THIS ISSUE OF THE E-NETWORK IS DEDICATED IN MEMORY OF **SCOTT GUZZO & KHRISTIAN GODFREY**

cca e-network

newsletter of children's craniofacial association

2023: ISSUE 2

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Left to Right: Mason, Anna (Mom), Makayla, and Raymond (Dad)

meet the perkins

by Annairis Perkins aka Dr. Hill

Born into this world was I. Labeled, defined, blameless, different, fragile, small, vigorous, persistent, strong-willed and confident. My name is **Annairis Perkins**, also known as **Dr. Hill**. I've always aspired to be a "doctor" and one day I will become one, and so the nickname remains fitting. I was born and raised in Brooklyn, New York and I identify as Afro-Latino, as my parents are natives of the Republic of Panama.

Upon my entry into this world, my parents were told by doctors that something was severely wrong and I failed my hearing test. Additionally, they said I would not walk, eat, talk or live past the age of five. After receiving such shocking and devastating news, my parents took me to numerous doctors in hopes of receiving answers to my unknown condition at that time. They were resilient throughout my medical journey, and as a result they eventually learned that I was born

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letter from the program director

"They say time flies when you're having fun and this holds true when it comes to the **Retreat**! We countdown the days until it's here and then, in the blink of an eye, it's over! It was so wonderful being back with all of you this year!

Every year, we try to rotate the Retreat to a different region of the United States and this was our first time to ever hold a Retreat in The North Star state, Minnesota, and it was so great to be there. We weren't sure what type of weather to expect seeing how they had snow in May, but it was definitely better than other locations we've been to... the milder summer weather was so "Minnesota Nice."

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with a rare condition only found in 1 in every 50,000 people. I was born with Treacher Collins syndrome (TCS), which is a condition that affects the development of bones and other tissues of the face. The symptoms vary substantially, ranging from almost unnoticeable to severe. Most affected people have under-developed facial and cheek bones, as well differences in the shape, size and position of an individual's eyes, ears, cheekbones, chins and jaws. Additionally, the syndrome can cause one or more conditions that affect a child's ability to nurse, bottle-feed, breathe easily and hear. Many people with TCS require reconstructive surgeries to correct facial differences, such as absent chins, cheek bones, cleft palates and such. To date I've had 35 operations. To name a few: I've had jaw, cleft palate, ear, and eye reconstructive operations. While there is no cure for TCS, surgery aids in making the quality of one's life better. Surgeries also help to improve cases of mild to severe craniofacial anomalies as well as speech, breathing, feeding, visual and hearing issues.

People often make the mistake to mislabel or underestimate the ability of people with TCS due to our facial differences. **I want the world to know that each and every one of us are brilliant overachievers. We are fearless, caring, loving, amicable, people who should be accepted as we are and not treated differently or analyzed because of our unfamiliar appearance.** While I did require a cleft palate repair, a feeding tube, speech, occupational, physical, and hearing therapy,

my intelligence is not affected by TCS and my fellow carriers also have genius cognitive abilities. In fact, despite the physical, emotional, medical and mental challenges we face, TCS carriers are incredibly resilient and intelligent. Numerous of my various achievements were accomplished during all the surgeries and struggles through-out my journey with TCS. As a child, I was an honor roll student from elementary through high school. I played on the basketball team from elementary to high school as a point guard. I participated in all clubs and extracurricular activities. I also played the steel drum in music band throughout middle school. I am a high school and college graduate. I obtained my driver's license at the age of seventeen, and purchased my very own first vehicle at the age of eighteen. I've also been employed since my freshman year of high school.

Having TCS is a journey. For myself there were, and are, stages to my diagnosis. Some of the stages I experienced were denial, grief, bargaining, anger, and acceptance. I am elated to say that I've reached the end of my journey and made it to the stage of acceptance. Arriving to this stage required lots of hard work, self-patience, grace, an abundance of self-love, care, therapy, confidence and faith in God. Therapy can be and is life changing. As a child or adult it's never easy having people stare, point or verbally make negative comments about your facial appearance, the way you talk or any other difference one may have. Thus, if you are living with TCS or are encountering any other type of struggle that you need help processing, I encourage you to try therapy. It's healing, and it's okay to get professional help. **One thing therapy has taught me is that hurt people, hurt people- but healed people, heal people.** Healing is a powerful experience and I'm so thankful to have experienced both the hurt and the healing because it has

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shaped me into this incredible person, that pays it forward each day in hopes that the gift of healing will keep on giving.

