



inside

CCA TEEN:
Ashanti Moore

CCA SUPER SIBS:
Smith/Moore Siblings

CCA ADULT:
Chelsea Buyalos

RECAP:
Craniofacial Acceptance
Month (CAM)

**SELFCARE FOR
CAREGIVERS**

CCA Development

OVERVIEW:
Dental Transition Q&A

CCA ATHLETE:
Jeannelle Rivera

**Remi & Small Big
Hearts Foundation**

**DONOR IN THE
SPOTLIGHT:**
The Bowers-Alters
Family

**FINANCIAL ASSISTANCE
TESTIMONIAL:**
Tandazo Family



White's Family Story

by Megan White

"You are so brave!" We have uttered those words more than any parents should to their child. My husband Jeff and I and our daughters, Charlee (11), Braylee (8), and Maddee (5), live in rural Wyoming in a town named Pinedale. Back on July 23, 2012, when Braylee was born, our lives were forever changed. Braylee was born with Apert syndrome, something neither we, nor anyone in the operating room for my c-section, had any idea about prior to her birth. The silence that broke out the minute they successfully delivered Braylee is something that I will never forget: She was crying, but everyone else was dead silent. The pediatrician grabbed her and then Jeff went over to take a



Letter from Board Chair

It is difficult to articulate all of the complexities the year 2020 has brought to the world. It seems I cannot go more than a day without hearing someone lament about 2020 and asking, "Is this year over yet?" It's often too easy to let negative thoughts occupy our minds and yearn for our previous "normal." However, when I take time to think positively and reflect upon the achievements and highlights of the past year, I am nothing but impressed and thankful for the CCA community who has

See **board chair**
Page 4

white's , from the cover continued

look. My doctor asked for samples of this and that and said they needed to be sent off to be tested: STAT. I was still trying to figure out what was going on . . .



Jeff eventually came back and sat down beside me. I could tell by the look on his face that something was wrong, but he didn't want to tell me anything until I was off of the operating table and out of harms way. The pediatrician, however, showed no such restraints, blurting out that Braylee had webbed hands and feet, a cleft palate, and a protruding forehead. They took Braylee out of the OR, and I made Jeff go with them so that he could watch out for her. I started wondering what went wrong . . . How could this have happened . . .

Eventually, I was moved to recovery and then they brought her to me. . .

My baby. . . Braylee.

I remember looking at her thinking, "Well, she's breathing on her own. That's good! This other stuff doesn't look that bad," and then they whisked her away to do a CT scan of her head. They wouldn't let Jeff go back with her, so we just sat there in silence. I'm not

sure if we said more than two words to each other the whole time. We were silent: not panicking, but worrying about the unknown.

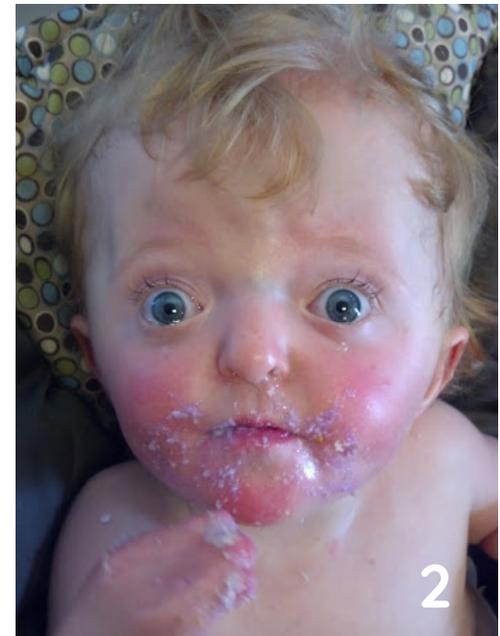
After they moved me back to my room and brought Braylee in to be with us, the pediatrician informed us that she wasn't sure what was going on, but she was going to go back to her office to do some research. Jeff immediately got on the computer and started Googling all of her symptoms, and figured out it was Apert syndrome six hours before the doctors told us the same thing. They would later confirm with a blood test.

Two weeks after she was born, we were sent to **Primary Children's Hospital in Salt Lake City, UT**, four hours away. There we met with a team of doctors who explained that Apert syndrome was a random, genetic mutation of the **FGFR2 gene**, and there was nothing we did to cause it. It happens in every 1 out of 160,000 births. They told us she would need several surgeries. From there, it has just been one day at a time. We have done, and will do, whatever needs to be done to help her live her best life.

Braylee has proven from day one that she is a fighter and the bravest little girl we've ever known. She has had nine surgeries to date. At six months old she had her first surgery, which was a cranial vault reconstruction (CVR) to fix her

bilateral coronal craniosynostosis. They made an incision from ear to ear, took the top part of her skull off, broke it, and then put it back together with plates and screws so that her brain would have room to grow. At 11 months old she had her cleft palate repaired and another skull surgery to remove some hardware that had come loose from her CVR. Later, she had three different surgeries on her hands to separate her fingers. Then, doctors performed a **LeFort I (SARPE)** to help expand her palate, a surgery to remove that expander, and then lastly a **strabismus surgery** on her eyes to help strengthen her eye muscles. Through all of them, she has shown so much strength and resilience.

We always tell her before any doctor's appointment and surgery that she is so brave! Now, every time she is done, she looks at us and says, "I was so brave!" Those words have built up her confidence. She knows she really can do anything.



white's, from the cover continued

Living with Apert syndrome sometimes makes simple tasks challenging. The finger joints of people with Apert aren't functional, so Braylee is unable to bend her fingers. Her thumbs are semi-functional, but very short, so she has always had to be creative with the way she does things, such as writing, grabbing things, getting dressed, etc. However, she is very determined. If we are patient and just sit back and watch, she will eventually figure out how to do it her own way.

