

# ccaenetwork

newsletter of children's craniofacial association

2023: ISSUE 3

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Left to Right: Mark (Dad), Shauna (Mom), Mason and Emelyn  
Photo Credit: Jessica Mills Photography

## meet the demarests

by Shauna McGillivray

Our son Mason is in the second grade, and he LOVES school. He's always been curious about how things work and is constantly looking for new things to explore. He enjoys reading, playing board games (the more strategy the better!), camping, toy building projects (from Legos to Hot Wheels), playing with his younger sister Emelyn and his best friends Ben and Hank, and making people laugh.

Our first clue that Mason would keep us on our toes was when he surprised us by arriving 5 weeks early, in mid-August, less than two days after my husband Mark and I celebrated our first anniversary together. There was an intense burst of activity in the delivery room when the medical team realized that Mason's umbilical cord was wound tightly around his neck, but they soon had him free. We noticed his eyes protruded, but I was far too wrapped up in the shock and joy of the sweet little boy in my arms

see mcgillivrays, page 2

## letter from the executive director



The past few months at CCA have been nothing but extraordinary in terms of the affirmation of the work we do, the families in our community, and the forward momentum we are making.

It all started when I attended the Moebius Syndrome Foundation Conference just one month after our Annual Family Retreat & Educational Symposium. I was still riding the Retreat high, proud of our community for having a Retreat that felt so intimate and yet still powerful.

But attending a partner organization's conference, which is set up so similarly to our Retreat, right on the heels of our event, was amazing.

see letter from ED page 6



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## demarests, continued from the cover

to pay it much thought. Happily, Mason was healthy despite having arrived so early, and my attention was consumed by the immediate demands of being a new mother, rescheduling our baby shower to now include the baby, ordering baby supplies, and trying to figure out breastfeeding with a preemie who wasn't yet quite up for it.

We first heard of syndromic Craniosynostosis on our second day in the hospital, when Mason's pediatrician came to examine his new patient. He told us how well Mason was doing, especially given his premature delivery, but noted that there were some issues. He also told us about Crouzon syndrome and that there were surgeries that could help. He assured us that the condition would not prevent Mason from having a full life. Although the medical journey would be hard at times, Mason would just be Mason to us, and this would be a part of that. After the pediatrician left, I burst into tears. What kind of surgeries would Mason need? How soon? How many? We would be the ones making huge medical decisions for him—would we make the right ones? Would he regret the choices we made for him? I still struggle with some of these questions. However, over the past eight years I have come to appreciate much of the advice that our family pediatrician gave us, even though at the time I could not fully grasp it.

The medical journey has indeed been challenging. Just trying to get timely appointments with specialists in the first weeks after birth was frustrating and overwhelming. A chance



cancellation got us in with a geneticist, who eventually confirmed the diagnosis of Crouzon. Concerned that Mason had not yet seen a neurosurgeon, the geneticist made some phone calls, which resulted in Mason getting his first CT scan just a few days later. ([My first lesson in the medical system: if you need to see someone quickly, have a doctor make the call.](#)) Mason had his first surgery at 7 weeks old, to treat hydrocephalus, and his second just two weeks later to place a VP shunt. At 5 months old Mason had a posterior cranial vault distraction, led by Dr. Kane at Children's Medical Center Dallas. The cranial vault surgery made the prior ones seem like a walk in the park. Mason's skull was so thin, it wouldn't hold the distractors. Dr. Kane devised a work-around by using a collagen plate to provide additional support. It worked (sort of) but the entire surgery took over 8 hours. Nothing could prepare us for the shock of seeing Mason so thoroughly bruised and swollen post-surgery. But he recovered quickly, and by

day three it was hard to keep him from bouncing out of the bed. ([Medical lesson #2: PICU nurses are AMAZING.](#)) Day 5 post-surgery we were sent home with a \$5,000 screwdriver (estimated price) and careful instructions on how to do the twice daily distractions. Unfortunately, the work-around failed by the third week. While we had gained some space for Mason's brain to expand, it would not be enough. We would be doing this again in a year.



