

ccanetwork

newsletter of children's craniofacial association

2022: ISSUE 3

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Left to Right: Raymond (Dad), Atlas, Athena, Mayari & Cassandra (Mom)

meet the shanklins

by Cassandra Shanklin

We first saw a brochure about the Children's Craniofacial Association while in the waiting room at Seattle Children's Hospital. Our son, Atlas, was 4 days old. He slept quietly in his carrier, his crooked head nestled awkwardly, yet comfortably, into the corner of the carrier. We knew what Crouzon syndrome was. My husband, Ray, has it and suffered through headaches as a child as a result of the intracranial pressure. We knew that having Crouzon wasn't good. Atlas would need a strong name to carry with him through life—we knew that the moment he was born. Ray had a few family members with Crouzon, and they all lived successful lives. We thought we knew something about Crouzon syndrome. What we were about to find out is that we were at the beginning of a journey that would change us, break us, and humble us. We would need a lot more help than we ever could have imagined.

see shanklins, page 2

letter from the outreach director



Since the start of CCA's formal outreach department in 2018, we have reached **over 68,000 individuals** across the globe through CCA's #Choose-Kind programming, Speakers' Bureau, speaking sessions and book donations.

CCA's outreach is what assists us to help bridge the gap between the craniofacial community and the general public. Over the years, so many of our CCA kids and adults have volunteered their time, skills, and efforts solely for the advocacy and acceptance of facial differences. Finally in 2022, I am SO excited to announce that CCA has taken steps to recognize some of these individuals through an annual award!

see letter from OD
page 6



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CAMERA TO MAKE A
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Double your donation
and be a part of our
\$20K Match Challenge
through 12/31/2022

shanklins, continued from the cover

There were two main reasons we were surprised when Atlas was born. One was that when we asked doctors about the possibility of Crouzons, both the OB/GYN and our pediatrician assured us it wasn't something babies were born with. Craniosynostosis was something that would develop over time, and it was something that they could watch for as the baby grew to be a toddler. So, with this knowledge we were confident that our baby would not show symptoms of Crouzons when he was born.

The other reason we were surprised by Atlas's features was because they were so extreme. The right side of his forehead ended in a sharp oval that protruded out, and the left side was almost completely flat and behind his eye. His forehead was sunken into a dent, which we soon discovered was the perfect place to kiss Atlas. Ray and I would press our faces against his forehead with our lips to the indentation in his forehead, as if to kiss away the fused sutures. We wondered what our oldest daughter, **Athena**, would say when she met him. Would she reject him? Would she have questions? She was a precocious child; we were ready for anything. Instead, when Athena met Atlas for the first time, she said, "He looks like Papa," (Ray goes by "Papa"). That was it. She began cooing and awing at him, and melted against his soft body as I held him. We breathed a sigh of relief.

The doctors, nurses, and medical staff were all very supportive.

2 They took great care of us during our brief stay, albeit I'm



sure they didn't know what to make of us.

One nurse asked if he would need a surgery. The same nurse caught me as we left the hospital. She must have seen my forlorn look as I looked around the maternity ward, not wanting to leave the safe enclave to go into a world that was a completely different place than I had left just days before. Everything seemed unfamiliar, and I was not ready. She gave me a big, much-needed hug.

As Atlas grew, he had more important things to do than to worry about his crooked head. He had a world to explore, fingers to eat, and smiles to give. He was one of the happiest babies I've ever met. He adored his big sister and would happily bounce around as high as he could in his bouncy chair, giggling all the while. As he grew, Atlas had a cranial vault expansion at 5 months, and an adenoidectomy at 11 months. Out of the blue, he stopped eating after the adenoidectomy. He was hospitalized for several days and went home with a nasogastrintestinal tube. It was the first of many additional medical complications that would make Atlas's journey more difficult.



shanklins, continued from pg 2

As with many children with Crouzon syndrome, Atlas developed severe sleep apnea. A solution was a tonsillectomy, and three subsequent surgeries to address a granuloma that continued to grow back in his nose. His next major craniofacial surgery was his orbital advancement, which was scheduled to take place when he was a year and a half old. By this point, we knew enough about the emotional roller coaster that craniofacial surgeries are and we just wanted to begrudgingly get them over with so we could deal with the long road to recovery. We were prepared for the look of our child when he came out of surgery. We even learned enough to know that if we were to see clear fluid coming from his scar after being home from the hospital for two days post-op, something was very wrong.