She is always such a happy girl; nothing really gets her down. Her smile is contagious, and she's oh, so funny: the girl loves to make people laugh. This last summer she learned how to ride her bike without her training wheels, and that was a huge milestone for her. She was so very proud of herself. She also loves playing with her sisters. She loves the winter, which is a good thing since we live in a part of Wyoming where there is snow 6-7 months out of the year. She has a snowmobile that she rides all over the place, racing her sisters, and if there is a single snowflake in the air in the fall, she is asking when she can get the snowmobile out.

She is now eight years old and in the second grade. She is on-track and keeping up with the rest of her classmates. The only assistance she needs at school is some occupational therapy and speech therapy. We are very fortunate to live in an accepting community. We still get some stares from kids who don't know her, but for the most

part, she is just like any other girl to the kids around here. Her friends are really protective of her: if anyone messes with her, they are always right there to back her up. We are very fortunate to have such a great support system. We've been told, "I don't know how you guys do it," by so many people, but honestly, most people we know would do the same thing and step up to be an advocate for their daughter. If I could take away all of the pain and everything she has had to go through, I would in a heartbeat, obviously! However, that's not our reality: We have to be the bravest and strongest we can be to help support her and her sisters through life.



We attended our very first CCA Family Retreat in 2018 in Salt Lake City, UT. When you go somewhere new with a child that has a craniofacial difference, you go into a "protective mode," keeping an eye and ear out for the kid that is going to come up, take one look at her, then run away screaming, or the kid that makes remarks about how "weird" her face is. We were ready for that fight, but walking into the hotel for the Retreat was the most magical thing: our protective barrier was nowhere in sight. It was a bunch of families just like ours that were laughing, hugging, and loving each other. They embraced us with open arms. From that day on, we knew we would be making the trip every year if we could. CCA has provided us, and other families like ours, with an outlet that we didn't know we so desperately needed until we had it. And for that, we will be eternally grateful.



white's , from the cover continued

Braylee will be having her tenth and biggest surgery this coming summer, 2021: the LeFort III (mid-face advancement). This is a necessary surgery to help open up her airway; however, we are anxious because not only is it an enormous surgery, but it will change the way she looks and we love her as she is! Even though it will change her facial appearance it will not change who she is. We've always said: it doesn't matter what you look like on the outside, it's about who you are on the inside that matters.

I'm so glad that during all of these trying times and surgeries we have our CCA family to lean on to answer our many questions and help guide us through our journey. We couldn't be happier to have found this organization and more people we can call family. 🌈🐾



board chair, from the cover continued

stepped up in big ways to meet every challenge 2020 presented.

Throughout the past several months, the CCA community has continued their mission to provide hope and serve as an unwavering support system for one another. Even though no one could give physical hugs at the First Ever Virtual Retreat, the connections and bonds between friends and families were palpable. I saw nothing but smiles and acceptance during every Retreat session.



CCA also successfully expanded their community, stretching to build connections with new families and individuals across the country and the world. During a time when the world felt like it was shrinking, CCA managed to grow and increase their reach!

Transitioning to a completely virtual Retreat is no small feat because as most parents and employees know, the transition to virtual or online learning and work is often bumpy, lengthy, and frustrating. However, CCA transitioned their programming to a virtual format without missing a beat. I was proud to see CCA be a leader in virtual

connections. Within a few weeks of stay-home orders being issued across the country, CCA hosted virtual Zoom meet-ups and planned a Retreat complete with a magician, Zoofari animal show, 14 group meet-ups, and a dance party!

After having the time of our lives at Retreat, CCA wasted no time turning their attention to other new, innovative programming. They still hosted a virtual art contest, did a story telling series, and continued adult group meet-ups. They hosted an extremely productive virtual Craniofacial Acceptance Month complete with yard signs, a CCA-wide Zoom meet-up and group photo, and weekly activities and events. All the while, CCA has continued to provide financial support to families, send care packages, and distribute *Wonder* curriculum to schools across the country. Spreading the message of choosing kindness continues to be critical as patience is tested and new challenges abound.

This year forced most individuals to consider their core values and make a conscious effort to create happiness and seek out support. For me, CCA easily made my list of places that help give me strength. CCA never fails to lift my spirits and I have observed firsthand how it has been a lifeline for many others both during the

board chair, from the cover continued

past several months and long before then. Now more than ever, we need to continue to focus on a mission of hope: hope that our loved ones can stay healthy, hope that our friends never feel alone, hope that we can find peace in our daily routines, and hope for a brighter future. Although CCA has persevered in continuing its mission during these unprecedented times, it has not been immune to financial challenges like most nonprofits and businesses. In order to continue to serve our families and increase our reach to spread more hope, I encourage every one who can to remember

CCA in their end of year giving. We are so thankful for those in the CCA family who have continued fundraising efforts despite events being cancelled or postponed. In 2019, CCA celebrated 30 years and spent time envisioning how to make the next 30 years even better; how to serve more families, create a bigger community, and provide more hope. Through generous donations and continued dedication from the CCA staff, board, donors, and families, we can still achieve those goals, global pandemic or not, we need your help!

Even though 2021 may look different from CCA's previous

"normal," I am excited to see what is in store. Creating virtual programming has allowed the CCA family to be in your living room and at your family dinner table. It has created frequent opportunities to connect on a deeper level with one another. I know I am excited to continue to engage with all of you and foster even more relationships across the country and world. CCA's mission is more important than ever and I look forward to continuing to serve CCA and am excited to see what everyone achieves in 2021!

by **Haley Streff**

CCA Board Chair 

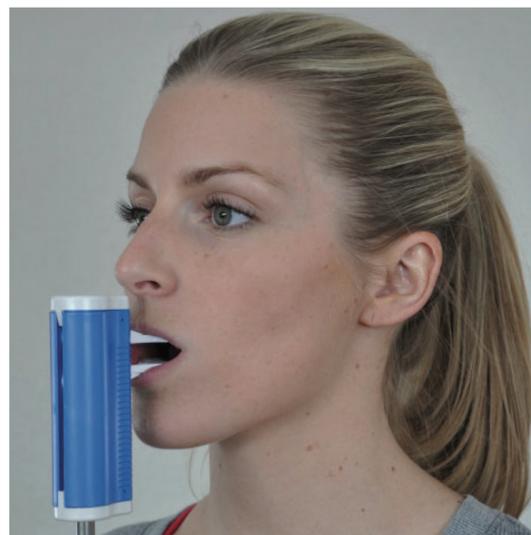
Recurring Jaw Ankylosis? Multiple TMJ Release Surgeries?