**demarests** , continued from page 2

The next few rounds of surgeries were minor by comparison. Surgery #4 (8 months) removed Mason's distractors, which were exhibiting signs of mild infection. Surgery #5 (9 months) was a follow-up debridement and irrigation to clean out the resurgent infection, and surgery #6 (14 months) was performed to remove the collagen plates that, it turned out, were the source of the infections. By this time Mark had begun to refer to Crouzon syndrome as "the many-footed beast", because it seemed like every time we thought we had a handle on things, another shoe would drop. In between these surgeries, another big one fell: Mason's breathing.

At around 8 months of age, we noticed that Mason stopped breathing while he slept. Fortunately, some calls from Mason's neurosurgeon got his sleep study moved up from the initial 6-month wait (see [Medical Lesson #1.](#)) During that first sleep study, the technician and doctor were so alarmed by the data that they admitted us directly into the hospital. Coincidentally that was Mother's Day weekend. We were discharged Monday with an oxygen concentrator and follow-up appointments to see an ENT and pulmonologist. This led to discussion of a tracheostomy, which came as a complete shock. We learned from other parents that some kids had success with CPAP, so we asked about this option. The ENT was skeptical, but the pulmonologist thought it was worth a try. Mason did way better than expected, and he has been on CPAP ever since.

[\(Medical Lesson #3: ask questions and advocate.\)](#)

In January, when Mason was 18 months old, we had his second cranial vault distraction. This one went MUCH better and created the space he needed. To give Mason time to heal, removal of the distractors was scheduled for early June. Mason's baby sister was scheduled to arrive at the end of June, and I hoped she would not come as early as he did! The surgery went well, but Mason needed an unexpected blood transfusion, and we spent an extra night in the hospital. We left the hospital on a Thursday afternoon with a huge sigh of relief. My water broke that night. We let Mason sleep in until 6:30 Friday morning and headed back to the hospital. A friend met us at the hospital and took Mason. Emelyn arrived a few hours later, three weeks early. Despite the CRAZY week, everyone was doing great.



The next year was uneventful . (Well, as uneventful as having a baby and toddler can be.) As a second-time mom with a baby who was, as our pediatrician described her, "medically boring", my daughter's infancy seemed like a breeze. Mason had regular checkups, an annual MRI, and ear tubes placed, but no major surgeries or hospitalizations. We learned around this time that Mason's eyes do not produce tears, and thus began administering eye drops throughout the day, and eye ointment at night. This calm period was shattered the following year when, just a couple of weeks after Mason's third birthday, Mark was waiting in the car line to pick the kids up from day care and noticed Mason was in distress. When he made it to the front of the line, he heard the reason why: Mason had a bad case of croup. They started to drive to the ER but did not make it more than a few blocks before Mason's airway collapsed. Unable to breathe, he lost consciousness and began turning blue. Mason spent the next two days sedated and intubated in the ICU while they pumped his body full of anti-inflammatories. Those two days were the most agonizing of our lives. Unlike past hospital experiences, this was not planned or controlled. Mark and I existed in a fugue state and rotated staying with Mason and caring for Emelyn. It was utterly nerve wracking when, on the third day, the doctors removed the breathing tube and brought Mason out of sedation. Would Mason wake up as fully himself? All anybody could do was wait and see. Miraculously,

**demarests**, continued from page 3

he did—unhappy to be confined to a bed and ready to explore. He did so well, they discharged him from the ICU that day. We went home just in time for Labor Day weekend. I have never enjoyed that holiday weekend more.

A few weeks later, Mason awoke in the middle of the night with another sudden case of severe croup, and we immediately raced to the ER. Even though it was only ten minutes away, we barely made it. The doctors decided to put Mason on Flovent, a long-term anti-inflammatory developed for asthma. Mason has been on this medication ever since (5 years now and running) and has not had another instance of croup. None of us—his parents or doctors—are eager to take him off it.