Atlas had been crying, grabbing his head. Not unusual, but we had been on top of his medicine. Cough, cough. Clear fluid. Is that normal? Let's take him back. We anticipated a short stay, so we packed a few things and threw them in the car and rushed back to Children's. Atlas was admitted for monitoring. He developed meningitis within days, followed by osteomyelitis, allergies, and C-diff. It was determined that Atlas had developed hydrocephalus post-op, and this was the reason for the draining cerebrospinal fluid. Atlas spent the next six weeks in the hospital. When he was finally allowed off of his lumbar drain, he had to learn to walk again.

The time in the hospital and the impact on his brain may have contributed to his delays; we may never know. Atlas didn't let that stop him. He continued being his happy self. We got Atlas a dog after he was discharged—the calmest dog we could find for Atlas. We needed a dog that wouldn't pull out his tubes and could cuddle him all day if that's what he needed. We were lucky to find the perfect dog for him, **Maggie**.

When Atlas was 3, his little sister was born. **Mayari** came into the world with zeal and feistiness. Within hours of being born, she lifted her head to look around the room. She walked along the furniture six months later, and was well on her way walking at 9 months. She must have known she had to catch up to her big brother. She has been the perfect playmate for Atlas,

and an (usually) affectionate sister. Mayari's craniofacial difference developed over time. She underwent a cranial vault expansion surgery at a year and a half, but has not suffered any negative side effects from Crouzons. We have been truly blessed that Mayari is a healthy, spunky 4 year old girl.

As for Atlas, he has benefitted from a loving extended family who is always there for him—near or far. Ray's young cousins, **Ty** and **Brody**, also have Crouzon syndrome, and their experiences have helped us prepare for Atlas's surgeries and familiarize ourselves with the medical timeline of care that we could expect. Ty, 15 years older than Atlas, has acted as a mentor to Atlas. They share a special bond, and I am so happy for Atlas that he has Ty to look up to.



shanklins, continued from pg 3

While having family around that is familiar with Crouzon syndrome has been helpful, we found that reaching out to the greater Craniofacial community has given Atlas a chance to see himself as part of something bigger. We were blessed to receive a scholarship to attend the CCA Retreat in Scottsdale, Arizona in 2019. The experience made us realize how lucky we are to be able to connect quickly with craniofacial families. What an invaluable asset we are to one another!

Our family was able to attend this year's Retreat in Dallas, Texas, as well! This time, Mayari was able to join in the festivities. Both kids had an incredibly fun experience. We are already looking forward to next year's Retreat in Minneapolis! We may come from a family with a history of Crouzons, but we still crave a human connection with others who have had the same experience. We know that as both Atlas and Mayari grow older, the connections they make from the CCA Retreat will help them to know themselves better. We are invested in staying connected to CCA! 🧡



craniofacial acceptance month

by Annie Reeves,
CCA's Program Director

Craniofacial Acceptance Month (CAM) might be over but, as always, we will continue to spread the message of Acceptance and Awareness all year long! September is always such a fun-filled month and we loved seeing so many of you participating, sharing your stories, holding fundraisers, and gathering together!

This year marked the 18th year that CCA has observed September as Craniofacial Acceptance Month. Our CAM theme was **"I Am Enough."** We kicked off the month with a 30-day Self-Care Challenge where we challenged our families to complete 15 or more of the daily challenges. At the conclusion of CAM, we held a drawing for a Self-Care Package for those who participated. It was a really fun challenge and our winner was **Joe Brooks!** Congrats, Joe!

One of the things we appreciate the most are the innovative fundraisers that often launch during CAM and which support our work all year long! We would like to thank everyone who held a Facebook Birthday Funder, CAM Funder or any other type of fundraising event! Thank you all so very much! Your support is not only critical; but it is also so appreciated!



craniofacial, continued from pg 4

We continued hosting our CCA Virtual Programming; including a Virtual Group Photo and 16 states proclaimed September as Craniofacial Acceptance Month. We would love to see this number increase next year and will be enlisting your help!

