

ccanetwork

newsletter of children's craniofacial association

2022: ISSUE 2

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Left to Right: Drew, Hunter, CJ and Jackson

meet the knightens

by CJ Knighten

We were smack dab in the middle of the Covid-19 pandemic when I became pregnant with Hunter. We were so excited to soon be a family of four and have two little boys! Nine months of working from home, quarantines and solo doctor trips flew by. The entire pregnancy seemed to be healthy and Hunter's DNA tests came back with no concerns. It was the night before my induction, Halloween Eve. Jackson was 18 months old and was very excited to meet his little brother but, more importantly that night, candy. We dressed up as the most popular pandemic Netflix show, "Tiger King" and took him trick-or-treating early. We soaked in our last moments as a family of three and packed the car to head to the hospital.

Just like Jackson, Hunter was born one day after a holiday. At 2:29 AM on November 1, 2020 we welcomed our... [see knightens, page 2](#)

letter from the program director



As I try to put into words how amazing it was to be back together at our first IN-PERSON Retreat since 2019, the song "Celebration" by Kool and the Gang instantly came to my mind.

*"There's a party goin' on right here,
A celebration to last throughout the years!
So bring your good times, and your laughter, too.
We gonna celebrate your party with you!"*

As we were assembling the Retreat welcome bags the day prior to the Retreat, I had a "moment" to where I looked at the staff and said, "I can't believe we are doing this, it's actually happening!" Being apart for three years was incredibly hard and we can't express how much we missed everyone!

[see retreat recap by PD](#)
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perfect little guy Earth side. Hunter was born with shoulder dystocia. During labor, I was so focused on delivering Hunter that I wasn't even aware of the emergency in the moment. I remember looking around at the people in the room – my husband, Drew, appeared shocked and even the nurses looked worrisome. They later explained that Hunter got stuck during labor and the doctor had pulled him so hard that the umbilical cord had ripped on its own. The room looked like a crime scene! I remember repeating, "Is he okay? I want to see him." They quickly put him into my arms and we instantly fell in love. Hunter Boone was here.

Moments after being able to hold Hunter the nurses took him to check all of his vitals. He kept making an odd breathing sound that I questioned and they responded that he probably just swallowed fluid during his grand entrance. They said everything looked great and they put him back into my arms. I held him close, cuddled him, and examined every inch of his perfect little existence. He had bruises on his head and his arms which can be a common result of shoulder dystocia. I noticed his ears looked slightly underdeveloped and questioned the doctor who didn't seem overly concerned. She explained that he most likely was laying a certain way in the womb or that his ears may have been folded during the pregnancy. I noticed that Hunter had "dents" below his eyes which I learned

from Google may be a result of dehydration. Again, I



questioned the doctor, but was told there was no need to worry. That night I awoke to two audiologists that wanted to do Hunter's newborn hearing screen. One was teaching the other on the software they use to test hearing. Holding Hunter and exhausted from labor, I had two strangers by my bedside as I watched Hunter drastically fail the hearing test. The audiologists told me it wasn't a big deal and they will re-test in the morning. This time they took him out of the room for the hearing test and told me that he had failed a second time. They explained that it was most likely due to water behind his ears and did not express any level of concern. The doctors seemed confident that

there was nothing for us to worry about and we were referred to see an audiologist the following month.

We left the hospital and were officially The Knighten Family of four, (CJ, Drew, Jackson and Hunter). Introducing Jackson to his new baby brother was a magical moment that we'll never forget. A few days later, we had our first appointment with the pediatrician. I mentioned Hunter's failed hearing tests and the underdevelopment of his ears. I asked if they were correlated and she suggested we have our audiologist appointment moved up to an earlier date. The first audiology appointment she couldn't get the testing tubes inside his ear canals to test. The ENT then saw us at this location and suggested we go to another location because he "does not see kids" even though this was who we were referred to from the hospital. We visited another clinic location in the same network and were passed around between doctors for almost three months, who continuously told us that Hunter's ear canals just needed time to grow. Each time they suggested that we return in a few



knightens, continued from the cover

weeks to see if the canals had grown at all to attempt a re-test. A day before our next appointment I received a call from the ENT office saying they were canceling my appointment because they couldn't help us. I was shocked. I understood that they needed to wait for his ear canals to potentially grow larger to test his hearing, however, I didn't understand why they were not willing to help us anymore. What could they not help us with? I knew that there was no history of hearing issues, including hearing loss, on either side of Hunter's family so I still did not feel overly concerned at the time, just confused. That night I sat down after the boys went to sleep and began to Google, "underdeveloped ears", "hearing loss" and "dents below the eyes." Within 10 minutes I came across a picture of a boy with Treacher Collins syndrome (TCS) and I immediately knew I had found a diagnosis for Hunter.