Despite having TCS as a child, I've always known that I wanted to have a family of my own which included children. No matter what life may serve me, I am forever grateful for all of my experiences both difficult and pleasurable. I find experiencing love to be beautiful and a blessing. I have been married to my amazing husband **Raymond** for ten years and we've created two awesome children together. If I received nothing else in life, or lost some things along the way, it is enough that I once experienced healing, love, and motherhood. Our daughter **Makayla** is our oldest child. She is ten and our son is nine and his name is **Mason**.

When an individual has TCS and the partner is not a carrier there is a 50% chance with each pregnancy that the child could have TCS. We knew this pre- pregnancy, and yes we were okay with this possibility. My daughter has TCS. She is my "identical twin." Her case was milder than mine. She does not have a cleft palate, require a feeding tube, or jaw surgery. She's had three surgeries to date which were really challenging for her but she is determined to keep striving. She does require hearing aids, and needed the support of occupational, speech, and hearing therapy. She is amazingly talented, outgoing, gifted, amicable and bright. She is an excellent swimmer, she is a National Honors Society student, plays the trumpet, ukulele, steel drum, and has a smile that lights up every room she enters. She is our little "light bright." Makayla's Irish twin, Mason is also an awesome child. He has Autism, which does not deter or limit him, and he is also a little genius. Mason is the sweetest son I could ask for; he has a heart and a mind beyond his years. He plays the piano and is a talented and gifted student in school. He also has an implausible vocabulary. His love for mankind, his mama, trains, legos. God and architecture will follow him through life.

My husband **Raymond** is incredible. He has accepted me for who I was from the day we met. I've also done the same for him which makes our relationship so seamless. He actually told me that the first thing he found attractive about me was my confidence. This was delightful to know. He is the most

accepting and supportive partner I could have. Together we have experienced the highs and the lows. Almost two years into our marriage, Raymond was diagnosed with stage four non-Hodgkin's lymphoma.

To say our world was turned upside down is an understatement. Having two babies under one and a half and a terminally ill parent and partner was novel and unprecedented. It was also scary, exhausting and humbling. However, he made it; we made it, and survived to tell the story. Though we had a recent scare of a recurrence a year ago, we thankfully remain in remission for almost seven years. There is so much more to share about our cancer journey. **Until then, know that we are thankful for life, the family we created and the air we breathe.** I encourage you to heal, forgive, laugh, love, be thankful and find your peace in accepting who you are, and where you are in life.

letter from PD, continued from the cover

The Retreat took place at the beautiful **Hyatt Regency Minneapolis** in the downtown area. The layout of the hotel was absolutely perfect for our group. Everything was close together which made it so much easier for our families to get to our events. We ended up having 136 families from 39 states attend as well as families from Australia, Canada and the United Kingdom. Of the 136 families, 38 families were first-time attendees.

While we had all of these amazing attendees, we did have a huge hole in our CCA community. Just the week before, on June 19, our beloved Mayor, **Scott Guzzo,** passed away just shy of his 40th birthday. We have suffered many losses this year, and enduring one so close to Retreat had us all feeling the grief. We were happy to be with one another to remind ourselves of the support our community offers, to share his memories, to comfort one another, and to send an outpouring of love to his family. It was all too fitting that everything this year was purple, his favorite color. Of course, the CCA staff had selected purple months ago because of Purple Rain (Prince's song) and the Minnesota Vikings, but I can tell you, not one person picked upon that. Every single one of you said, "Purple for Scott!" and that's just how we want to remember it, too. Yes, Scott, we all donned our purple shirts, lanyards, and totes in your honor.

The Retreat kicked off on Thursday morning and it was very touching to see the new families instantly bonding with families they have "met" on social media. Plus, it was extra special for those who couldn't attend last year, finally reuniting with other families. Hugs, laughter, and so much love filled the lobby of the ballrooms and echoed throughout the hotel. The connections seemed to happen faster than ever before and it was incredible to witness.