Many states now require local families to sponsor the proclamations. If you are interested in helping with this process, please email our Outreach Director, Khadya Moten, kmoten@ccakids.com and you can help get that number back up and beyond!

For the 15th year, CCA held National Picnic Day in September. It was so nice to see everyone gathering during CAM! It was CCA's first in-person picnic since 2019 and it was truly wonderful to be back together. Thankfully our weather here in Dallas was actually tolerable that day which made it even better!

Numerous organizations and hospitals also celebrated CAM along with us! Thank you for your continued support!

We would also like to thank EVERYONE who participated and send out a special thank you to the following volunteers:

- Carol Ardelean
- Casey Deakins
- Lisa Bowers & Family
- Rose Seitz & Family
- Kellie Dowd & Family
- Heather Sutton and Family
- Karen Kelly & CCA's Ambassadors, Ducky
- Sally Derrick from Children's Hospital of Dallas
- Paul Quinn & the students from the Biomed Academy at RL Turner High School
- DJ Joe Mir
- Ron Shover, Balloon Artist
- Spring Creek BBQ
- Carrollton Police Department
- DFW Avengers
- Papa John's Pizza
- Those who fundraised and donated for CCA through Facebook Funders

We couldn't have done this without all of you. Our hearts are truly full! 🧡



Utah Picnic



Utah Picnic



Pennsylvania Picnic



Pennsylvania Picnic



Pennsylvania Picnic



Michigan Picnic



Michigan Picnic



Kentucky Picnic

letter from OD, continued from the cover

The **David Roche Award for Excellence** in Advocacy is now an annual award bestowed on a speaker, educator, storyteller, artist, medical professional, or family member in the facial difference community. This individual must demonstrate that they have gone above and beyond for persons with facial differences, promoted acceptance and appreciation of appearance diversity. The Roche awardee challenges the stigma surrounding all physical differences.

The award is named in honor of the esteemed **David Roche, CM**, for his lifelong dedication to opening minds and connecting hearts and his invaluable mentorship and support to the staff of Children's Craniofacial Association.



On September 29th, we partnered with David and his wife, **Marlena Blavin**, leaders of "**Love at Second Sight**" and the funding of the **Ananda Foundation** for the inaugural award and virtual event known as **Encounter!**

The mission of **Encounter** was to create an engaging event framework that would amplify the voices of professionals and leaders in the facial difference community. We wished to create an event platform which had both entertainment and educational value, with the vision to inspire new stakeholders from different sectors to invest in the unique skills of CCA speakers. The event was live-streamed on YouTube (and can still be found on our YouTube page.)

David was our emcee and began with brief introductions. We heard from CCA's Executive Director, **Erica**

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Klauber, about CCA and the origin of the Speakers' Bureau. The

conversation continued with Marlena premiering the **Love at Second Sight** music trailer which encourages children to have the courage to stand up

against bullying and "take a second look."

Rasheera Dopson, MPH, spoke to us about "Moving from Equality to Equity." She encouraged us to go beyond inclusion to equity, challenging us to bring this notion into our daily professional and personal lives.

Dr. Jaz Gray, shared her spoken word piece titled: "Story Transforms the Soul." In it she described her emotions and surroundings growing up with a facial difference and concluded with sharing:

"Meaning is made when we decide to see, seek, and seize."

Rasheera and Dr. Jaz have consulted with CCA over the years in an effort to create a more inclusive space. The two were the first recipients of the inaugural David Roche Award for Outstanding Advocacy.

The award ceremony was then followed by **Peter Dankelson** performing his original song: **Can't Stop Staring**. Check it out on Spotify!

The event concluded with



David Roche

a short panel discussion with our speakers on topics surrounding the weight and responsibility of being an advocate, having conversations outside the facial difference community, using speaking as a platform to break stigmas and help advocate for and around the needs of the facial difference community.

Thank you to all of those who assisted in the lead up to the event including:

- **Lindsey Adams**
(Producer/Marketing)
- **Kimit Sekhon**
(Technical Advisor)
- **Mike Pinte**
(Video Trailer Editing)
- **Speakers' Bureau Members**

Additionally, I am so proud to announce that we took a step in improving CCA's Speakers' Bureau. We created a financial component to recognize the time, effort, and skills of our speakers.