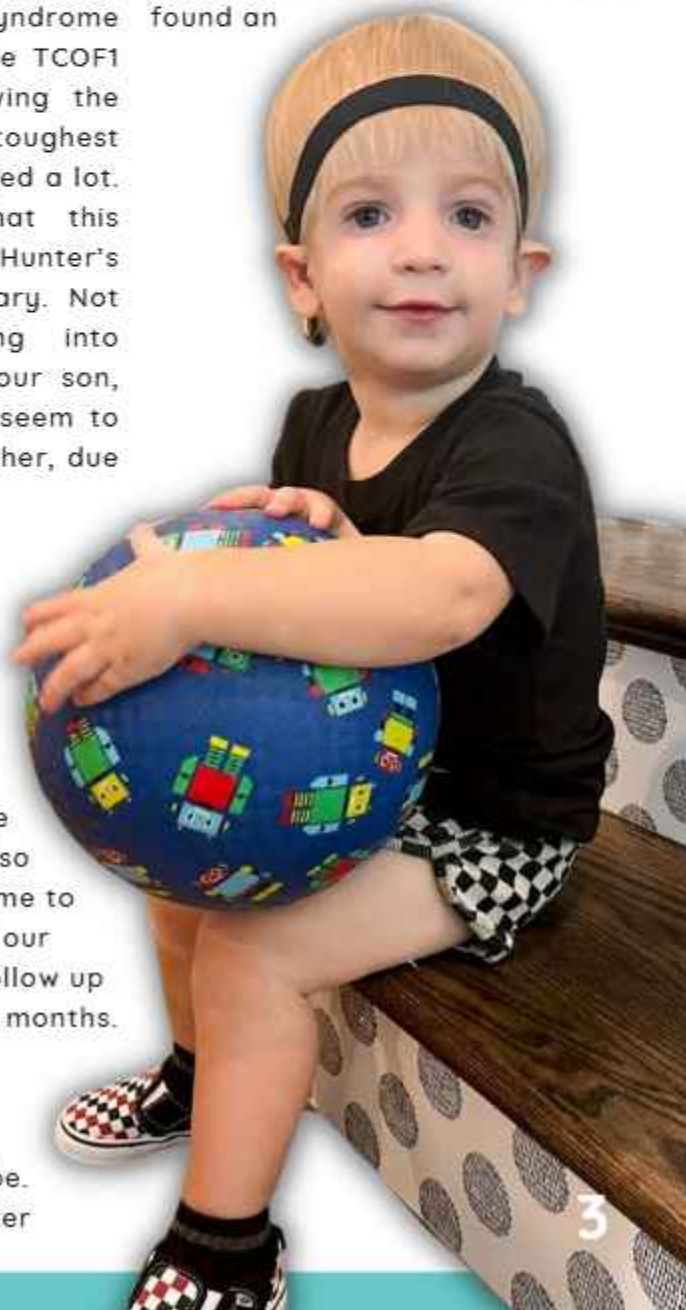
That is a night that I will never forget. It was 10pm and I had just self-diagnosed my three-month-old son with a rare syndrome we had no idea he had, nor did any of the dozen doctors that we had seen up to that point of his life. For hours, I went down a rabbit hole of information on Treacher Collins syndrome. I woke Drew up and we sat up for hours crying and talking. I found contact information for a craniofacial physician at our local medical university - I emailed a recap of our doctor visits thus far along with a picture of Hunter before going to sleep that night.

I checked my email first thing the next morning to find that I'd already received a response from the physician. She agreed that she noticed features of TCS in Hunter and wanted to schedule an appointment to see him as soon as possible. We attended our first craniofacial appointment within one week and a blood-drawn DNA test was performed on Hunter.

We received those DNA test results a few weeks later which confirmed what we expected to be true - Hunter was diagnosed with Treacher Collins syndrome due to a mutation on the TCOF1 gene. The weeks following the diagnosis were the toughest weeks of our lives. We cried a lot. We did not know what this diagnosis meant for Hunter's future and that was scary. Not only were we walking into unknown territory with our son, but the doctors did not seem to know much about TCS either, due to its rare occurrence. A few of the doctors and surgeons at the medical university hospital had previous experience with TCS patients, but we still left with little to no advice or insight as to what Hunter's future may look like. We were also empty handed when it came to resources for Hunter and our family. We scheduled a follow up appointment in another 6 months.

What we didn't know at the time is how beautiful Hunter's life would truly be. At three months old, Hunter

received his PONTO's (Bone Anchored Hearing Aids), he could finally hear us. I cannot explain how overcome with joy we were, and still are, to hear Hunter say "Mama" and "Daddy" after being told he may struggle with speech due to his hearing loss. We are continuously learning about Hunter's needs and searching for resources and doctors with knowledge of TCS. We are so grateful for the connections we have made with other TCS families. We went to our first Children's Craniofacial Association Retreat this year. There, we found an





amazing community that continues to grow. After e-mailing the governor of South Carolina he proclaimed the first South Carolina Treacher Collins syndrome Awareness Day on May 28, 2022, and we met other South Carolina families that live close by. Our family of four is thriving.