Once again, this year we had expert speakers in the field of craniofacial research and medicine hold sessions for our families during the 15th Annual Educational Symposium. We would like to thank the following speakers.

- **Kevin M. Vukovich, M.S., MED-EL**
- **Dr. Jo Barta, Gillette Children's Hospital**

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- **Martha McGrory, CRNP, ANP, Gillette Children's Hospital**
- **Dr. Cheryl Anderson-Cermin, Gillette Children's Hospital**
- **Kasey Wade, M.A. CCC-SLP, Family Chatterbox**
- **Tricia Armstrong, M.A. CCC-SLP, Family Chatterbox**

We would also like to thank our Keynote Speaker, **Iva Ballou**, who did a very informative session called "Cleft is My Superpower. What's Yours?" Iva Ballou is the Community Development Manager for **Smile Train**, a speaker and facial difference advocate who uses her gifts to increase awareness and education for the facial difference community. Furthermore, Iva co-hosts the Love Meets Joy podcast, sharing her valuable insights, her cleft journey and all things cleft lip and palate with others. Through her website RealSophisticatedJoy.com, she now empowers others to pivot from shame to confidence in their journey. She is a shining example of how we can all conquer our fears and doubts and achieve our full potential. She had the audience so engaged and mixed in some humor as well. Her wonderful Mom, **Carolyn Ballou**, was also in attendance which made it even more special, and we thank her for sharing her insights during the Q&A.

A very special thank you also goes out to **Rita Albert, JD, & Cashel Gaffey, MSW**, from **ConnectMed International,** who held a session for our CCA Teens; CCA's Executive Director, **Erica Klauber, MBA**, for hosting a session on Advocacy for Ally's Act; **Austin Attebery** from Sing Me a Story, who held a session for our CCA Kids and CCA Siblings; and last but certainly not least, CCA family member panelists **Jessica Bock, Greg Daniels, Joseph Hernandez, Kevin Irvine & Karen Tamley, Jono Lancaster, Andrew, Kristy & Oliver Lund, Paige Peterson, and Amelia Sanborn** for answering all the questions presented them with truth, humor, and candidness.

We also had exhibitor booths again this year and would like to thank them for being part of our Educational Symposium: **MED-EL, ConnectMed International, Born a Hero, and FACES**.

A special thanks goes out to the **Foundation for Faces of Children, FACES, Roseann Opdyke, Smile Train and Diana Sweeney** from **Craniofacial Connection** for being scholarship sponsors. Thanks to your generosity, nine

families were supported to attend our Retreat. This was our first year to award the **Lentil Bean Memorial Hotel Scholarship** and the **Opdyke Memorial Scholarship** to Retreat families.

And last but not least, a HUGE thanks goes out to all of our amazing families and friends who volunteered their time during the symposium, registration and retreat: **Rita Albert, JD, Sharon Allbright, Carol Ardlean, Bette & Jessica Barbalaci, Paul Bearmon, Lisa & Jessica Bock, Aaliyah Booker, Cheryl Papciak-Brooks & Joe Brooks, Lori Brown, Megan Brown, Lia Burton, Lindsay Condefer, Greg Daniels, Kristine, Jeremy Tommy & Cody Dale, Dede & Peter Dankelson, Deena Dyson, Cashel Gaffey, MSW, Brooke Hall, Joseph Hernandez, Elsa Higbie, Kevin Irvine & Karen Tamley, Melissa Jurek, Ed & Amy Kern, Michelle Kryzanowski, Jono Lancaster, Jennifer Lucas, Andrew, Kristy & Oliver Lund, Doug & Janis Macut, Stacy McAllister, Amy McLaughlin, Johnny & Jessica McMahan, Harlena Morton, Eva Nicholas, Tyann Nordness, Stephanie O'Brien, Roseann Opdyke, Carlos Quinonez & Sonia Lara, Paul Bearmon, Erin Richmond, Laurel & Amelia Sanborn, Meghan Kujawa-Smith, Paul Tice, Tosha Walker, Dorina Watkins** all of our raffle ticket sellers, those who helped during the raffle and everyone who brought and bought raffle items/baskets.