The newly established speaker honorarium fee. This will be given to each speaker to offset the cost of travel to the speaking engagement. Up till

letter from OD, continued from pg 6

now, speakers would cover these costs on their own. This is slated to begin in January 2023.

We believe in the impact of speaking sessions and based on the testimonial feedback we receive, so do organizations who have worked with our speakers.

Personal experiences and interaction create empathy, understanding, and bonds!

A HUGE thank you to all those who spoke for years on their own dime. We hope this step is a small sign of gratitude for your efforts!

Our certification process to become a speakers' bureau member is currently under renovation. Therefore, we are currently not accepting new applicants. However, if you are interested in the program and would like to be amongst the first to know additional information please email me with your interest at kmoten@ccakids.com.

- Khadija Moten

CCA's Outreach Director 

about the David Roche Award for Excellence in Advocacy

- The award will be given each September, which is Craniofacial Acceptance Month.
- The award will come with a monetary honorarium of \$500.
- The award will be selected by the David Roche Award for Excellence in Advocacy committee, which is made up of Children's Craniofacial Association Executive Director, Outreach Director, David Roche, and past award recipients.
- Nominations for the award will be solicited each year from June-July and the committee will meet in August to review nominations and select a winner.
- Selected recipients may come from submitted nominations, but do not have to be chosen from the nominations collected.
- The award is meant to be received only once per person.
- The recipient should display characteristics that embody David's lifetime of work: remarkable spirit, warmth, wit and authenticity.
- The award will be presented live virtually, if possible, every year.

OVERVIEW: Grand Journeys

by Kara Jackman, with help from Melanie Howington

My grandmother was a huge part of my days recovering from surgeries. She would bring her pastel crocheted blanket to the living room, and create a makeshift bed out of the loveseat in front of the TV. I remember these days fondly, and I am sure she did, too, as she was able to put her nursing assistant skills to work with her own granddaughter. Grandparents, along with family and friends who act in a grandparent-like capacity are a vital part of the family network that supports children and individuals affected by facial differences. They care for us, their kids, and their grandbabies in so many different ways.

Encouragement and moral support is one way to help support the family member with a child with a craniofacial difference. As a grandparent, there is not much you can do to take away the suffering of your grandchild, but there are ways to smooth the inevitable bumps in the road, like major surgeries and other medical care. You can send text messages, write positive notes, volunteer to babysit, and write affirmations to encourage caretakers to remain uplifted in front of

their affected child. Care packages sent to the hospital, or packed before a big surgery are also a welcome support, too. Things like quarters for the vending machines, favorite drinks, snacks, and chocolate can go a long way in making them feel your love from a distance. Another wonderful tradition we heard about from the Laugharn/ Lance family is the "Surgery Eve Sendoff." Before a big procedure or surgery, both sets of grandparents take the family out for pizza. It's a nice way to bolster both your children and grandchild(ren)'s spirits and something to look forward to amidst the anxiousness...

OVERVIEW CONTINUED
ON OUR BLOG AT:
CCAKIDSBLOG.ORG

> GRAND JOURNEYS: TIPS
AND TRICKS FOR GRAND
CAREGIVERS





meet hannah

hi, my name is Hannah Brown. I'm 33 years old and live and grew up in a small town in Illinois, just 30 miles Northwest of Chicago, called Fox River Grove.

I first want to thank CCA for letting me be a part of their newsletter. This past June was my first time attending a CCA Retreat and it was definitely an incredible experience and one I will always remember. This was also my first time in Dallas, Texas and it was SO HOT! Instead of walking (which we did, but not often) we Ubered all over. I loved meeting the many families, hanging out in the lobby with new friends, and taking the trolley around town with others and of course, the Retreat dance. I can't wait to see everyone next year in Minneapolis!

I was born premature with something called **Apert syndrome**. Statistically, Apert syndrome occurs 1 in every 60,000 - 80,000 births. That seems like a big span, however, the year I was born, and the town I was born in, had two other families that had babies with Apert children. (Per my mom, we did end up meeting both families.) Apert syndrome is a genetic condition that causes fusion of the skull as well as the bones of the hands and feet. It is characterized by an underdeveloped growth in the skull, face, teeth and skeleton. Throw a few extras in there, like, cleft

palate, perforated eardrum and a tracheostomy (all which I had) and it really comes down to many years of hospital visits, surgeries, doctor visits (again and again,) long recoveries and life challenges! But, I'm going to leave it at that because I'm sure many of you have already or are beginning to know what I mean and have experienced what I have gone through or something similar. I feel we could all write the same book, but in our own words, places and experiences. I love a shirt that my good friend Shellie gave me. It says "Apert syndrome doesn't come with a manual. It comes with a warrior that never gives up." That is me. I've never let Apert define who I am. It is a part of me.