I am happy to report that while Mason still has numerous routine doctor's visits, he has been medically stable for the past several years. "Stable" is not quite the same as "boring"—for example, there was the time a couple of years ago when the eyelids of one of Mason's eyes slipped back so that it looked like his eye had popped out. Fortunately, it was only that way for a few minutes before the eyelids shifted back into place with some coaxing from Mason himself. THAT was an excitement we hope never to experience again. Otherwise, it's been calm. Mason and Emelyn have the typical sibling relationship where they love each other and drive each other crazy. He gets tired of all the doctor's appointments, especially when they cause him to miss school

(which they nearly always do.) Even when you only see each doctor once or twice a year, it's still a lot of doctors and thus a lot of appointments. Despite this, he has an amazing attitude. He rarely complains and is very pragmatic for an 8-year-old (this is just part of what I need to do.) We dread his next major surgery, the fronto-orbital advancement, but we also know we will get through it. We have appreciated the knowledge and support of the CCA community and meeting so many parents and kids who have navigated this before us. We are grateful for the wonderful doctors and nurses who have provided the care that has allowed Mason to flourish, and value our relationships with them not just as doctors but as allies and friends of our family.

Most of all we are thankful for Mason and how much he has taught us. It's been a crazy journey but there is no kid we'd rather be on it with. As hard as the medical journey has been, our pediatrician was right on that first day: **we can't imagine who he might be any other way, and we love him exactly as he is.**



PHOTO CREDIT: JESSICA MILLS PHOTOGRAPHY



**ABOUT THE PHOTOGRAPHER: JESSICA MILLS PHOTOGRAPHY**

Jessica is a headshot and portrait photographer based in Prosper, TX. Her journey to CCA was deeply influenced by her love of her nephew who was born with a cleft lip and palate. Jessica is dedicated to serving the CCA community, as she would her nephew, by capturing images that spotlight every individual's sense of self-assurance and pride.

To contact Jessica, visit her website: [www.jessicamillspography.com](http://www.jessicamillspography.com) or call (469)-287-8374

# full shelves and full hearts!

by Christine Andler

Thank you to DN Tanks and the DN Tanks Foundation from the DFW office for the most successful care package drive we have had to date! We are very grateful for the partnership and to be chosen as one of the first group of The DN Tanks Foundation Central Region Community Charities. It is so special to be valued by this wonderful company and their Building Communities Initiative.

We want to give a special thank you to Roberto Gonzales for finding us and pitching CCA to the #buildingcommunities committee. Through a series of calls and meetings and with Roberto's recommendation, we were selected as a designated charity for the Foundation.

In September, during Craniofacial Acceptance Month, DN Tanks ran a two-week care package drive and made it a competition with five different teams! It was truly amazing to see nearly 8,000 items collected by their employees in this short time. A big thank you to the winning team who collectively of just 14 people donated over 3,500 items alone!



Our care package closet was quite low and with the uptick in surgeries in the fall and winter - these items came just in time to give our kids joy when they need it most!



## 3 cheers for volunteers! interns

For the fifth 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.

We are so grateful to high school student, Chasitie Hartfield. Chasitie assisted us with writing proclamation requests to state governors in honor of Craniofacial Acceptance Month. Additionally, she was involved in graphic design for our social media pages and even dabbled a little in some in-kind requests for our Development Department.

Also, in the fifth year of partnership



was the summer internship program provided by Ursuline Academy of Dallas. We were so lucky to receive two amazing rising senior high school students, Anna Kim and Marina Guandolo. They helped us with so many projects under Development from filing to sourcing in-kind requests. They also assisted with prep for Retreat 2023, care package sorting and sending legislators letters to advocate for ELSA and Ally's Act in congress.

We are grateful for the hours these incredible young ladies volunteered on top of their busy summers preparing for college. We thank each of you so much!

“Greetings Everyone! My name is Chasitie Hartfield. I'm 17-years-old and I am the 2023 Intern for CCA. I was inspired and honored to be a part of the Craniofacial Association family and being able to do everything I could to lend a helping hand. Being part of CCA this summer has been an outstanding opportunity because along the way I've gathered information and learned about the differences of many people with craniofacial syndromes.

Thank you to all the Directors of Children's Craniofacial Association and to all the people who have facial differences!



## letter from ED, continued from the cover

I was inspired in a new way and my already energized spirit was galvanized in realization that we are truly a unique type of extended family. While I started as “an outsider” or a “first timer” at MSF, I quickly felt that familiar craniofacial community step in to bond with me across syndromes and borders.