We have had long-term success with a non-surgical therapy to prevent the recurrence of ankylosis in craniofacial patients.

Contact us to learn more about the TheraPacer™ Jaw Mobilization system for the treatment and prevention of joint dysfunction and ankylosis in the temporomandibular joint (TMJ).

Benefits:

- **Non-Surgical, In-Home Therapy**
- **Easy fit for infants to adults**
- **Patient Controlled**
- **Insurance Coverage and Direct Pay Options**



CranioMandibular Rehab, Inc.

We specialize in therapies for the head, neck, mouth, and jaw.

EMAIL: Support@CranioRehab.com
CRANIOREHAB.COM 1-800-206-8381
HELPING PEOPLE SAY AHHHHH!





meet ashanti

hi, my name is **Ashanti Moore**. I am 17 years old and I have Apert syndrome. Everyone knew I would be very special when I was born because I made my surprise arrival months early on April 1st (April Fool's Day). The biggest surprise was that no one knew that I had Apert syndrome before I arrived! Even after I was born, the doctors did not know because I was the first baby to be born at Helen Keller Hospital in Sheffield, AL with Apert syndrome! I spent my first few hours of life flying to Birmingham! Since then, I had over 12 surgeries, 10 sleep studies, and I recently got my braces off. Mom and Dad call me a "Super Trooper" because I will have a procedure and be back to my normal self a few hours later with no complaints.

I'm in the 10th grade at Sheffield High School. Due to the COVID-19 pandemic I wasn't sure if I would be able to attend school this year, but luckily, I am and I'm loving it. Art and music are my favorite subjects. I have participated in our local Special Olympics since the first grade and I have a few ribbons for softball throwing.

I love spending time with my family. I enjoy hanging out and watching TV with my dad and mom, Chris and Shan. I have three older siblings that I love dearly: my brother Dominique, my sister Katlyn, and my sister Aubriana. They have always

been there to love and spoil me, since I am the baby of the family.

In my spare time I enjoy dancing, singing karaoke, video chatting with my friends, swimming, going to Panama City Beach, and attending Auburn Football games - War Eagle! My favorite celebrities are: Dwayne "The Rock" Johnson, Cam Newton, Ellen DeGeneres, Flo-Rida, and Beyoncé.

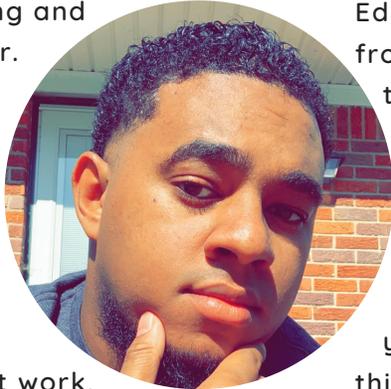
Thanks for letting me share a little bit about myself. My family and I are looking forward to attending the CCA Annual Retreat next year and meeting some more awesome people like me. 🎓💖

ccateen

ccasupersibs

meet dominique

my name is Dominique Moore. I am Ashanti's oldest sibling and only brother.



I manage all the online sales at Dick's Sporting Goods. When not at work, I enjoy playing basketball, cooking new recipes, and shopping. Being a big brother to Ashanti is one of my greatest joys in life. We frequently play board games. Our favorites to play are Jenga, Trouble, and UNO. She's currently on a 6-game winning streak in Trouble. Watching movies together is also an activity we love doing together. Anything Disney or featuring Dwayne "The Rock" Johnson is a must watch for us. Aside from the general brother/sister annoyance, this is how we will always show each other affection.

degree in Elementary Education and am currently pursuing a EdS in Elementary Education from UNA. Two of my favorite things in the world are being a teacher and Ashanti's "KK." Ashanti has always been a constant inspiration in my life. As a big sister, you're supposed to help watch over your little sister and teach her things. Some people see it as a chore but it was always my favorite thing to do. Watching the look on Ashanti's face when she would learn new things or explore new ideas was always one of the best feelings. The "AHA" moment in her eyes and on her face filled me with a joy that I could never explain. It led me to be a teacher and get to see that moment every day in so many students. Having a sibling with Apert syndrome has hands down been the biggest blessing of my life. Ashanti reminds me to be humble, kind, and show love to everyone around me. Being Ashanti's

"KK" is the best part of who I am.



meet aubriana

my name is Aubriana Smith, and I am 24 years old. I graduated from Auburn University with a Bachelor's degree in May of 2019, and I'm currently a second-year medical student at the University of Alabama School of Medicine in Birmingham, AL.

I love when people ask me why I chose to pursue a career in medicine because the answer is simple - my little sister, Ashanti. She has always been my biggest inspiration and greatest motivator. Because of Apert syndrome, she has already experienced many obstacles in her life, but she never fails to overcome them with a smile on her face. Her cheerful and silly personality inspire me to remain positive regardless of the situation and remind me to focus on the bigger picture. As a medical student, I sometimes feel overwhelmed or stressed out, but a quick FaceTime with Ashanti can completely change that. Her sass and attitude never fail to make me laugh and brighten my day. As her big sister, I hope that I've taught her many things over the years, but I know none of that will ever compare to how much she has taught me. She is one of my biggest blessings, and I am so grateful God chose me to be her sister. 🌸

meet katlyn

my name is Katlyn Moore and I am 24 years old. I am a second grade teacher. I obtained my Bachelor's degree from the University of North Alabama. I also have a Master's



meet chelsea buyalos

My name is Chelsea Buyalos and recently I took the plunge and embraced my uniqueness by becoming a certified CCA Speakers' Bureau member. I know I'm late to the CCA party, but my journey leading up to this big plunge of embracing one's self has definitely been an interesting one, with many twists and turns, ups and downs, many successes, and a few failures along the way, too. My decision to open up and share my story was reaffirmed this past June when I attended my first ever CCA Retreat. That weekend pushed aside any fears I had about opening up about my journey and allowed me, in some ways for the first time, to feel comfortable in my own skin.