Jackson and Hunter are the best brothers and friends to each other. Every day is a new adventure in our household filled with dinosaurs and toy trucks. We're extremely lucky to have such a supportive community around us in Mount Pleasant, South Carolina. We are grateful to have so many friends and family members close by that love our

boys endlessly. Hunter's hearing aids don't mix well with water, but that doesn't stop us from enjoying summertime at the beaches nearby. Hunter is a huge fan of the snacks, especially Oreos. Eating may be his favorite hobby! He loves playing "T-Rex" with Jackson and Daddy before bed each night (super fun game where Jackson and Hunter attack the dinosaur aka Daddy!). The giggles echoing from their room is my favorite part of the day. Hunter's favorite stuffy is a Mickey Mouse that is almost as big as he is - it's adorable to watch him carry Mickey around the house. Hunter hasn't learned to pronounce the "s" sound yet so he calls Mickey Mouse "Mou". It's so cute that I don't think we will ever correct Mou's name in speech therapy.

Year 1 was tough, but we got through it together and we wouldn't change a thing. We are living a beautiful and blessed life with our boys. 🐉💕



retreat recap by PD,

continued from the cover

Let's just say there was lots of celebrating, good times and laughter throughout the course of the entire Retreat weekend!

Leave it to the great state of Texas to have a heatwave the week of our 32nd Annual Family Retreat and Educational Symposium! Thankfully all of our events took place indoors, at the beautiful and spacious Sheraton Downtown Dallas, from June 23-26. The hotel had the largest Ballroom and Grand Hall we've ever had... so, yes, everything is bigger in Texas! Having this much space for our families to spread out and for the kiddos to run off some of that energy was perfect! We ended up having 131 families from 36 states attend as well as families from Australia, Canada, Mexico and the United Kingdom. Of the 131 families, 30 families were first-time attendees.

The Retreat kicked off on Thursday morning and I can't begin to tell you how excited we were to get down to Registration so we could see everyone! What I witnessed was an overwhelming outpouring of love. Families reuniting with one another, literally running towards each other, hugs and, high fives, but mostly more hugs, first time retreat families talking to families they have only ever "met" thru social media and overall HAPPINESS! It was such a beautiful sight to see and one I will never forget.

Once again, this year we had expert speakers in the



field of craniofacial research and medicine hold sessions for our families during the 14th Annual Craniofacial Symposium. We would like to thank the following speakers.

- **Huay-Zong Law, MD,**
International Craniofacial Institute
- **Monica Kemp, MS, CCC-SLP,**
International Craniofacial Institute
- **Janet Lane, MS, CCC-SLP,**
MED-EL
- **Joshua Huppert, Au. D,**
MED-EL

We would also like to thank our Keynote Speaker, **Lizzie Velasquez**, who did a very powerful session called "Dare to be Brave!" Not only is she a Motivational Speaker, she is also an Activist, Author and YouTuber. Both Lizzie and her Dad, **Guadalupe**, answered questions from the audience following her session and our families truly loved having her there.



More very special thank yous also go out to **Liz Irwin, CTRS**, who held a SibShop and Siblings Panel for our Super-Sibs and last but certainly not least, CCA family members **Vanessa Acero, PsyD, MS, APCC**; **Josie Barton**; **Aaron Guzzo**; **Jennifer Kilmer**; **Johnny, Jessica & Hunter McMahan**; **Harlena Morton**; and **Kyra Wetmore** for either holding

sessions or participating as panel members.

Presenters discussed topics including "Lifetime Treatment of Cleft and Craniofacial Differences: Advancements in Care at the in Care at the International Craniofacial Institute,"

"Empowering You and Your Child as We Make Sense of Hearing Technology Options," "Social-Emotional Navigation Through School Ages," "You Are More Than Your Shell: Finding Confidence to Be Yourself!" and "Radical Healing."

We also had sponsored exhibitor booths again this year and would like to thank them for being part of our Educational Symposium: **International Craniofacial Institute Cleft Lip and Palate Treatment Center**, **MED-EL**, **Nationwide Children's Hospital**, **ConnectMed International**, **KLS Martin Group**, **Children's Health of Dallas** and **FACES**.

A special thanks goes out to **Foundation for Faces of Children**, **Smile Train**, **FACES** and **Barrow Cleft & Craniofacial Center** for being scholarship sponsors! Thanks to your generosity, seven families were able to attend our Retreat!