For the fourth year in a row, CCA held "Camp CARE" which is a counseling opportunity that takes place during the Retreat. We would like to thank

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We would like to thank **ConnectMed International, Rita Albert, JD, and Cashel Gaffey, MSW,** for offering this important service to our families.

On Thursday night, **Norm the Magician**, performed for kids gathered at the front of the stage and ended his show with shooting toilet paper into the audience. This toilet paper frenzy was a hit, and we needed that tissue to wipe up our tears from laughing so hard.

Friday's hit event was the Group Meet-Ups, which were one of the highest rated and commented on events of the Retreat, based on our Retreat Satisfaction Survey. These groups give our families the opportunity to meet others and learn in smaller (okay small-ish) groups. This year we offered groups by syndrome and by topics. Some of the group topics included: "American Sign Language (ASL) Basics," "Advocacy in Action: Ally's Act," "Finding Your Future," and more! We have LOTS of suggestions for next year, not only to add topics and age groups, but also to do more group meetups throughout the weekend. We will certainly try to accomplish this request. We rely on volunteers to lead these, so if you are willing, please reach out to me in the coming months.

We also heard you that you need sound amplification in these groups, and trust us, we will try to find ways to help everyone access these important times of meeting and connection.

We held the CCA Retreat Celebration Carnival again this year on Friday. We offered a variety of fun-filled booths for our families which included arts & crafts by **Ziggy's Art Bus**, a CCA swag area, selfies with characters

(A.K.A. as the CCA Staff), arcade/carnival games, face painters, live music from **Michael Riddle of Riddle Me Music**, an animal booth from the **Minneapolis Zoo**, a chance to dance and have your picture taken with **Goldy the Gopher** and more. It was fun to see everyone running around having a fun-filled time, in a casual atmosphere. We couldn't have pulled this off without the generosity of so many. Thank you to everyone who came out and participated!

After all of the excitement, families had a small break and then gathered once again for our Family Night. Part of our Family Night is our Hometown Basket Raffle which is where our families from across the United States and beyond brought baskets of goodies from their areas for CCA to raffle off. These baskets always amaze me and this year they were out of this world. Our families truly go above and beyond and their generosity shows in what they bring yearly. We had over 70 baskets and raised over $3,000.

Saturday morning started with breakfast which was followed by a group photo. It takes a lot of work to gather over 450 people for a group photo but with the help of our amazing photographers, **Eva Nicholas** and **Paul Tice** and the direction and the help of others, we got it done. Seeing everyone together in one spot is so powerful and heartwarming. And don't worry, we already have some ideas up or sleeves to make next year's photo even better and a much smoother process. Thanks to everyone who shared their ideas. Sometimes it may seem obvious to attendees, but the staff does not come up with the same great ideas you do. We truly appreciate everyone's patience during the process and willingness to help out.

The highest rated event of the weekend was definitely the "CCA's Got Talent" Talent Show. We sound like a broken record but the Talent Show just gets better and better year after year! We had a variety of performances this year which included singing, dancing, instrumental performances, a comedy set, a heartfelt letter of appreciation and more. It takes a lot of courage to get on stage and perform in front of an audience and you all did such an incredible job. We are super proud of everyone! A huge thanks goes out to our emcees, **Aaliyah Booker and Peter Dankelson**, who were such a dynamic duo, very entertaining and kept things going smoothly, as well

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as the talented **Johnny McMahan**, who created the playlist and made sure everything stayed on track. He didn't miss a beat! A special thanks goes out to **Jessica McMahan** for helping with the stage setup for each performer. We couldn't do it without you all!

Saturday evening, everyone headed to the beautiful ballroom for our (now-second) most popular event... the Dinner/Dance. After everyone was finished eating, it was time to hit the dance floor and show off those moves! Let's just say the dance floor was packed the entire night and we had a special tribute to our beloved and sorely-missed **Scott Guzzo**. We dialed up his parents, **Paula and Bob Guzzo**, on FaceTime and the DJ cleared the floor for a memorial circle of Wipe Out. While Scott was not in the center of it this year, he was certainly in the center of our hearts. To forever honor his legacy, we will now continue to play Wipe Out every year and invite all the wheelchair users who so desire to come to the center of the circle for a dance.