As you can see from some of the pictures, I am no stranger to the stage. As a classically trained singer, a big part of my life is spent sharing the stories of the characters that I take on and creating moments for others musically. With this commitment

to the arts you'd think I would be comfortable with sharing my own story. Surprisingly, this has not always been the case, with that, here it goes...

Music is universal, it knows no bounds and it connects each and every one of us. During these last few months we have found ourselves in a time of great uncertainty, and in recent days and weeks, many have experienced a vast range of emotions such as anger and pain. During moments such as these we oftentimes turn to things that bring us comfort.

At birth, I was diagnosed with **Goldenhar syndrome**. This diagnosis was a shock to my parents and with my entrance into the world it turned their world upside down. Let's just say, from the start, I was a little diva in training. In my case, I have most of the common features that are associated with Goldenhar syndrome: missing right ear, asymmetry of the head and facial structures, several conditions of



the eyes, and a few internal issues surrounding the heart, lungs, and esophagus. Like many others, I have had numerous surgeries since birth to improve my quality of life. Some of which include: lung surgery, esophageal reconstructive surgery, several ear reconstructions, and a facial reconstruction that was a doozy... I get chills when I think about that one... The list goes on and on.

At an early age, I realized that in some ways I was a little different, my life was comprised of many surgeries, constantly fielding questions about my appearance and abilities, and moments of self-doubt and isolation. During some of these moments I would look for an outlet that I could turn to and escape from the world. I found that escape in music, which has brought me



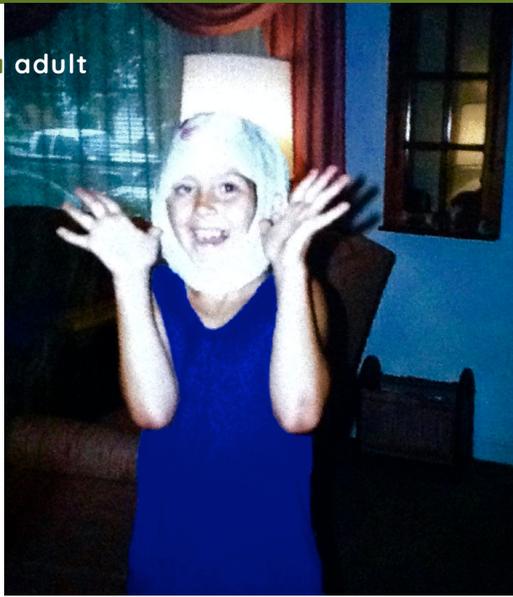
cca adult

chelsea, continued from the cca adult

comfort during some of the darkest moments of my life. As a child, music was a constant for me and allowed me to express myself fully. Some of the earliest memories I have involving music are of me listening to the Met Opera broadcasts on NPR with my Nanny B in the car and proclaiming to her that I would love to take the stage and become an opera singer one day. What kind of kid makes the bold proclamation that they want to pursue a life in the opera at the age of six? Let's just say that kid was me!

Fast forward to now, I'm a 30-something-year-old classically trained singer, teacher, arts administrator, and craniofacial advocate who defied the odds that were placed against her at an early age. I realize that singing is a true gift because, as I've been told many times over, from a medical standpoint I shouldn't be doing it. Considering all of the challenges that come with Goldenhar syndrome, I'm grateful that my voice box and vocal cords even developed and that they withstood the surgical procedures that were needed to reconstruct my esophagus. Despite my situation, despite the cards I have been dealt, I found my silver lining and it is a gift that needs to be embraced, refined, and shared.

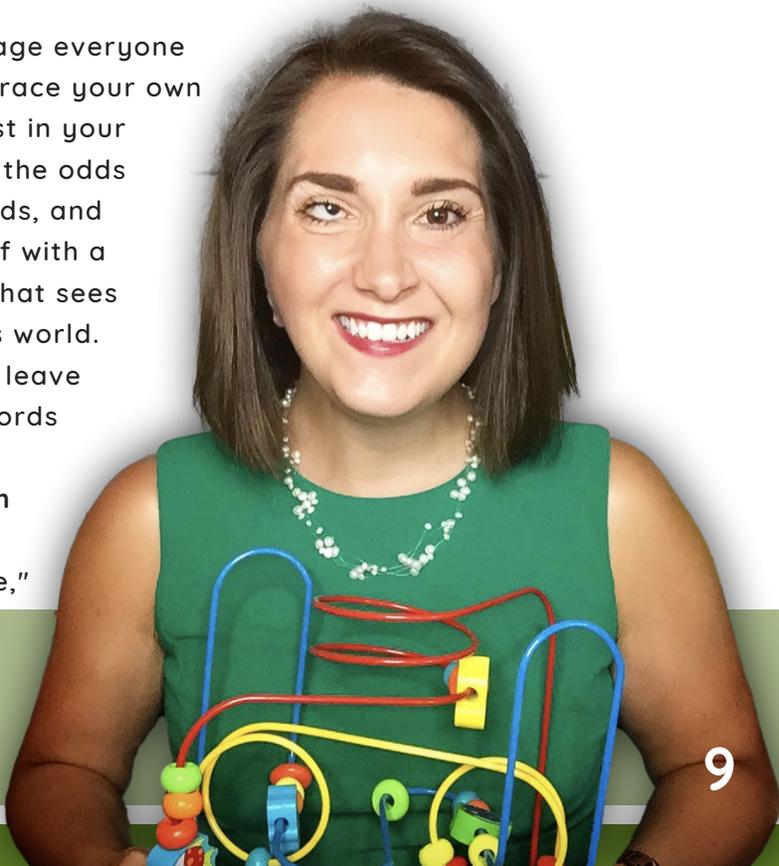
I made a commitment to myself that I would not allow my diagnosis to define me or set boundaries on my life aspirations. If, by some chance, someone out



there with a physical difference is inspired by seeing me doing what I love, boldly performing on stage as a singer, at the front of a class leading instruction, or sharing my personal journey as craniofacial advocate, then these first few chapters of my journey have been worth it. They are my experience. I would not go back and change a thing, even if I could. Seeing the spark of someone else's own belief in themselves is a beautiful thing to witness.