This year we were also able to provide boxed lunches for our families during the symposium, thanks to a very special donor, who wishes to remain anonymous. We thank you and



retreat recap by PD, continued from page 5

so do our tummies. They were delicious! The addition of the lunch helped our families stay onsite on Symposium day and have enough time to eat and get back in time for their afternoon sessions. We would love to provide this meal again, in the future if we can secure more donations like this one.

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 (I've only listed those not previously named): Rita Albert, JD, Sharon Allbright, Liz Anderson, Taylar Aumann, Mishele Baldwin, Janette Barton, Lisa Bock, Lisa Bowers, Lori Brown, Megan Brown, Chelsea Bualos, Sarah Cloes, Ryan Coody, Kristine, Jeremy Tommy & Cody Dale, Emerald Demor, Sally Derrick, Fed-Ex CARES employees, Karen & J.R. Foley, Cashel Gaffey, MSW, Carrie Greer, Paula Guzzo, Kelsey Harris, Whitney Hollingshead, Kevin Irvine & Karen Tamley, Karen

Kelly, The Italian Club of Dallas, Tyeisha Jefferies, Melissa Jurek, Jennifer Johnson, Maddie Johnson, Ed & Amy Kern, Matthew & Araceli Kimberlin, Crystal Kouri-Reynafarje, Jono Lancaster, Janis Macut, Matt Morris, Harlena Morton, Eva Nicholas, Chirrisse Owen, Liz Prince, Erin Richmond, Laurel Sanborn, Rose Seitz, Patricia Simon, Char Smith, Summer Thomas, Courtney Vysocky, Megan White all of our raffle ticket sellers and everyone who brought raffle items/baskets.

I would also like to personally thank my friend, Lexie Beard, and RAK (Random Acts of Kindness), for donating items for our goodie bags! They were such a nice addition! For the third year in a row, CCA held "Camp CARE" which is a counseling opportunity and decompression room that takes place during the Retreat. We would like to thank our dear friends at ConnectMed International, Rita Albert, JD, and Cashel Gaffey, MSW, for offering this important service to our

families. This addition was the direct result of requests from our families, but only made possible because of the willingness of our nonprofit friends to collaborate. Together, we are working to fill as many needs as possible, as we learn about them.

The Retreat kicked off Thursday night and the families munched on cheeseburger sliders while announcements and welcomes were being made. We had a couple of "Texas" surprises up our sleeve for the evening. Not only did we have a Cowboy Stilt Walker, we also had the Dallas Cowboy's Mascot, Rowdy, in attendance. They both entertained our families and took pictures with them. For the Dallas Cowboy's fans in attendance, this was a dream come true! Following this excitement, we had another surprise for our families. Our very own CCA Adult, Bianca Moon, put on a concert, and wowed the audience with her astounding voice.



retreat recap by PD, continued from page 4

Friday morning started with breakfast, and then the families gathered for Group Meet-Ups, one of our most popular parts of the Retreat. These groups give our families the opportunity to meet others and learn about each other in a (slightly) smaller setting. This year we changed it up a bit and offered groups by syndrome and by topics. Some of the group topics included "Genetics: Q&A", "RED Device Advice," "Act It Out Workshop," "Fun with Hearing: TeleDraw Game," and more!

We offered a variety of fun-filled booths for our families which included arts & crafts, a CCA swag area, a selfie photo table, real-deal arcade and carnival games, a balloon artist, face painter, caricature artist, live music from the **Dallas Symphony Orchestra**, a make-up demonstration from our resident celebrity MUA, **Crystal Kouri Reynafarje**, an animal show from the **Dallas Zoo**, hair accents by **Dry Bar**, strolling Marvel characters and a Jedi show from the **DFW Saber Guild**! It was two hours of non-stop FUN! We couldn't have pulled this off without the generosity of so many. Thank you to **Ron Shover**, Dallas Symphony Orchestra Members: **Scott, Lydia, Jennifer & Nora**, Dry Bar Dallas, **DFW Avengers** and **DFW Saber Guild**!

After all of the excitement, families had a little break and then gathered once again for

our Family Night. Part of our Family Night is our Hometown Raffle which is where our families from across the United States and beyond brought baskets of goodies that represent their hometowns (or any theme they really love, such as, Harry Potter) for CCA to raffle! These baskets always blow me away with their creativity and awesome things you can't just "Amazon" to your door. Our families truly go above and beyond and their generosity shows in what they bring yearly! This year we raised over **\$4,000** with nearly 80 baskets.

While parents were buying raffle tickets with the hopes of winning one of the fabulous raffle items, the teens were watching some magic tricks and dancing the night away in a room with a breathtaking view of downtown Dallas from the 38th Floor of the Sheraton. Teen night wouldn't be possible without our amazing chaperones. Thank you all so much! And, thank you to our DJ, **Joe Mir**, who generously donated his time and service to ensure our teens had fantastic time!

