(a)(3), and as such, contributions to the Association qualify for deductions as charitable contributions. However, income generated from activities unrelated to the Association's exempt purpose is subject to tax under IRC Section 511. The Association generated no income from activities unrelated to its exempt purpose for the year ended December 31, 2023.

Accounting for Uncertainty in Income Taxes

Management has concluded that any tax positions that would not meet the more-likely-than-not criterion of FASB ASC Topic 740-10, *Accounting for Income Taxes*, would be immaterial to the financial statements taken as a whole. Accordingly, the accompanying financial statements do not include any provision for uncertain tax positions, and no related interest or penalties have been recorded in the statement of activities and changes in net assets or accrued in the statement of financial position. Federal and state tax returns of the Association are generally open to examination by the relevant taxing authorities for a period of three years from the date the returns are filed.

Note 1: Summary of Accounting Polices (Continued)

Use of Estimates

Management uses estimates and assumptions in preparing financial statements. Those estimates and assumptions affect the reported amounts of assets and liabilities, the disclosure of contingent assets and liabilities, and reported revenues and expenses. Significant estimates used in preparing these financial statements include the use of assumptions for the functional allocation of expenses. Actual results could differ from estimates.

Accounting Pronouncement Adopted in 2023

In 2016, the FASB issued Accounting Standards Update (ASU) 2016-13, *Financial Instruments – Credit Losses (Topic 326): Measurement of Credit Losses on Financial Instruments*, which changes the impairment model used to measure credit losses for most financial assets. Under the new model the Association is required to estimate expected credit losses over the life of its trade receivables, certain other receivables and certain other financial instruments. The new model replaced the existing incurred credit loss model and generally results in earlier recognition of allowances for credit losses. The Association adopted this guidance in 2023 using the modified retrospective approach, and the adoption did not have a material impact on the financial statements or disclosures.

Date of Management's Review

The Association has evaluated subsequent events through August 29, 2024, the date the financial statements were available to be issued.

Note 2: Investments and Fair Value Measurements

Assets measured at fair value on a recurring basis consist of the following as of December 31, 2023

	Total	Level 1	Level 2	Level 3
Mutual funds	$ 482,335	$ 482,335	$ -	$ -
Exchange traded funds	356,223	356,223	-	-
	$ 838,558	$ 838,558	$ -	$ -

Investment return, net for the year ended December 31, 2023 consists of the following:

Dividends and interest	$ 37,800
Realized gains (losses)	12,385
Unrealized gains (losses)	65,634
Investment fees	(5,432)
	$ 110,387

Note 3: Leases

The Association has obligations under noncancellable lease agreements for the use of office space and equipment. The leases expire through August 2033. The lease agreements do not contain any material residual value guarantees or material restrictive covenants. The Association has no material related-party leases.

The following represents lease costs and required information for the year ended December 31, 2023:

Operating lease costs	$ 20,573
Short-term lease costs	-
Non-lease components	-
Total lease costs	$ 20,573

Other information:	
Operating cash flow paid for operating leases	$ 16,668
Weighted-average remaining lease term	9.67 years
Weighted-average discount rate	3.61%

Future minimum lease payments required under these agreements are as follows:

For the years ended December 31,	
2024	$ 25,380
2025	25,593
2026	26,019
2027	26,235
2028	26,667
2029 and thereafter	127,009
Total lease payments	256,903
Less interest	(40,618)
Present value of lease liabilities	$ 216,285

Note 4: Net Assets with Donor Restrictions

Net assets with donor restrictions consist of the following at December 31, 2023:

Choose Kind Project	$ 13,108

Net assets released from donor restrictions during the year ended December 31, 2023 were as follows:

Choose Kind Project	$ 63,000
Family retreat	1,892
	$ 64,892

Note 5: Liquidity and Availability

As part of the Association's liquidity management, the Association's liquidity policy is to structure its financial assets to be available for general expenditures, liabilities and other obligations as they come due. Monthly revenues and expenditures are deposited in and deducted from the operating accounts.

In addition, the Association is partially supported by restricted contributions. Because a donor's restriction requires resources to be used in a particular manner or in a future period, the Association must maintain sufficient resources to meet those responsibilities to its donors. Thus, these financial assets may not be available for general expenditure within one year.

The following reflects the Association's financial assets, reduced by the amounts not available for general use because of contractual or donor-imposed restrictions within one year of the statement of financial position date.

Financial assets	
Cash and cash equivalents	$ 757,559
Investments	838,558
Total financial assets	1,596,117
Less amounts not available for general expenditures within one year due to:	
Donor-imposed restrictions	(13,108)
Total financial assets available to meet cash needs for general expenditures within one year	$ 1,583,009