The MSF attendees wrapped me in love and showed me new topics and treatments I'd never before considered, even though the format felt so similar. The sessions they held were fascinating, insightful, and delivered with passion and expertise. I am hoping we are able to bring some of their speakers, families, and topics to our next Symposium in 2024. We have already partnered with them for two webinars, available on YouTube.

Furthermore, the Retreat satisfaction survey yielded a new generation of craniofacial advocates who not only are ready and willing to serve, but who literally demanded representation! **Hello Teenagers!** We heard your feedback and issued a teen survey. The responses were fascinating! You guys want to lead panels, be put to work on advocacy topics, and spearhead inclusivity and accessibility. Young people stepping up is really incredible to witness and

nothing is more exciting than learning how you all want to continue our legacy of “families helping families, people supporting people,” that I consider to be the hallmark of CCA.

Shortly after these events, we hosted the virtual event “The Power of the Bucket List,” with Turtle Boy author, **Evan Wolkenstein**. Hearing how his personal story of growing up with micrognathia led to a cool, page-turning YA fiction novel, was inspiring. But even more inspiring was the stories our teens shared in the Zoom of things they wanted to cross off their bucket lists. It was very intimate as many of the bucket list items proved to be immense challenges because of our physical differences in anatomies. Together we talked about how someone with fused elbows might do a cartwheel or someone who has never eaten by mouth might learn as a young adult to taste and enjoy food like her peers. These are the types of hopes and dreams we workshopped together, and again, it reminded me that young people have goals that we need to listen to beyond our assumptions.

But perhaps the most astounding and life-affirming part of my summer was reading the nominations submitted for the **David Roche Award for Excellence in Advocacy**.

There were 71 nominations submitted, representing 29 amazing people. What we saw was advocacy that went way beyond public speaking. We recognized people working towards legislation such as **Ally's Act** and **ELSA**, which would

mandate coverage for hearing aids and craniofacial dental surgeries and procedures. We heard campaigners from **Face Equality International** and other organizations, working to define facial differences as a human rights issue. With this distinction, they are pushing harder than ever before for protections due to people with facial differences to understand and claim, when appropriate, the membership in and responsibility to the disability community.

Still other types of advocacy are evident across the virtual landscape, with increasing media representation and showing different lifestyles of people living with facial differences. We still love **Stephanie Cooper's** famous line, “**more shares equal less stares,**” and we also believe “**if kids can see it, they can be it.**” These advocates showcasing different lifestyles, careers, races, genders, and abilities on our social platforms, website, and video channels are doing critically important work.

Still more stories poured in of grassroots advocacy: organizing parent support groups; working tirelessly to connect new parents to veteran parents, patients to doctors and hospitals; and offering hours of supportive communication.

We reminded our families that it is advocacy to be the first patient undergoing a new type of distraction and it is advocacy to allow residents and fellows to sit in your team appointments. It is advocacy to broadcast “different is cool,” on YouTube and to perform your talent on a stage.

## letter from ED , continued from page 6

We saw advocates being up-standers when a classmate was being bullied and advocates who are willing to cry in the dark over the phone with a bereaved parent. All of these types of advocacy and more spilled out of grateful hearts into an online form that I got to read.

From our amazing volunteer-driven Retreat, to the MSF partnership, to the virtual programs that are still evolving and growing, to the daily work of providing care packages and emotional support, **all this work is done out of love.**

So the reason that I bring all this up, is because I also suffered some of my lowest emotional lows during this summer, right along with the joys.

My work with CCA has helped me and grounded me, and above all, reminded me that when I doubt that the world is a safe place, I remember that love is a verb. When we receive these actions, we are accepting the love that exists in this world. When we witness these actions, we are also recipients of this love. And when I do these actions, I am part of the love that improves this world one act at a time.

I am so grateful for the love you all share generously, selflessly, and widely. I am in awe of your stories and the hearts who share them. Thank you for continuing to bless my life with love.

My last and final thought I want share, is that we do need your help to continue these labors of

love. Our financial assistance will top \$70K this year - more than ever in CCA history! Our next year's Retreat will cost more money to host than years' past because of inflation and the desire to offer more scholarships. We want to continue offering workshops and speakers that inspire hope and healing, and while so many volunteer their time, oftentimes we need to pay professionals for their work. Furthermore, we would like to provide opportunities to access mental healthcare and must compensate these (overworked!) professionals for their time. Rest assured, your dollars are going to fund the work we do and the work we do is successful. We know that because of the feedback we receive and use it to both fuel our work and improve it.