Saturday morning started with breakfast which was followed by a group photo. It takes a small village to gather over 400 people for a group photo but with the help of our amazing photographer, **Eva Nicholas**, and the direction and "voices that carry," we got it done and it's such a powerful photo. We also appreciate everyone's patience and suggestions on the survey about how to make this massive undertaking even easier next year. Seeing everyone

together in one spot really puts things into perspective.

Following the group photo, everyone had time to go grab lunch, and get back in time for our "CCA's Got Talent" Show. Every year we say it was the best one yet and this holds true once again! REALLY, how do you guys get better and better every year? We had everything from singing, dancing, instrumental performances, joke telling and more! It takes a lot of courage to get on stage and perform in front of an audience and you all did a superb job! A huge thanks goes out to our emcee, **Chelsea Bugalos**, who was a true star and kept things going smoothly, as well as the talented **Johnny McMahan**, who created the playlist and made sure everything stayed on track. They didn't miss a beat!

Saturday evening, everyone came together for our most popular



retreat recap by PD, continued from page 4

event...the Dinner/Dance. Before kicking off the dancing, families were once again able to enjoy some beautiful music from the Dallas Symphony Orchestra. Thank you to DSO members, **Clay, David, Don, Glen & Timothy** for donating your time and creating such a nice ambiance. After everyone was finished eating, it was time to hit the dance floor! Let's just say the dance floor was packed the entire night. And, as always, once the last song played, the crowd begged for "ONE. MORE. SONG!"

Sunday morning is always bittersweet and comes way too fast. There were hugs being shared, numbers and photos exchanged, laughter, tears, social media friend requests and a sense of belonging

like no other filled the room. The goodbyes were a bit harder this year since it had been so long since we have all seen each other. But, rest assured, we all had the TIME OF OUR LIFE! I don't know about you, but my heart is full and I hope we never go that long without seeing one another again. Thank you all for being YOU!

We plan to open registration for the 2023 Retreat at the Hyatt Regency Minneapolis, June 22-25, 2023 very soon. Stay tuned for more information, and as always, scholarships will be due Dec. 31, 2022. You can request one by emailing me at AReeves@ccakids.com.

And be sure to read about a first-time retreat attendee, **Carol Smith**, and her family's experience (pg 9)

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



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first time retreat attendee family testimonial

by Carol Smith

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

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

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

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



Encounter: The Power of Facial Difference

September, 29 2022 at 5 pm PST / 7 pm CST

Children's Craniofacial Association is pleased to invite you to an informed and inspired event about fearlessly facing the world. During the event, we will highlight what it is like to live with multiple intersecting differences and those differences will be recognized, celebrated, and honored with the inaugural David Roche Award for Excellence in Advocacy.

Both of our award recipients, Dr. Jaz Gray and Rasheera Dopson, MPH, are professionals in the disability advocacy community. Both are available for workshops and presentations on intersectionality, DEI (diversity, equity, and inclusion), and disability advocacy.

Please register at: ccakids.org/encounter



David Roche, CM

Inspirational Humorist,
Author, Speaker



Rasheera Dopson, MPH

Advocate, Author, Researcher,
Entrepreneur



Marlena Blavin

Bodywork Therapist,
Storyteller, Hospice
Volunteer



Jasmine Gray, PhD

Researcher, Assistant
Professor, Storyteller, Patient
Advocate

Save THE Date

A new virtual program
from CCA Kids!



REGISTER AT:
ccakids.org/encounter

PAR Premier Tournament

by Christine Andler

On Monday, May 16, 2022, **Property Advisers Realty (PAR)** and **PAR Capital Partners** hosted their 6th Annual Premier Golf Classic Benefitting Children's Craniofacial Association at Timarron Country Club in Southlake, Texas.

The event was attended by local and out-of-town supporters and raised over **\$80,000!**

CCA won the bid for this tournament in early 2020 originally to be played in the fall of the same year, but because of the pandemic it was moved and rescheduled three times. The CCA staff was incredibly grateful to **Jerry Reis, President and Owner**, and his team for not giving up on CCA and making this incredible event happen. After two years of planning and rescheduling, the event went off without a hiccup! It was truly wonderful to see so many people excited to be out playing together for our kids and programs.

Prior to the tournament, the **Reis Family** hosted a dinner at the Club for out-of-town sponsors, CCA board, and the staff from PAR and CCA for an intimate evening of conversation, food and music by CCA's own, **Peter Dankelson**. It was a great night to share the passion for CCA and the importance of philanthropy with an amazing room of people dedicated to this event. Peter wowed all with his acoustic guitar and a playlist of rock classics to 10 original scores of his own.

We were so grateful to have board members Dede, and her husband Darin Dankelson, and Bill Mecklenburg in attendance for this special event supporting the efforts.