I want to encourage everyone out there to embrace your own uniqueness, invest in your passions despite the odds or social standards, and surround yourself with a support system that sees your value in this world. Finally, I want to leave you with these words gifted to us by Dr. Randy Pausch from his book "The Last Lecture,"

"We cannot change the cards we are dealt, just how we play the hand."



making the power of real food accessible with:



Imagine having to eat the same thing all day, every day ... forever. That's what so many children with facial differences experience if they need a feeding tube -- they get prescribed a formula that they are meant to have for every single feed every day. For a long time, formula was the only option presented to parents when their child needed a feeding tube, and if their child reacted badly to the first formula, they were simply prescribed a different formula (along with medications to manage their symptoms). There has been a movement toward real food for people with feeding tubes, however, and Real Food Blends offers an easy way for families to give their loved one with a feeding tube 100% real food for every meal.

Real Food Blends co-founders Julie and Tony Bombacino turned to a blenderized diet for their son, AJ, after he failed multiple formulas. While there are a whole host of formula intolerance symptoms that people can experience, for AJ it meant struggling daily with vomiting and constipation. Julie started blending for him at home and saw immediate improvements in AJ's symptoms. However, when the Bombacinos looked for a commercial real food option to make it easier to give AJ real food when they weren't at home, there was nothing available. That's what sparked the idea to create Real Food Blends, with the company starting with three shelf stable 100% real food meals with no added preservatives, sugar, or synthetic ingredients. Today Real Food Blends offers six different 100% real food meals for people with



feeding tubes, each with 5-7 real food ingredients, 320-340 calories, and still with no added preservatives, sugar, or synthetic ingredients.

While Real Food Blends started by selling meals online (and anyone can still order cases of Real Food Blends without a prescription at RealFoodBlends.com and on Amazon), the meals are now also covered by many insurance companies. More information is available about insurance coverage at: RealFoodBlends.com/Insurance, but the best way to start is by calling your current home healthcare company and asking if they carry Real Food Blends.

What started with one family looking for something better for their son has turned into so much more, with millions of meals sold and growing, enthusiastic support from medical professionals who are embracing the benefits of real food for their patients with feeding tubes. Find more information about all things

Real Food Blends at RealFoodBlends.com

or by calling 888-484-9495.



“Our family is extremely grateful to Julie and Tony Bombacino and the Real Food Blends family. We had been making home blends of table food for Scott's 5-day meal rotations for about 28 years when Real Food Blends came along. We've jokingly been referred to as pioneers of home blending. Real Food Blends is a game-changer in four ways: 1. It's so easy to open a couple of packages and add a tiny amount of salt, a multivitamin, and a liquid to thin for the day's tube-fed meals, 2. The product is covered by insurance, 3. Travel with Real Food Blends means we no longer have to blend ahead, freeze, and take along a cooler full of home blends, and 4. The company's commitment to informing consumers and the medical community about the health benefits of real foods for tube feeding has validated what our family already knew and has made home blending so much more acceptable than we ever imagined possible.”

-Paula Guzzo



RECAP: Craniofacial Acceptance Month 2020

by Annie Reeves

Craniofacial Acceptance Month might be over but we are still in awe of how wonderful and special the entire month was, thanks to all of you!

This year marked the 16th year CCA observed September as Craniofacial Acceptance Month across the nation. Although we weren't able to host picnics like we usually do, we were able to come together virtually and in so many other ways. To say we had a month full of FUN is an understatement!



A YARD SALE AND LEMONADE STAND

SPEAKERS WEEK AND ADULT STORYTELLING SERIES



VIRTUAL FAMILY MEETUPS



VIRTUAL CAM GROUP PHOTO

A LARGE NUMBER OF FACEBOOK FUNDERS



SOME OF OUR FAMILIES WERE FEATURED IN LOCAL NEWSPAPERS AND ON LOCAL NEWS STATIONS



WE HAD CONCERTS TAKE PLACE BOTH FOR FUN AND FUNDRAISING

INTERVIEWS, PODCASTS, AND STORIES BEING SHARED ON SOCIAL MEDIA.

EDUCATIONAL WORKSHOPS



PAINTING KINDNESS ROCKS



OUR CAM POSTER FEATURED ON BILLBOARDS IN PA



In addition to all of these exciting things, 17** states proclaimed September as Craniofacial Acceptance Month!

Numerous organizations and hospitals also celebrated CAM along with us!

We would like to send out a special thank you to both the **Libra Group** for hosting workshops for our families and to **ConnectMed International** for hosting family meet-ups. CCA is extremely grateful for both of these groups and we look forward to our continued collaboration.

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



PICTURES OF OUR CCA FAMILIES WITH THEIR CAM SIGNS

cam recap, continued

- ACPA
- Lisa Bowers-Alters and Family
- CCA Ambassadors, Mr. Ed Ducky & Foster Mom, Brittany Kegley
- Chelsea Bugalos
- Josh Daniel
- Peter Dankelson
- LaDarius Davis
- Tammy Flynn | OnAir Advocate
- Christian Hadjipateras
- Marianna Hadjipateras
- Arielle Hobbs
- Ryan Hollingshead and Family
- Lamar Advertising of Wheeling
- Melissa McGowan
- Magdalena Newman
- Erin Richmond
- David Roche
- Rena Rosen
- Patricia Simon
- Carolina Sommer
- Manny Ventura
- Political Sputnik Radio

Accepted Proclamations 2020



**This count is slightly lower than last year because several states placed honorary proclamations on hold due to the pandemic. However, next year we hope to double this number! If you'd be willing to help in your state, please contact our Outreach Director, Khadija Moten, at: kmoten@ccakids.com.