Who am I? I'm a daughter, sister, aunt, cousin, niece, follower of faith, and a friend to many. And what do I love? I love:

To Travel: Growing up our family of 4 was always on the go. (Mom: Lori, Dad: Gene, Younger brother: AJ, and myself). AJ was a ski jumper for our local ski jumping club and eventually the USA Men's Ski Jumping team. It started as weekend trips to wherever he was competing to full week getaways when he started competing nationally. Places we went were: Utah, New York, Colorado, Wisconsin, Michigan, Vermont, Minnesota, and



Alaska. I was his biggest fan. I was so proud to be with him in Park City, UT, at the 2018 Olympic Trials. What a neat experience and one I will always remember. Although he has retired from ski jumping, we try to still travel together as a family. These trips often involve fishing up North someplace or visiting my grandparents down South. I love my family, but I've also loved having the chance to go solo on a few occasions. Flying to my friends home in Ohio as well as Myrtle Beach on one of the many Apert Family get-togethers. I really enjoy my independence.



To Cook: I love using my Instant Pot. For my 30th birthday, this was one of the many wonderful gifts I received (going to Disney World for the first time was right up there as well). Using my Instant Pot has given me the confidence to make things for myself without asking for help (well, except for chopping up onions as my eyes won't stop tearing). If you follow me on FB you know I love to post what I make. I have downloaded and printed off over 100 recipes that I've put in a 3 ring binder - I've made many already. Often I walk to our local grocery store (I don't drive, but would like to someday) and buy what I need for what I am making. Both my parents work full-time so I know I'm helping in some way. I also like to see my mom's reaction when she comes home. She always says she loves it when she can come home from work, walk in the door and sit down to a meal someone else has made.

meet hannah, continued from pg 8

To Shop: One of my favorite things to do is go to estate sales. It is always exciting when we find those great deals. I also like going to resale shops as well as garage sales. Really, I love any kind of shopping (if it involves a stop for a latte or a mocha on the way, even better.)

Being Active: Through my elementary, middle and high school years, I was involved in many sports (with my schools as well as the local special recreation association.) I played soccer, softball, basketball and track. In 2010, at age 21, I was chosen to represent the State of Illinois in Women's Basketball for the USA Special Olympics National Team in Nebraska. What a great experience! Over 3000 athletes attended from all over the United States. It was fun meeting and exchanging pins from those I met from different states and events. However, my favorite part of the experience was the opening and closing ceremonies and being able to be a part of them. Today, I mostly enjoy walking, kayaking and boating. So, now you know a little bit about me. At 33 years of age, I feel I've lived a blessed life. I have a wonderful, supportive family (if you count aunts, uncles, cousins, etc...), a very large supportive family who has never treated me any differently because of how I was born. Sure, I've had challenges in my life and still do. Those occasional stares, questions, having to repeat myself because I sometimes can not be understood, having to ask for help because I physically can't do something, or just everyday things that come up, I may struggle with. That doesn't stop me though from enjoying life and being the best me I can be. In my room I have many plaques and wall hangings with inspirational messages. If you know me, you know I love anything with encouraging messages, from inspirational quotes, Bible verses and Christian music. One of my favorite plaques, which hangs above my bed, says, "You are fearfully and wonderfully made." I believe that about me, and I believe that about you as well!

Hope to see you all in June. Thank you CCA. 🍕

ccasupersib

meet a.j. brown

My name is A.J. Brown. I have the privilege of being Hannah's younger brother. I am 27 years old and work for my father selling industrial supplies as well as doing everything else that goes into helping run a small business.



Some of my favorite activities include fishing, traveling, cooking, outdoor games, video games, and playing with anything that has a motor. Like my sister, I'm down to do just about anything when friends and family are involved.