Breakfast tacos and a Bloody Mary bar welcomed approximately 75 golfers in some great spring weather. The players were given curated gift bags with PAR and CCA goodies, including a copy of R.J. Palacio's book, "Wonder," and a custom polo shirt sponsored by **Inwood Bank**.

A noon shot gun start made for a great day of play with lunch on the course with a burger station and a BBQ station by Spring Creek BBQ sponsored by **PURE Wellness**. **Power Brokers** sponsored the hole-in-one contest, where players tried to win a brand-new, custom Tesla at hole 17. Thank you to **Tesla NorthPark** and **Tesla Southlake** for showcasing your cars and donating raffle prizes.

The afternoon was followed by a cocktail reception with awards, raffle drawings, speeches, and fun sponsored by **Mach Private Risk**. The **Reis family** once again went above and beyond to make sure CCA



and the sponsors felt appreciated, opening up their home for a wrap-up party after the event.

A special thank you to **Jerry and Kerry Reis** for championing the fundraising efforts with their personal networks, donating their precious time, underwriting the vast majority of the event costs, and for opening their home to make this the most successful event in their tournament history!

We also give a big thank you to **Katy Reis**, PAR Special Events Coordinator and **Patrick Reis**, Executive Vice President of Operations and Partner, who worked hand in hand with the CCA Staff to execute a successful event with countless emails, meetings, and phone calls over the last two years.

"Thank you to all our sponsors for your generous support of our Charity Golf outing this year benefitting Children's Craniofacial Association. We raised over \$80,000! I think it can be said the event was a huge success, and enjoyed by all." Said Jerry Reis, President and owner of Property Advisers Realty and PAR Capital Partners.

A big thank you to all the Tournament Sponsors: Inwood Bank, Mach Private Risk, Power Brokers, Woodring Foundation, M. Terry Enterprises, Inc., PURE Wellness, Stephen Breen Memorial Foundation, Bowling Family Trust, Excell Electric, Naylor Commercial Interiors, AJ Gallagher, KPost Company, Brava, Dana Haywood

Construction, Marlin controls, Green2b Dallas, Carrington Coleman, McMillan James Equipment, Eataly Dallas, and TESLA NorthPark and Southlake. We are so grateful for this event to return in June of 2023

-Christine Andler

CCA's Director of Development



Spring Craniofacial Picnic in Michigan

by Tricia Brusk



This year, my friend and fellow craniofacial mom, Kelly and I organized our first annual Spring Craniofacial Picnic in West Michigan! Spring is a tough time for most children to make a Saturday work with sports and end of school year festivities, but we still had about 15 kids and young adults with craniofacial differences come to our cloudy day (oh that Michigan weather!) at Cascade Township Park.

The Park provided a pavilion with picnic tables and an inclusive playground, surrounded by lots of grassy areas to play in. We ate donuts and sub sandwiches while painting kindness rocks. Most important of all, we strengthened our friendships and made a few new friends.

When it comes to Craniofacial differences, community is the most important thing. At times, you can feel isolated and lonely. Getting together with others that have walked that same road allows us to not feel so alone. One of the young men that was in attendance had never met a person with Apert syndrome around his same age until our picnic. And that is the reason for our get-togethers!

The next Michigan-based craniofacial gathering will take place on September 17th at Shelden Park in Livonia, Michigan. We will gather to celebrate Craniofacial Acceptance Month. 🌈





meet haellie

hello, my name is **Haellie Wolf**. I'm 9 years old and was born with Frontonasal Dysplasia and a Cleft Palate. I've had over 37 surgeries to date and my parents say I'm a very strong little girl.

One of my favorite things to do is to draw stick figures and paint unicorns! I own a big unicorn painting book and absolutely love it. When I'm not drawing or painting, I enjoy spending time with my older sister, **Miranda**. We ride bikes together and even sing songs together. Our favorite song to sing is "Scars to Your Beautiful" by Alessia Cara. She is such a supportive sister.

I just recently started 3rd grade and my favorite part about school is gym and art class. When I grow up, I want to be a doctor. It will require a lot of hard work but anything is possible.