Sunday morning always seems to show up sooner than we would like for it to. There were hugs being shared, photos, laughter, tears, social media friend requests being made and a sense of belonging like no other. The goodbyes are never easy but knowing we will all be back together in no time makes it a touch easier. And, as always, I can tell you we all had the TIME OF OUR LIVES!

I always leave the Retreat feeling refreshed and overcome with joy and love. Thank you all for being YOU and for making my life even better!

We can't wait to be reunited with everyone next year in Baltimore, MD, June 27-30.
Once registration opens up, we will be sure to let you know. Until then, enjoy the rest of your summer!

- **Annie Reeves**
CCA's Program Director

Please be sure to read about a first-time retreat attendee **Whitney Wright**, and her family's experience on page 8.

upcoming events

AUGUST 27, 2023 | 11AM to 1PM CST
Virtual

TEEN & YOUNG ADULT WORKSHOP: THE POWER OF THE BUCKET LIST
Presented by Evan Wolkenstein, Author of Turtle Boy | In partnership with ConnectMed

REGISTER HERE

SEPTEMBER 6, 2023 | 7PM CST
Virtual

CAREGIVER SUPPORT GROUP

REGISTER HERE

SEPTEMBER 6-7, 2023
California

MECK INVITATIONAL GOLF EVENT

CONTACT: Christine Andler, candler@ccakids.com

SEPTEMBER IS CRANIOFACIAL ACCEPTANCE MONTH (CAM)

SEPTEMBER
Nationwide

SEPT 9 AT 1:00PM: HARMONY, PA

SEPT 16 AT 10:30AM: MIDDLEFIELD, OH

SEPT 16 AT 11:00AM: LIVONIA, MI

SEPT 23 AT 11:00AM: HOPKINTON, MA

SEPT 23 AT 11:00AM: PHOENIXVILLE, PA

SEPT 23 AT 12:00PM: PADUCAH, KY

SEPT 30 AT 11:00AM: DALLAS, TX

SEPT 30 AT 3:00PM: CONCORD, NC

FOR DETAILS ON PICNICS VISIT:
HTTPS://CCAKIDS.ORG/ACCEPTANCE-MONTH.HTML

CONTACT: Annie Reeves, areeves@ccakids.com to host a picnic

SEPTEMBER 14 | 5:30PM CST
Virtual

CAM GROUP PHOTO

SEPTEMBER 18, 2023 | 7:30PM CST
Virtual

ANNUAL AWARD CEREMONY
Presenting the David Roche Award of Excellence and Advocacy
See page 11 for more information | Register Here

SEPTEMBER 25, 2023 | 7:30PM CST
Virtual

ADULTS & ALUMN GROUP

REGISTER HERE

OCTOBER 8-9, 2023
Las Colinas, TX | Hackberry Country Club

7TH ANNUAL DFW PAR PREMIER GOLF TOURNAMENT FOR CCAKIDS

CONTACT: Christine Andler, candler@ccakids.com

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

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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!

ccaadult

meet bryttani

Bryttani Gore is 24 years old and is still followed by the craniofacial team at **Children's Hospital of Philadelphia (CHOP).** She was born with a midline facial cleft that extends through her nasal structure. She was born without her left eye and has a prosthetic. She has a coloboma of the optic nerve in right eye. She also has total situs inversus. When she was 14, she was diagnosed with severe sleep apnea and required a tracheostomy. We are hoping that her tracheostomy can be removed soon.

Despite the many surgeries that Bryttani has had and her visual impairment, Bryttani has accomplished a lot in her 24 years. In 2005, while attending a craniofacial conference in Las Vegas, Bryttani met **Laura Greenwald** and was featured in Laura's book **"Hero's With A Thousand Faces."** When Bryttani was 13, she was asked to be a part of **CHOP's Face to Face Project.** The project paired each child with an art student to have their story told through the eyes of an artist. Bryttani was paired with **Leona Shanks**, wife to the well known artist **Nelson Shanks**. The portraits are hung in the hall of the craniofacial department at CHOP. In November 2012, at age 14, Bryttani spent 3 weeks in CHOP while she had her tracheostomy placed. During that time, **Carrie Underwood** came to the **Ryan Seacrest Studio**. Bryttani and several other patients were invited down to interview Ms. Underwood. As if that isn't enough, In 2016, **Dr. Scott Bartlett** and the rest of the craniofacial team nominated Bryttani as a **Children's Miracle Network Champion** for CHOP and the State of Delaware. She was able to serve 2 terms as they were revamping their program and kept the Champions on for an additional year. During that time, Bryttani helped raise about $20,000 for CMN through golf tournaments and having a colored pencil drawing sell for $8,000 at one of their auctions. She also met the Surgeon General and was involved in a conversation with him and other Champions and their parents about the importance and great need of health insurance covering kids medical procedures. Bryttani also went to Orlando for CMN's Hospital Week where she met **Nick Cannon**.