Growing up with Hannah was unique in the best way. Despite all the hospitals, surgeries, and inconveniences that came with her "disability," it seemed there was rarely a time it affected her ability to do anything. She had (and still has) an eagerness to be a part of whatever excitement was going on around her. Whether it be softball, basketball, track, or any other extracurricular activities, she never slowed down.

Through all her pursuits, she has remained dedicated to her role as my big sister. We made cookies together, rode bikes, went swimming, played outside, and traveled all over the country. When I was skiing, she came to support me whenever she had the opportunity. No matter how much I tormented her (my dedication to my role as her little brother) she would not be deterred. Even if it was just to drop me off at the airport in the middle of the night, Hannah was going to be there to send me off.

(Or maybe she was just excited to get rid of me.)

Along with Hannah's determination, she emits a glowing aura of positivity. She leaves a lasting impression on those who meet her simply through her smile and presence. It is not an uncommon occurrence for me to introduce myself to a stranger and be met with, "Oh! You're Hannah's brother!" It is a title I will always be proud of. 🍕



3 cheers for volunteers!

by Khadija Moten
CCA's Outreach Director

for the fourth year in a row CCA was approved to have a sponsored summer intern, thanks to the Dallas Mayor's Education Initiatives at The Dallas Foundation. This year we were blessed with not just one intern, **BUT TWO.**

We are so grateful to high school senior, **Layla Carr** and high school junior, **Rebecca Cawi Sang**. The two of them assisted us in reaching out to schools across the nation about CCA's complimentary educator resources and creating graphics for CCA's marketing.

"When this summer began, I was focused on getting internship experience but got so much more within my work at CCA. I learned about how education is necessary to spread awareness of those with craniofacial differences. My work focused on expanding awareness through outreach. It was satisfying to see the response and proclamations for CAM return. Through my small actions and hard work, I was able to make a difference."

- Layla Carr, CCA Intern

Additionally, Layla was also heavily involved in our preparations for Craniofacial Acceptance Month through graphic creation and writing proclamations to various state governors to proclaim September as Craniofacial Acceptance Month. While Rebecca assisted us with #GivingTuesday

10 promotions, graphics and thank yous.

"The experience I had while working at CCA was inspiring. I never knew such organizations like CCA existed. I was relieved to know there are many individuals who care about the wellbeing of children with craniofacial differences. During my internship, I remember rushing to send out emails regarding CCA's curriculums because I was so motivated. I'm grateful CCA took the step to educate and bring awareness to many more individuals out there. I'm super honored to have been an intern this summer! Thank you!"

- Rebecca Cawi Sang, CCA Intern

.....
We would also like to recognize our virtual intern, **Aaliyah Booker**. Aaliyah is a junior in college studying Biology. Thanks to her university's **NSF STEM TREX Internship Grant Program** we have had the privilege to work with Aaliyah for the past few months starting from early summer till the end of this year. Aaliyah has been heading up the effort on our YouTube interview outreach series. Check out CCA's YouTube page to view Aaliyah's interviews with those in the facial difference community! 🌟



CCA's 2022 Summer Interns:
Layla and Rebecca

cca virtual intern: aaliyah booker



it has been such an empowering opportunity interning with CCA! CCA has molded me into the person I've always wanted to be. Being able to share my craniofacial journey and to be a light for others has truly been a blessing. Throughout my childhood, I've always struggled with embracing my facial difference; always felt unaccepted and ashamed of my appearance. I was known as the brave and heroic girl due to the amount of medical procedures I underwent, but always kept to myself fearing what others thought of me. CCA has made me feel accepted and understood right from the start, immediately welcoming me with open arms. Being the face for CCA "Outreach Series" is the highlight of my college career and has opened doors for me that I'd never thought even existed. Shoutout to my boss, Khadija Moten, who is the outreach director of CCA; she has helped me break out of my shell and take that step outside of my comfort zone and into the confident human being I strive to become. 🌟

Thank you CCA for the opportunity and acknowledging me!



meet cormac

by Meg Donahue

Cormac Donahue is a kid with a lot of nicknames. We call him Corms, Cubby, Cormy Corm, little brother, big brother; but when he came home, he was **Cormac the King**. He keeps us on our toes. Since day one, Cormac writes his own story each day with things that make him unique, different, and totally wonderful. Each chapter has plot twists, excitement, and keeps us wanting to know more. He is quite the character.