This summer I attended my first CCA Retreat in Dallas, TX. It was my first time to ever fly and visit the state of Texas. I had such a fun time and especially loved the Superhero's during the CCA Celebration as well as the prizes during Family Night and the Dinner Dance. Making new friends was the best part though! I'm hoping to go again next year!



ccasupersib

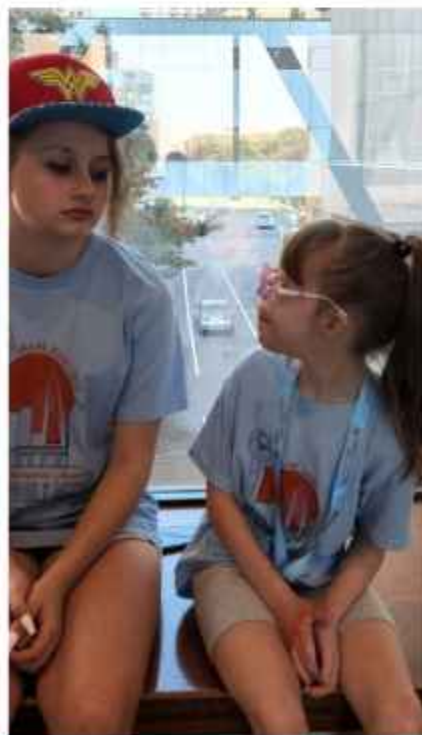
meet miranda

hi, my name is **Miranda Wolf**! I just recently turned 16 and started online classes for my 9th grade year. When I'm not doing my online school, I enjoy painting skull flowers and dream catchers. Reading scary stories and watching scary movies is also one of my favorite things to do. I would have to say "The Boy" and "IT" are two of my top watched movies. When I grow up, I want to work in a diesel body shop and join the Army.



My younger sister, **Haellie**, is very cool and we love spending time together. We have a really special bond and I feel very protective of her. When I see someone staring at her, I kindly ask them to stop.

A few months ago, I attended the CCA Retreat in Dallas, TX, and met lots of other kids, teens, and adults with facial differences. I loved all of the activities and making new friends. Knowing we aren't alone was so refreshing and I can't wait for next year's Retreat! 🥰



upcoming events

SEPTEMBER 2022

Nationwide
18TH ANNUAL CRANIOFACIAL ACCEPTANCE MONTH (CAM)

SEPTEMBER 10, 2022 | 11am-1pm
Dallas, TX | Mary Head's Carter Pavillion
(2320 Heads Ln., Carrollton, TX 75066)

15TH ANNUAL DALLAS CAM PICNIC

CONTACT: Annie Reeves, areeves@ccakids.com

SEPTEMBER 10, 2022 | 1pm-5pm
Paducah, KY | Noble Park
(2801 Park Ave, Paducah, KY 42001)

CAM PICNIC

CONTACT: Carol Ardelean, cardelean90@gmail.com

SEPTEMBER 10, 2022 | 1pm-6pm
Harmony, PA | 465 Scott Ridge Rd. Harmony, PA 16037

PITTSBURGH'S 4TH ANNUAL CCA PICNIC

CONTACT: Lisa Bowers, bowerszoe@zoominternet.net

SEPTEMBER 10, 2022 | 5:30pm-8:30pm
Salt Lake City, UT | Murray City Park, Pavillion #3
(5175 S. Parkside Dr., Salt Lake City, UT 84107)

CAM PICNIC | IN MEMORY OF KATIE WHICKER

CONTACT: Heather Sutton, heatherjsutton@msn.com

SEPTEMBER 10, 2022 | 1pm-3pm
Harmony, PA | Sheldon Park
32901 Plymouth Rd., Livonia, MI 48150

CAM PICNIC

CONTACT: Kellie Dowd, kdowd22@gmail.com

SEPTEMBER 29, 2022
LIVE Virtual Event

ENCOUNTER: THE POWER OF FACIAL DIFFERENCES
(SEE PG. 9)

CONTACT:
Khadija Moten, kmoten@ccakids.com

Back to School

#CHOOSEKIND

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Our curriculum is based off books that encourage students to embrace **DIVERSITY, UNIQUENESS, & EMPATHY** rather than fear differences & disabilities

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motts glamour day

by Kara Jackman

Craniofacial patients at C.S. Mott Children's Hospital in Ann Arbor Michigan were treated to a day of beauty, and then invited to walk the catwalk during the craniofacial team's Glamour Day at the J Douglas Aveda Institute. This annual event provided kids with facial differences time to explore new makeup, manicures, and hair styles, while hearing an inspirational message from CCA speaker's bureau member, **Rasheera Dopson**. Participants left feeling confident inside and out.

This year, CCA played a larger role in making this day extra special. CCA Mom, **Tricia Brusk**, and her daughter, **Amelia**, born with Apert syndrome, shared the power of CCA with the glammed-up goddesses. Amelia also benefited from the Aveda Institute's glam squad. She really enjoyed her moment in the limelight getting her nails, makeup, and hair done. Lunch was served, so everyone had an opportunity to nosh and network with one another. At the end, Amelia joined all the other girls as they giggled their way down the catwalk like professional models. While Amelia enjoyed her salon services and pageant experience, Tricia shared CCA's resources with the group of parents and patients. Brusk says, "I set up a table with CCA information and goodies to give to these amazing families who each have walked similar roads as us. I found that a lot of these parents didn't know what CCA was! It was truly an honor to be able to share what they do for families like ours

14 and for children like theirs. Having connections with



other craniofacial families helps not only the parents not feel as isolated, but the children as well, knowing they're not alone in their journey and feelings."