As we near the year end, it's critical that we close our budget gap. This is usually the time where we receive the majority of our funding and this year, at the time of writing, CCA still needs to raise over \$140,000 to meet our 2023 budget expenses. Yes, we have fundraisers coming up and our annual appeal, but please know that we rely mostly on our individual donors to really step up and donate this time of year.

Thank you for your support all year long ... it is the reason we are able to do what we do, with all the love we have! Let's celebrate the holidays in love and light! Happy Holidays, to you my dearest friends and family!

- Erica Klauber  
CCA's Executive Director



## upcoming events

NOVEMBER 1, 2023 | 7PM CST  
Virtual

CAREGIVER SUPPORT GROUP

NOVEMBER 19, 2023 | 12pm CST  
Rookies RocHaus  
96 W. Main Street, West Dundee, IL 60118

COTERIE METAL MAYHEM CONCERT  
for Children's Craniofacial  
Association featuring Peter  
Dankleson and others!

\$10 advance  
\$15 at the door



NOVEMBER 28, 2023  
Nationwide

#GIVINGTUESDAY

CONTACT: Christine Andler,  
candler@ccakids.com

DECEMBER 5, 2023  
NorthPark Center  
8687 N Central Expy, Dallas, TX 75225

GINGERTOWN

CONTACT: Christine Andler,  
candler@ccakids.com

DECEMBER 7, 2023 | 6pm CST  
Stetson Dancehall  
San Antonio, TX

3RD ANNUAL CHRISTMAS  
GIVE GALA -HHI EVENT

CONTACT: Christine Andler,  
candler@ccakids.com



JUNE 27-30, 2024  
Baltimore, MD | Hyatt Regency  
Baltimore Inner Harbor  
300 Light Street, Baltimore, Maryland, 21202

34TH ANNUAL FAMILY RETREAT  
AND EDUCATION SYMPOSIUM

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# pests'r us 30th anniversary party benefitting cca kids

by Eric Papadeas and intro by Christine Andler

In March, a long-time donor and volunteer for CCA, Eric and his wife Melinda Papadeas, hosted the Pest'R Us 30th Anniversary Party in Chandler, Arizona. Papadeas is the owner of Pest'R Us, a pest control company serving the Phoenix metropolitan area with a long list of loyal customers. It was a beautiful night with over 125 people celebrating the success of the company and their longtime clients turned true friendships. The event also showcased Children's Craniofacial Association, a charity close to Papadeas's heart, with a speech by Christine Andler, Director of Development, and a night full of a live auction, raffles and silent auction all benefitting CCA. In all, the event was a big success and grossed **\$14,670!** Eric shared a few reasons below why CCA is important to him. Thank you so much to Eric, Melinda and the entire family for supporting our important work!



"When the movie 'Wonder' came out in theatres, my uncle told me I needed to see this movie. Although, I was older in age, the movie had a great impact on me, as I have Treacher Collins syndrome. In my early years, the diagnosis wasn't as known as it is today. At the time when my wife and I left the theater, I felt the need to learn more about how the movie came about... and this is how I found CCA! We made a donation to the organization that year and quickly learned about the Retreat in Utah. I was blessed to meet the staff, those in the movie, and many young kids with the same syndrome. I found an extended

family through CCA.

Ever since, CCA has had a huge impact in my life and I have attended many Retreats, including helping with the Retreat in my home state of Arizona. Thank you CCA for all you do to bring awareness to many syndromes and helping families in need. I will always be a part of this God-blessed organization for years to come where and whenever needed." 🙏

- Eric Papadeas

## want to host a fundraiser?

download our fundraiser toolkit!