Our story began like so many other families with craniofacial differences, and for that reason we have been so thankful for the CCA community. He arrived with many surprises for us. We didn't know his gender which was different from our first pregnancy. We thought it would be the biggest surprise that day, but his Treacher Collins diagnosis was the bigger surprise.

In his 6 almost 7 short years of life, he has done many typical kid things and also many other "extras." If you asked Cormac what his favorite things are he would

say, "I'm not telling you." "you know," or "blah blah blah." He is "extra!" The kid loves to joke and has a wild sense of humor. Humor is his "go to" and he loves to make people laugh. He is the joy in the room and the life of the party. He is always looking to explore and is open to adventures.

He loves to travel, especially to the Black Hills to visit his grandparents. He would go by plane, minivan, or if he was lucky enough, by TRAIN!

Cormac can't get enough of his trains. He has loved trains for as long as he has been able to say "choo choo" and connect the cars together.

He is the second baby of the Donahue family. He has to make sure as the middle child that his presence is known. And known it is. He has an older sister, **Juniper**, who often complains that he is "little brothering." He also has twin toddler brothers, **Quentin** and **Llewyn**. He is quite the brother and has a lot of different roles to fill including, younger annoying brother, older protector, bad idea generator, and more. To me, his mother, he fills

my heart up with so much love and compassion. He has made me more gentle and at the same time a fierce protector and advocate. My husband would describe him as his gamer bud with witty humor beyond his years. We are truly looking forward to the future and his role with us and the rest of the world. He changed us in so many ways, and I know it has been for the better.

Cormac loves all of his nurses, doctors, therapists, and teachers. He can be quite the performer when put in the spotlight. He has grown to be inquisitive and creative with his mind. He loves math and could care less about reading. He stays pretty busy with video games, YouTube, Roblox, Minecraft, and all things kids love these days.

"Cormac is a playful but also coy six year old. His intellect is well beyond his years and it is second only to the love he feels for his family, which is usually displayed by being the instigator of practical jokes on them."



"Cormac is the most fearless and funny kid I know. Although he is not a man of many words, he is expressive in a way that leaves no question about what is on his mind. His exuberant energy is contagious—contracted mostly through close physical contact."

"Cormac is a clever boy with compelling passion. Inspection of my red tool bag is mandatory, followed by a hands-on role in every project. Inquisitive from start to finish."

"We see Cormac's wheels constantly turning as he examines the hows and whys of his world. He is full of energy and love of life, but deeply sensitive as well."

ccakid

cca raises \$150,000 at the meck invitational

by Bill Mecklenburg

On September 7th and 8th the Mecklenburg family hosted the 11th annual Meck Invitational benefitting the Children's Craniofacial Association. There were 36 golfers from across the country and several others who attended dinners and participated in a significant way. CCA Rockstar, Peter Dankelson, held a jam session following the first day of golf, and the guests also had the pleasure of meeting Superhero Shane Vysocky and our rising Wonder spokesman PJ Reynafarje. They heard inspirational speeches by Morgan Mecklenburg on the importance of CCA and the Wonder #ChooseKind message in shaping her life, along with CCA moms' Dede Dankelson and Crystal Reynafarje, describing the importance of the CCA community for their families. The final night was capped off with the inspirational storytelling of Dr. Jaz who walked us through her incredible journey and her commitment to teaching all CCA Kids to tell their story and maximize their potential.

We are so grateful for our committed friends and neighbors who join us for this two day event, that continues to raise the bar each year.

Mike Del Giorgio and Todd Klosterman dominated the field to take home the championship. Robert Reader and Ted Rigoni tied for the runner up honors with Kent Penwell and Brian Beswick; however, the true champions of the tournament were our CCA Kids who inspired this small group of friends, corporate sponsors and auction participants to contribute over \$150,000 to benefit the Children's Craniofacial Association. A



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A special thank you is also deserved for Shawn Craig and Holly Jaenichen for providing incredible golf experiences for the auction along with TaylorMade Golf for allowing CCA to benefit from its Charity



meck invitational, continued from pg 12

Purchase Program. We also want to thank **Steven King** and **Greg Daniels** for providing incredible auction experiences that went for record amounts this year.