CCA's impact on this year's event continued with speaker's bureau member, **Rasheera Dopson**, speaking to the crowd. She shared her story with the young women and parents, encouraging them to let their inner beauty and self esteem shine. Her message focused on the importance of self worth and self confidence. She reflected after the event, "seeing all the young ladies with varying degrees of facial differences made me so aware of how much of our beauty is needed in these spaces."

Part of her remarks included these empowering words, "The world will tell us that in order to be beautiful you have to look a certain way, you have to act a certain way, you have to dress a certain way but each one of you has something so unique and absolutely beautiful that the world cannot take away and that is your difference."

After **Rasheera** spoke her words of encouragement and the girls showed off their new hair, nails, and makeup, CCA gifted a Retreat Scholarship to a family in attendance at Glamour Day. The family attended CCA's Annual Retreat and Educational Symposium at the end of June in Dallas, Texas. **Tricia** reflects on Annual Retreat's impact, "From my experience with the retreat in the past, I know how amazing it is and how great it is for each member of the family in attendance."

The event brought together the C.S. Mott craniofacial teams' patients and introduced them to CCA's inviting and inclusive community. CCA wants to thank the craniofacial team at C.S. Mott Children's Hospital, the J. Douglas Aveda Institute, **Rasheera Dopson**, and the **Brusk** family for making this such a successful event. 🌸



IFEW Recap

by Kara Jackman

In May, CCA celebrated **International Face Equality week** with nonprofits and non-government organizations around the world from May 17-24, 2022. The focus of this year's International Face Equality Week was facial difference is a human rights issue. CCA supported Face Equality's call and theme with video content and social media posts about ways you can share your story and stay informed about advocacy that is happening in the world beyond our CCA family.

CCA hosted an online lunch and learn with a video followed by a panel discussion about disability in the facial difference community. We watched **Rasheera Dopson** talk about the Americans with Disabilities Act and the word disability, then a panel of **CCA, FEI, and Many Faces of Moebius** colleagues responded to questions about how they feel about the term disability in the facial difference community.

Next up we hosted a YouTube video premiere of **Taking Center Stage**, featuring **Dr. Jasmine Gray**. She spoke about the importance of owning your craniofacial story through sharing it with others. Dr. Gray, professor of communications at **Pepperdine University**, encouraged individuals with facial differences to advocate for their needs through the power of storytelling.

Finally, we were updated by the **National Federation of Ectodermal Dysplasia's Becky Abbott** on the progress of the **Ensuring Lasting Smiles Act**, better known as **ELSA**.

Becky, Manager of Treatment and Research, sat down with CCA

marketing coordinator, **Kara Jackman**, to discuss more about who the act helps and what it would mean for people with facial differences. ELSA hopes to guarantee coverage of dental care for medically-complex children, improving their ability to eat, breathe, and drink. These videos and online events were sprinkled throughout the weeklong face equality awareness celebration on social media alongside many of CCA's and FEI's print and written resources. You can find these resources in FEI's educational hub. Education and the birth of the educational hub was the theme during 2021's International Face Equality week.

CCA continued to educate people this year, too. We filled our social timelines with information about ways people in and out of our community advocate to improve the lives of people with facial differences. Education empowers us to be our best advocates in c'l areas of our lives. To that end, CCA shared its many educational resources, personal stories, research opportunities, events, and more. If you've not already, subscribe to our YouTube channel to see these videos.

Additionally, FEI requested that participants take the pledge, declaring that face equality is a human rights issue. They also created an Instagram selfie filter for people to share on their profiles to raise awareness. We hope you learned a bit more about why face equality is a human right

through social media posts and online activities.

Next year, we look forward to our annual, global celebration and continued collaboration with Face Equality International and its partner organizations. Please take a look at FEI's social media channels and website, to learn more about the vision for the future. Together we hope to advance their mission, helping "the facial difference community to live freely, without indignity or discrimination." 🌸



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children's craniofacial association

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thank you to our 2022 facebook fundraisers:

names are listed in alphabetical order by the fundraiser campaign owner

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- visit: www.facebook.com/fund/ccakids/
- click - Raise Money
- click - "Non Profit" and then search for "Children's Craniofacial Association"
- click: Children's Craniofacial Association
- select - a goal amount and end date
- click - Next
- enter - a title for your fundraiser - Birthday or CCA Fundraiser, etc
- enter - tell your audience why you are raising for CCA (We already have some words in there but it is all totally customizable)
- click - Next
- select - a cover photo - we have a bank of photos to choose from or you can upload your own
- click - Create

IT'S THAT EASY!

thank you

The views and opinions in this newsletter are not necessarily those of CCA.