Many states require a resident to request the proclamation!

Additionally, everyone who purchased CAM Yard Signs, Marketplace items, and web store items, those who fundraised for CCA through Facebook Funders and Marketplace profit shares. And, of course, all of our amazing donors who donated throughout the month!



We couldn't have done this without all of you. Our hearts are truly full. September might be over but we will continue to promote acceptance and awareness all year long. I would like to leave you with one of my favorite quotes...

*"We must find time to stop and thank the people who make a difference in our lives."
-John F. Kennedy*

That's YOU! Stay well.

-Annie Reeves
CCA's Program Director

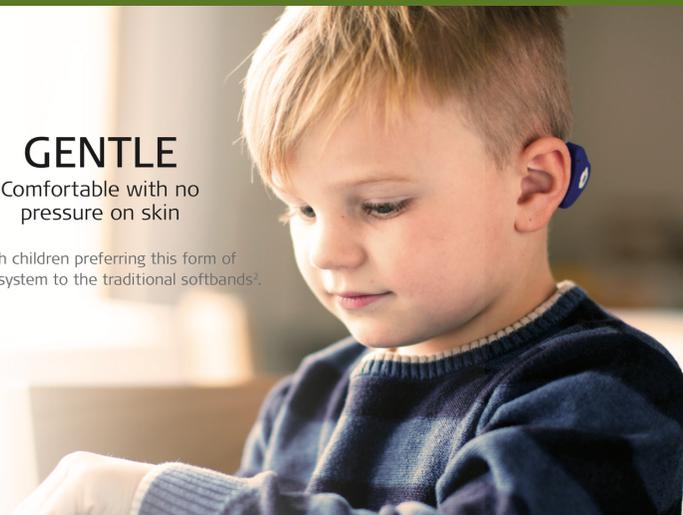




EFFORTLESS

Adhesive, non-surgical solution

Kids and parents demonstrate high levels of satisfaction with the device¹.



GENTLE

Comfortable with no pressure on skin

- with children preferring this form of hearing system to the traditional softbands².



RELIABLE

Stays in position, offering consistent access to sound

Average ADHEAR wearing time was 9 hours per day across all recipients².



APPEALING

Sits discreetly behind the ear

Eighteen of the 21 children reported feeling more confident when wearing ADHEAR as compared with their previous hearing aid devices².

1. NEUMANN et al, 2019 International Journal of Pediatric Otorhinolaryngology
2. OSBORNE et al, 2019 Otolology & Neurotology



Simple hearing

ADHEAR is a revolutionary bone conduction hearing system which offers a world full of sound in an incredibly simple way: **Stick. Click. Hear.**

CONDUCTIVE HEARING LOSS • TEMPORARY OR PERMANENT • UNILATERAL & BILATERAL

medeladhear.com

888-633-3524



MEDEL.COM

selfcare for caregivers

by Kara Jackman

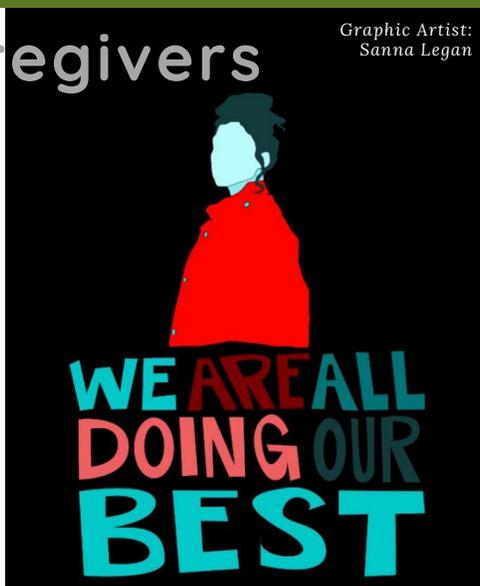
Graphic Artist:
Sanna Legan

What a year! Let's all take a breath. In and out: Ahh! 2020 has been one for the books with regard to anxiety and depression. Many are self-medicating with food, substances, and other guilty pleasures. Some of us are wearing pajamas 24/7, while others are making risky decisions just to be out, in person, with people!

We are all doing our very best under pandemic-level circumstances, but everyone has a limit, so we need to be prepared when we hit ours and know how to rest and recharge. The caregivers, whom we celebrate during the month of November, hold the weight of this additional stress. Our Moms, Dads, Aunts, Uncles, Grandparents, and Guardians are experiencing some serious distress with surgeries canceled, therapies postponed, taking on the role of teacher, and finding innovative ways to connect with the host of specialists our CCA Kids need to thrive. The once mundane trips to the pharmacy and grocery store have become wrought with fear of exposure to the coronavirus, or at the very least a new host of additional inconveniences.

So, to find some "COVID Silver Linings," how can caregivers practice self-care when there is no time for it?

I am here to tell you there is hope. I am here to tell you that in the words of graphic artist and Dear Loneliness Project contributor Sanna Legan "There is no survival guide, we are all doing our best."



Your best may not be perfect, but rest assured it is perfect for this moment in time.

Here are a few suggestions to help you manage your anxiety and stress. Follow the Acronym TIP.

T: is for **Temperature**. Activate your body's dive response to calm your nervous system. Place a cold ice pack around both of your eyes, or stick your face in an ice water bath for 15-30 seconds. This act will stimulate your parasympathetic nervous system. Feel the extra, short breathe come quickly after a deep inhalation. A true shock to your system, but in the best possible way.