[ccakids.org/fundraising-ideas.html](https://ccakids.org/fundraising-ideas.html)





# ccateen

## meet jace

**W**e all have a story to be told and mine goes a little something like this:

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

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

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

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



# meck invitational 2023 raises \$158,000 for cca

On September 6th and 7th the Mecklenburg family hosted the 12th Annual Meck Invitational benefitting the Children's Craniofacial Association. There were 40 golfers from across the country and several other dear friends who attended dinners and participated in a significant way. This year's tournament was dedicated in memory of Scott Guzzo and PJ Reynafarje who were amazing members of the CCA community and who both touched the Mecklenburg family in immeasurable ways. Bob Guzzo and Crystal Kouri shared the meaning of the CCA community in the lives of their sons.

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

Ben Briscoe and Heath Fisher dominated the field to take home the championship. Corey Tabor and Jim Horvitz brought home the runner up honors and Jane Jacobson captured the Ladies Championship. 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 \$158,000 to benefit the Children's Craniofacial Association.



# meck invitational, continued from page 10

A special thank you goes out to our Sponsors:

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- Kathleen and Dale Philippi

A special thank you is also deserved for Shawn Craig, Holly Jaenichen, Jay Walkinshaw and Tom Jaronski of Invited Clubs for providing incredible golf experiences for the auction.

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 Coto de Caza.

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 including Kathleen Philippi who flew out from Wisconsin to volunteer for the cause! 🙏❤️





# meet dani

hi, my name is Dani Trejo I'm 9-years-old. My favorite school subject is science. I really enjoy drawing, dancing and playing baseball. During my free time I like to make videos and play games with my brothers. I like going to Texas to visit my grandparents. I also enjoy going to watch baseball games, soccer games and football games with my family. This was my first year attending the CCA Annual Retreat. I was beyond grateful to be a part of this amazing community. I got to make new friends. The best part was that my brothers got to be a part of this experience with me. 🎉



# ccakid

# ccasupersibs

## meet nathan

**m**y name is Nathan and I'm 13-years-old. I'm the oldest. My favorite subject at school is Spanish Class. I'm a Miami Dolphins fan. I enjoy playing football. In my free time I like working out, playing video games and hanging out with friends. I like spending quality time with my family. My favorite place to travel was Minneapolis. This year was our first year attending the CCA Annual Retreat. I was extremely happy to have been part of this amazing experience for my little brother. I was thankful that I was able to participate in the Symposium. Lastly, I'm grateful that I got to meet other siblings. 🥰



## meet anthony

**m**y name is Anthony and I'm 12-years-old. I'm the second oldest. My favorite school subject is math. I'm a Dallas Cowboys fan. I really enjoy playing football and baseball. I like watching NFL games with my dad on Sunday nights. I enjoy spending time with my family. I like to visit my grandparents in Texas. My favorite part of going to Texas is being able to go to the Cowboys Game. This year was our first year attending the CCA Annual Retreat. I had so many different emotions. Most of all I was grateful that we got to do this for Dani and for him to know that he has a community of friends and families. 🥰



## meet santiago

**m**y name is Santiago. I'm the baby of the family. I like watching Blippi and Mrs. Rachel. I like playing with my brothers. I like going to my brother's football games. I like playing with cars with my brother Dani. I also like coloring. 🥰

# 7th annual PAR premier tournament benefitting cca kids

by Christine Andler

On Monday, October 9, 2023, Property Advisers Realty (PAR) and PAR Capital Partners hosted their 7th Annual Premier Golf Classic Benefitting Children's Craniofacial Association at Hackberry Creek Country Club in Las Colinas, Texas. The event was attended by community supporters and raised over **\$81,000!**

CCA was lucky to be granted its second year as being the beneficiary for this premier tournament in DFW! The CCA staff is incredibly grateful to Jerry Reis, President and Owner, and his team for awarding us another year of this incredible fundraiser that is entirely underwritten by PAR. The event was a huge success with many new faces and corporations supporting our kids and programs. Including our first Platinum Corporate sponsorship from **CheckSammy**, a sustainability company.

Prior to the tournament, the Reis Family hosted a dinner at their Headquarters in Las Colinas for out-of-town sponsors, CCA board, and the staff for an intimate evening of conversation, food and music by CCA's own **Matthew Kern!** 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. Matt wowed all with his guitar with a playlist of classics to an original score of his own!