Coto de Caza Golf and Racquet Club was the host venue and all out-of-town participants stayed at the **Balboa Bay Resort** in Newport Beach, California. Private dinners were held at **Hanna's Restaurant and Bar** in Rancho Santa Margarita and at the **Balboa Bay Resort**.

CCA and the Mecklenburg family would like to thank all of the volunteers, participants, contributors and auction item donors who made this a memorable and meaningful event **Kathleen Philippi** who flew out from Wisconsin to volunteer for the cause! 🇺🇸



upcoming events

NOVEMBER 29th, 2022 | all day
ccakids.com/Donate

#GIVINGTUESDAY

CONTACT: Christine Andler, candler@ccakids.com

DECEMBER 6, 2022
Dallas, TX | North Park Center
48687 N US 75-Central Expy 1000, Dallas, TX 75225
GINGERTOWN DALLAS 2022

CONTACT: Christine Andler, candler@ccakids.com

JANUARY 24, 2023 | all day
Nationwide

MOEBIUS SYNDROME AWARENESS DAY

JUNE 22-25, 2023
Minneapolis, MN | Hyatt Regency Minneapolis
1300 Nicollet Mall, Minneapolis, Minnesota, 55403

33RD ANNUAL FAMILY RETREAT AND EDUCATION SYMPOSIUM

ONLINE APPLICATIONS ARE LIVE!!

- December 31, 2022: Deadline for Early bird discount [price increase January 1st, 2023]
- December 31, 2022: Scholarship Application deadline
- March 22, 2023: Registration Closes (or when all available rooms are booked)

CONTACT: Annie Reeves, areeves@ccakids.com



October 16, 2023
Irving, TX | Hackberry Creek Country Club
1901 W Royal Ln, Irving, TX 75063

7TH ANNUAL DFW PAR PREMIER GOLF TOURNAMENT FOR CCAKIDS

CONTACT: Christine Andler, candler@ccakids.com

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financial assistance testimonial

by Cindy Avila

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



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

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



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



legacy giving

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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



bling bling bling! **Brooklyn Nicholl** of Olathe, Kansas loves all that glitters. She expresses herself in the way she knows best with diamond painting using Diamond Dotz. Brooklyn works as a package handler for FedEx during the day and attends college classes at night. She, like many of us, sought out a calming and creative way to relax after a long day. Diamond painting was the answer.

Diamond painting involves purchasing a kit with the tools needed to create these masterpieces. The kit holds tiny, sparkly gems and a tray to place them in, a canvas, a stylus, and wax to adhere them to the canvas. Artists like Brooklyn can create using the codes to place the dots in the right place, or create their own designs with the supplies provided. Brooklyn says, "I got Diamond Dotz as a Christmas

present a few years ago and really enjoyed seeing my creation come to life! It made me excited to try to do the other designs as well. I've done some of my own creations with my own color choices, too!"

Creating these artworks provides Brooklyn with a sense of confidence and calm. She says, "I feel excited to create something special and different and I feel confident that I can do it even with different hands than most people." Brooklyn was born with Apert syndrome, a craniofacial condition that affects other parts of the body including hands and feet.

What is great about diamond painting is that one can create on their own or as part of a group of friends. Brooklyn enjoys working alone as she can go at her own pace, and enjoy the creative process, "I haven't worked with anyone because I have my own creative way of doing things." She has plenty of time to share with

friends when she goes out to work, classes, or shops with friends and family. After her adventures, Brooklyn also enjoys scrapbooking as a way to capture memories shared with loved ones. "I have a bunch of big books full of my creative pages and love to go through them and remember all the fun times I've had and the memories I've made," she reflects.

With the pride that comes with a completed work of art, Brooklyn entered her diamond paintings into the CCA Talent Show at the 2022 Annual Family Retreat and Educational Symposium in Dallas, TX. We all look forward to more art from her and our other Retreat attendees in years to come.

Her advice to others who may be interested in this art form are, "start slow and steady. Do a little at a time and then as you build confidence in your abilities you can do more! I started with the smaller Diamond Dotz packs and have slowly started doing the bigger pieces." Additionally, if you are interested in pursuing this way of art, Brooklyn is there for you, "I'm always willing to share what I learn and create with others."

Keep shining bright, Brooklyn. We can see you gleam from miles away! 🌟



children's craniofacial association

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