I: if you are not keen on cold temperatures for a hard reset, you can try this next part of "TIP." The "I" stands for **Intense Physical Exercise**. Run up and down the stairs, drop and give me 20 burpees, or do some short burst of activity that will get your heart rate up above its normal rate. Increasing your heart rate will result in stress reduction.

P: is for **Progressive Muscle Relaxation**. This final part of the "TIP" helps us remember that the meditative practice of the body

scan while tensing and relaxing the muscles one body part at a time can be helpful in pursuit of calm. Find great meditations that include progressive muscle relaxation here on [Youtube](#).

Do You Breathe Right?

No, not those nose strips snorers "you" wear at slumber parties... I am asking do you breathe properly from the diaphragm, or the belly area? You will note when you are sleeping that your belly rises and falls first, then your chest. This is proper breathing technique. Breathing through the nose has added benefits. You can add that in when you conquer diaphragmatic breathing. Breathe slowly and deeply, lengthening the exhale as much as possible. The key is the lengthy exhale. Really take it slow to calm your body down.

Press Your Off Switch

Finally, this last one is a new personal favorite. I learned about it this year and have been using it often. Grab one of your feet and find the center of the sole of your foot. There is a flat, muscle right in the center. You will know you found it when the skin and muscle feels as if it is pushing back at you. Press as hard as you can, breathe deeply. Notice and wait for one more sip of air to come just after you breathe. The center of your foot will help to calm your entire nervous system.

These are my suggestions for managing your anxiety, stress, and worry as we move forward into these winter months. Check out the [CCA Kids blog](#) where I will share more ideas soon. 🌈

recap of 2020 from our Director of Development

by Christine Andler

If you would have told me in January the 2020 Development Letter to you all would shape up anything like this, I would have thought you were on another planet! It was nothing short of heart-breaking to see the cancellation of two CCA golf tournaments, countless family fundraisers, and to have most of our large sponsorships for Retreat pull support as the ripple effects of this pandemic took its toll on us. While this time has been beyond challenging, there are some incredibly beautiful silver linings to this year. The one I want to illuminate is how the pandemic gave us the opportunity to re-imagine (and fast) how we fundraise -- with the help of so many of you!

I am incredibly humbled by the efforts of our CCA community. From our amazing families, staff, board members to new incredible friends who wanted to give and found us during an extreme time of need. I would especially like to extend our thanks to these shining stars:

Early in this year we were able to get in two wonderful in-person family fundraisers for CCA. **Lisa Bowers-Alters** (please check out her feature on page 23 to see all of her efforts!) partnered with **Madelyn Karchut** for her Senior Give Back project: a Spaghetti Dinner Night that raised over \$7,000! Also, **Liz and Nova Cox** did



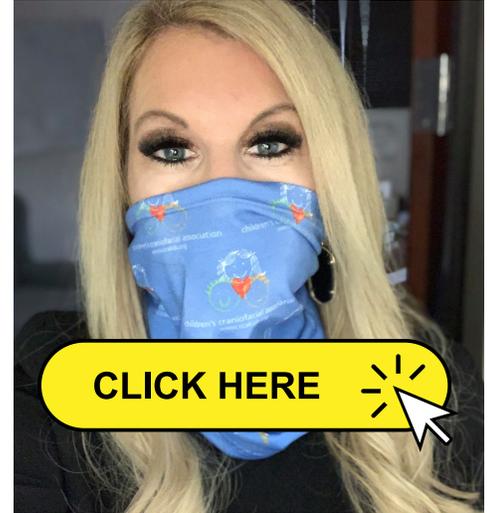
an amazing job at securing CCA as the beneficiary for the 2020 Massachusetts State Breaking Championship, which raised over \$5,000!

As the year went on, we saw other socially-distanced “events” and fundraisers come about to help us raise money. The CCA Marketplace became a wonderful tool for us to find friends and families to profit share a portion of their sales back to CCA. **Sue Giles** led the way with her girlfriends **Boon Supply Co.** shopping event, **Michele Gonzales** sold **Jayden’s** hand drawn sugar skull stickers,

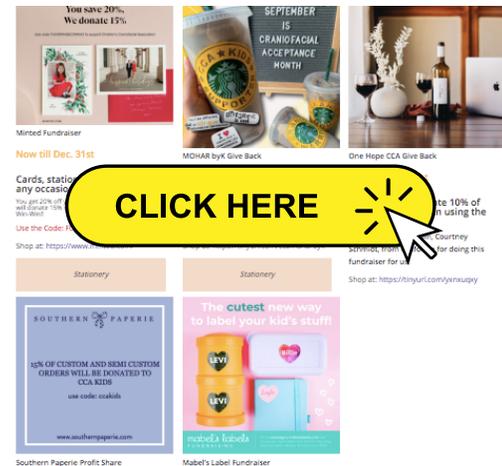


Courtney Schmidt offered her **One Hope Wine** fundraiser, artist **Julie Lyles** pledged support with her original watercolor paintings, **Allie Quinn** and **Jenny Solymossy** shared their **Color Street** businesses, **Maigan Baker** hosted a successful **Cards for a Cause** party, our Outreach Director, **Khadija Moten**, crafted vinyl decals and custom Starbucks cups via her **Etsy** shop, plus other companies are still helping us “shop for a cause” on an ongoing

basis. We’d also like to send a huge shoutout to **Patricia Simon** for investing in the CCA logo gaiters that we have been able to sell to help stop the spread of germs!



We truly thank all of you who purchased from our Marketplace and webstore. Please take a look at our current offerings for great gifting options throughout this holiday season! So far, the CCA Marketplace has brought in nearly \$5,000!



While some of us utilized retail therapy, some of you have been working on your “Quarantine Bodies” and got into the fitness craze. We are so thankful for the folks who hosted fitness fundraisers for CCA!



URU Yoga in Pensacola, FL, and Tula Yoga, in Aberdeen, NJ both gave benefit yoga classes. Recently, Crystal Kouri taught kickboxing in the park to raise funds in honor of her son, PJ, and they were able to donate over \$300 from their high intensity efforts.