The golf day started off with breakfast tacos and a bloody mary bar sponsored by **The Bowling Family** as around 92 people came out to play in the great fall weather in North Texas. The players were given curated gift bags with PAR and CCA goodies. Players warmed up on the driving range sponsored by

**14** Gallagher and throughout the day players enjoyed beverages



sponsored by **Green2B**.

A noon shot gun start made for a great day of play with box lunches sponsored by **Drawbridge, LLC**. Contests holes were sponsored by **Logical Solutions Inc** and **Priority Power** sponsored the hole-in-one contest. The afternoon was followed by a cocktail reception with awards, raffle drawings, speeches and fun sponsored by **KPost**. We were so grateful to have **Ed, Amy, and Matthew Kern** with us plus our amazing Board Member, **Bill Mecklenburg**, for speaking and supporting this special event. **Ric Hobby**, President of Sales from **CheckSammy** and **Keith Post**, CEO and owner, from **Kpost** shared a few remarks on the



## PAR, continued from page 14

success of the day and why they support our organization. It was truly nothing short of amazing to see this corporate support!

A special thank you to Jerry Reis for championing the fundraising efforts with his personal network, donating his precious time, and underwriting the total event costs.

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 and hand with the CCA Staff to execute a truly successful event!

**“I am so proud of all the great efforts extended by everyone...to make this such a huge success. Our fundraising efforts are touching the lives of more people each year...and the goodness will multiply.”**  
said Jerry Reis. 🍷

A big thank you to all the Tournament Sponsors:

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# David Roche award of excellence in advocacy

by Khadija Moten

On September 18, 2023, the Children’s Craniofacial Association (CCA) presented the David Roche Award for Excellence in Advocacy for the second time. The award is named in honor of David Roche, a lifelong advocate for people with facial differences and a mentor to the staff of CCA. This award is given to an individual who has gone above and beyond to advance the status of people with facial differences, promote acceptance and appreciation of appearance diversity, and challenged the stigma that surrounds physical differences.

This year we received numerous nominations from you, the community, totaling 71 submissions representing 29 people. We met as a committee to read through the beautiful nominations of people advocating in their communities and across the globe. It was a difficult decision, but ultimately CCA and the committee were honored to award Aaliyah Booker as the recipient of the 2023 David Roche Award of Excellence in Advocacy. Aaliyah has played a key role in CCA’s outreach in her short time with us as an intern and the face of the CCA’s YouTube Outreach Series. She has interviewed over 25 individuals thus far with many in the pipeline for the next few months. In addition to her work with CCA,

Aaliyah is a tireless advocate for inclusion and diversity. She has partnered with like organizations in their programming and recently advocated for access and inclusion of resources for the facial difference community in D.C. on Advocacy Day for the ELSA ACT. Congratulations Aaliyah!

### POSTHUMOUS AWARD

This year was unimaginably hard as we lost two incredibly loved, cherished and important members of our community. There is no adequate way to sum up what these two people meant to our craniofacial community.

The committee agreed to award two David Roche Awards for Excellence in Advocacy Posthumously to: Paul Patrick “PJ” Reynafarje and Robert “Scott” Guzzo



“ All my life I’ve struggled with self-acceptance, self-love, anxiety, self-rejection, and my biggest one “fear”, fear of being viewed and displayed in today’s society knowing I don’t fit in with today’s beauty standards. People automatically judge me based on my physical appearance, never giving me a chance to prove my worth. The shame, the guilt, the pain, the embarrassment I felt every time going in and out of the hospital having surgery after surgery, knowing I will never be normal. Being able to prove to myself now and to others that the impossible is possible has been the greatest blessing ever. Especially, proving to myself that I am worth something and that my differences do not define me has made me mentally stronger to the point where I’m advocating not only for myself but for the craniofacial community and for anyone who’s struggling on finding self love & self acceptance within themselves. Overall, thank you CCA for this award, for this opportunity and most importantly for accepting me for me. Remember... don’t ever try to fit in when you were BORN TO STAND OUT!



PJ was born when the movie Wonder was still in theaters. Along with his mom, they began a virtual and in-person speaking tour to schools around their community and beyond. PJ was the face of Wonder for thousands of students and was always invited back year after year to the schools and libraries he visited. Through his platform, PJ’s Play-house, on Instagram, he reached over 91K followers with messages of kindness, anti-bullying, and the message to love your-self.