When Bryttani isn't dabbling in celebrity status, she likes to relax by creating digital art on her iPad. She has done many portraits of her family members and friends. If she doesn't have a portrait of someone to work on, she just draws with a cartoony style. Bryttani also loves photography. She will often take pictures on her walks through parks, as she loves nature and macro photography. Taking pictures allows her to feel connected to her late grandfather on her father's side, as Grandpa taught her how to take pictures when she was younger.

meet abel

hi, my name is **Abel**. I'm from Los Angeles, CA. I have Treacher Collins syndrome, like Auggie from the movie "Wonder!" I'm 17 months old and so far I've had 5 surgeries. I'm a strong and brave boy! When I was a week old, **Mama** and **Dada** were introduced to CCA by good family friends. CCA has changed our lives and given us so much hope, happiness, and love which is all I've ever felt! My fav food is french fries! My hobbies consist of taking baths, saying "mama", going to Disneyland, playing in **Grandma** and **Grandpa's** backyard and pulling my big sisters hair! I am also fascinated by bubbles! I like catching them with my tongue! I have bilateral microtia so I'm learning ASL. My favorite sign is "eat". I love hanging out with my sister. She does the coolest things. I want to be just like her so I copy everything she does! I also like going into the kitchen with Mama. I help her reorganize the pots, pans and Tupperware. I think it looks better messy! I'm not sure what I want to be when I grow up. All I know is that I'm going to make a difference!

ccasupersib

meet kalia

hi my name is **Kalia**, I'm **Abel's** big sister and I'm 2! Abel and I are 13 months apart so we're pretty much best friends. Abel has Treacher Collins syndrome, but really he's no different than me. We dance, play, sing, fight and hug each other all day long. I call Abel "Papash." I always make sure Abel doesn't lose his paci. I can tell when Papash needs a nap he gets cranky! I love swimming, Disney trips, bath time and playing with all my toys. We go to Disney a lot, my favorite ride is King Arthurs Carousal and Jessie's Critter Carousel. My favorite dessert is chocolate. My favorite song is "The Wheels on the Bus." Abels is such a cool little brother, he wakes me up in the morning to play with him. I love having a baby brother! I love squeezing him! I'm so blessed and excited to have Abel as my lifelong best friend!

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.

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If not, serious brain damage could have occurred! Once again, so many people prayed for our little Parker and those prayers were answered as he recovered remarkably and shocked all the doctors and nurses! He's a strong little guy! He still has 12 months of helmet therapy, but we feel that the hardest part is behind us.

Though my mom struggled with infertility (had 11 years of trying for children and 5 miscarriages before she got pregnant with me), nobody in my family really had any major birth defects, so I never imagined myself as having a child with a serious issue. Going through this trial has transformed my understanding of what so many parents face with their children. You want to give your child the best opportunity to thrive, but often many obstacles obstruct your way. For us, CCA not only removed a major obstacle for getting the right care for our little guy, but it also encouraged us in a very discouraging time. We can't say thank you enough to all those that make CCA possible!

children's flight of hope partnership

We are so happy to announce our new partnership with **Children's Flight of Hope** in our financial assistance program. Working with **Leigh Longino, COO,** and **Marisa Daly** and **Carly Rosenkampff,** Mission Delivery Coordi-nators, we are helping more CCA families get to the medical care they need.

CFOH provides commercial flights to children traveling for medical appointments.
From CFOH,

To ensure our resources are used well, we assess each family's medical and financial need for assistance. Families complete CFOH's New Client Application with information about their child's treatment needs and key medical and financial contacts. Requirements for acceptance are listed below.