Scott was insistent on being a part of life and letting nothing stand in his way of exploring and enjoying everyday things and larger-than-life experiences, alike. He wasn’t afraid to stand up when something he encountered was not accessible for him, and often he and his parents wrote letters to businesses and gave feedback to advocate for better accessibility around his community and everywhere he visited. He was privileged to carry the 2004 Olympic torch and the 2016 Indiana Bicentennial torch.

Congratulations to our 2023 Award recipients! We will be accepting nominations for 2024 in the summer of 2024. We look forward to continuing this tradition each year of recognizing truly amazing individuals for their work in the craniofacial community as advocates.

Did you miss the LIVE ceremony? View it on our YouTube page!



# craniofacial acceptance month 2023

by Annie Reeves

Craniofacial Acceptance Month has come and gone but, as always, we will continue to spread the message of Acceptance and Awareness all year long! September is always such a busy and exciting month and we truly enjoyed seeing so many of you participating, sharing your stories, holding fundraisers and sharing all of our customized graphics. A huge thanks goes out to our Outreach Director, Khadija Moten, for designing everything!

This year marked the 19th year that CCA has observed September as Craniofacial Acceptance Month. Our CAM theme was "The Future Is Inclusive." 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 Christine Clinton! Congrats, Chrissy!

One of the things we appreciate the most are the number of individuals who hold fundraisers that often launch during CAM and which supports our Programs & Services 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 greatly appreciated!

We continued

hosting our CCA Virtual Programming, including a Virtual Group Photo and 9 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



## CAM, continued from page 17

interested in helping with this process, please email our Outreach Director, Khadija Moten - [kmoten@ccakids.com](mailto:kmoten@ccakids.com), and you can help get that number back up and beyond!

And, for the 16th year, CCA held National Picnic Day in September. It was so nice to see everyone gathering during CAM and be back together for this fun-filled Annual event! We even had some new locations added this year!

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



MI PICNIC



MI PICNIC



NC PICNIC



NC PICNIC



TX PICNIC



TX PICNIC

## CAM, continued from page 18


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

- Carol Ardelean
- Lisa Bowers and Family
- Casey Deakins
- Ashley DiPaul
- Kellie Dowd and Family
- Kara Jackman
- Shannon Reicherts
- Jesanne Roden-Reynolds
- Beads of Courage
- Deborah Carrillo from Texas Art & Play Therapies
- DJ Joe Mir
- Ron Shover, Balloon Artist
- Spring Creek BBQ
- JJ & Heather Henson

- Paul Quinn and the following students from the Biomed Academy at RL Turner High School:
- Kaya Davis
- Andrea Delgado
- Chris Figueroa
- Joslyn Olivares
- Karishma Pilla
- Anika Yalamanchili
- Nawal Zafar
- Those who fundraised and donated for CCA thru Facebook Funders

We couldn't have done this without all of you. Our hearts are truly full and we thank you.

Big hugs,

Annie Reeves  
CCA Program Director 




KY PICNIC



TX PICNIC

Check your mailboxes for a **A Little Rhea Sunshine**, our Year End Appeal Featured Family!



 Donate Today




## CCA's Speakers' Bureau


Let's break the stigma surrounding facial difference by inviting a CCA speaker to your schools, organizations, clubs, and corporations!

Personal experience and interaction have impact. Take it a step further and become a speaker yourself through sharing your expertise, passion, and journey.

As of the Fall of 2022, with the generosity of the Ananda Foundation and our mentors, we have taken the Bureau a step further by establishing a speaker's honorarium and travel fee. The honorarium and fee not only supports our speakers but a portion of the fee will be reinvested in a scholarship fund and continuous mentoring and



 Scan to Apply

training programs for our speakers. The scholarship fund also allows us to never deny a school or civic organization a speaker due to their inability to pay. While the training program grants us the opportunity to continue investing in the growth of our speakers. 

LEARN MORE ABOUT THE BUREAU AT: [CCAIDS.ORG](http://CCAIDS.ORG)



# children's craniofacial association

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## financial assistance testimonial

by *Brittany Williams*



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