After an application is approved, flight requests can be submitted for the child's travel to medical appointments or treatment as needed moving forward. The CFOH Missions Team works directly with client families to choose flights and provide reservation information. CFOH commits to helping with flights for the duration of a child's treatment needs.

ACPA80™ ANNIVERSARY

PHOTO: Leigh Longino and Erica Khabbaz at the ACPA Annual Meeting in Raleigh in May

CCA is happy to coordinate this process automatically. If your family applies for financial assistance and meets CFOH's require-ments, we will connect you with them.

We are so happy to have the opportunity to work with the CFOH team and are amazingly grateful for this resource they provide.

Learn more at:
https://www.childrensflightofhope.org/

ATTENTION

WE HAVE MOVED OFFICES

PLEASE UPDATE

NEW ADDRESS:

15851 N. DALLAS PKWY.
STE. 245
ADDISON, TX 75001

PLEASE UPDATE YOUR RECORDS AND ANY RECURRING DONATIONS ACCORDINGLY.

THANK YOU!

CS Mott Glamour Day

One of the best parts of our craniofacial community is getting together as a group and having a good time. It's even better when you're getting pampered!

On Sunday, April 16, **Erica Klauber, Executive Director**, joined the Craniofacial Team and the talented stylists of the **Douglas J. Aveda Institute in Ann Arbor, MI,** for the annual Glamour Day with the patients and parents of the **Craniofacial Anomalies Program at CS Mott Children's Hospital.**

The stylists provided mini makeovers with hair and makeup and the CS Mott team provided lunch, photography, and fun! It was wonderful to see all the girls together, confident, laughing and then walking the runway on the red carpet.

Erica Klauber spoke to the families before the fashion show kicked off and her message included three of her favorite mantras to live by:

1. See your body as an instrument, not an ornament.
2. You can be sad and still rad.
3. What you seek is seeking you.

With these three things in mind, and Erica's stories about them in her own life, she encouraged the girls' to live life on their terms and celebrate their differences. Growing up isn't easy for anyone, but can be complicated when you look different or feel different than everyone else. You can change your life by finding words or mantras that are meaningful to you and calling them up in the hard times.

We want to extend a special thank you to **Jen Nordin, NP**, team coordinator, for allowing CCA to be a part of this special day and to all of the team members of CS Mott who truly show love and appreciation for all of their patients and their families.

PHOTO CREDITS:
"Craniofacial Anomalies Program at C.S. Mott Children's Hospital" Facebook Page

Annual Award Ceremony:
Presenting the David Roche Award for Excellence and Advocacy

SAVE THE DATE:
September 18th, 2023 at 7:30pm
Register Here

Join us for our second annual virtual award ceremony presenting the **David Roche Award for Excellence and Advocacy**. Last year we had an event: Encounter, to introduce the award.

The award is named in honor of the esteemed **David Roche, CM**, for his lifelong dedication to opening minds and connecting hearts and for his invaluable mentorship and support to the staff of Children's Craniofacial Association.
David is a champion of love. He seeks to break down barriers and build bridges between diverse communities.

Last year's recipients were **Dr. Jaz Gray** and **Rasheera Dopson**. Tune in at 7:30pm CST to hear from our 2023 recipient and about a few of our runner ups.

PHOTO:
David Roche holding his own award for the camera at 2022's Encounter Virtual Event.

SCOTT GUZZO Memorial T-Shirts

Available in White, Blue, and Lavender

Casey Deakins is hosting a fundraiser for CCA honoring the legacy of our beloved Scott Guzzo.
She is selling memorial t-shirts featuring the artwork of Scott Clarke and Caden Reeves.
$30 each; shipping included; $10 goes to CCA.
They can be purchased by emailing:
scottysmemoryshirts@gmail.com
Order & payment instructions will be replied to you.
Sales end Aug. 28, 2023.

minted.
CARD FUNDRAISER

Order your cards and stationary at:
minted.com
Use our code:
FUNDRAISECCATX

Receive 20% off and minted donates 15% back to us! Win-Win!

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

children's craniofacial association
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