Two amazing ladies, our Program Director, Annie Reeves, and Board Member, Kelly Cunha, went the extra mile and dug into their own personal networks to raise incredible amounts on behalf of their birthdays - together they raised almost \$10,000!

Speaking of incredible Board Members, Bill Mecklenburg did not let the early effects of the pandemic halt his fundraising efforts one bit. I was blown away how his network, who usually give and participate in the annual Morgan Meck Match Play Invitational (MMI) golf tournament, gave and gave generously even after learning the event was canceled. In all, the 2020 MMI raised \$70,271 and continues to

see funds come in even as this letter went live. This amazing group of donors are loyal and a true testament of Bill's love and hard work he does constantly for CCA.

Our board keeps delivering miracles. Board Member, Steven Weiss, his wife, Petty Weiss, and his mother, Ellen Weiss, campaigned and delivered an incredible CAM fundraiser totaling over \$16,000 in just a few weeks from their own network of generous friends and family. This is the type of giving that truly moves the needle for CCA. The Weiss family gathered all of this financial support via a completely zero cost "virtual" fundraiser. Even though we call this fundraiser a "virtual" one, we know that the time invested was real and significant and the work done by Petty and Ellen entailed phone calls, emails, and endless enthusiasm. Thank you, Weiss Family, for this spectacular job!

In addition to all the virtual activities CAM brought this year,

we also had some of our CCA community do a special CAM month funder that generated amazing results, too. Thank you to our top fundraisers: Chrissy Clinton, Khadija Moten, Ray Merenstein, Dana Fernando, and Shannon Marie LaBarbera.

Thanks to the connective force of social media, we gained invaluable new friends. Manny Ventura ran with his handsome smile for the entire month of July for Cleft and Craniofacial awareness and raised over \$12,000 for five different charities including CCA. He has grown into a big piece of our CCA virtual programming and we are grateful for his friendship. LaDarius Davis, too, became a CCA [Speakers Bureau member](#) and a huge part of our outreach programming. For CAM, he and his sister, Ceaira Davis Fruster gave 50% back of a custom embroidered CCA face mask to CCA and raised over \$300!



Another amazing soul we have e-met is Chelsea Buyalos, who has become a beautiful champion of acceptance and has used her talented voice to do virtual benefit concerts on behalf of CCA (check her feature on page 8.) Speaking of music, thanks to Instagram we connected with the utterly talented Josh Daniel's Band (check his

transitioning from pediatric to adult dental care: why, when and how?

Dr Priyanshi Ritwik BDS, MS • Diplomate, American Board of Pediatric Dentistry • Professor
Department of Pediatric Dentistry • The University of Texas Health Science Center at Houston School of Dentistry

1) Why should I think about transitioning my child from pediatric to adult dental care?

It is likely that through most of childhood and adolescence, your child has been under the care of a pediatric dentist or a general dentist who focuses on care for children. As your child approaches adulthood, their dental and oral health needs are better served by a dentist who has expertise in the recognition and management of oral health needs of adults. Planning for the transition of your child's oral health to an adult-centered dental home will maximize uninterrupted patient-centered, high-quality oral and dental care in adulthood.

2. At what age do I need to start planning for a transition?

Transition to an adult dental care setting should happen by the time your child reaches the age of majority. However, transition is not a single event; rather it is a sequence of planned and coordinated steps. Planning for the transition of care may start during the mid-teen years (15-16 years). Although all children eventually transition from their pediatric dental homes to an adult-centered dental practice, this transition can be challenging for children with craniofacial differences. As you start planning on transition of care, include your child in discussions and information sharing so that your child is aware of their own dental history and their future needs.

3. What resources exist for parents planning their child's transition?

The best resource to plan for transition of oral and dental health is your child's current dentist. Since he/ she is familiar with the extent of your child's needs, they may be able to refer your child to a colleague who would best match your child's needs.

Some professional organizations can also help you find enlisted oral health providers. These organizations include the American Dental

Association (www.ada.org), Special Care Dentistry Association (www.scdaonline.org) and the state dental association. You may also inquire at the dental school if there is one in your area. If your child has dental insurance, you may check with the insurance carrier for a list of providers.

Your child may be seeing dental specialists such as an oral surgeon and/ or an orthodontist. It is important to have the discussion on transition with all oral health specialists involved in your child's care. Most oral surgeons and orthodontists are usually able to provide continuity of care into adulthood but it is important to have this discussion with them and establish explicit communication to confirm it.

4. Is the process different from medical transition?

The process is similar to medical transition, but there are some differences to keep in mind. The search to identify the right oral health care provider may take longer and it may be difficult to find a provider close-by. You will also need to take into consideration the limitations which may be imposed by the dental insurance carrier for your child's continued dental coverage after they turn 18 years old, or in some states, after they turn 21 years old.

5. How should parents prepare financially for continuity of care?

It is important to discuss with all your child's oral health providers and specialists about the anticipated future treatment needs and how they will be covered by dental insurance. It is also important to inquire about the estimated cost of routine preventive care. These discussions will help you determine if you need to plan for additional out-of-pocket expenses. You may consider contributions to pretax health savings account to maximize your employment benefits.

© 2020 children's craniofacial association

6. If a patient has been many years without a special craniofacial dentist or orthodontist, where does she start to find someone qualified as an adult?

The following professional groups can help you find a craniofacial team close to you so that you can get started (it is never too late to start!)

Children's Craniofacial Association:
www.ccakids.org

National Craniofacial Association:
www.faces-cranio.org

American Cleft Palate Craniofacial Association:
www.acpa-cpf.org

7. How does an adult patient "fill in" a new provider on their previous work and how do you recommend parents help prepare for that time (without bringing along mom's plastic "medical records bin")?

Fortunately, now many dental practices utilize electronic health records and transfer of patient records between providers can be accomplished safely and efficiently. Once you have identified the practice to which your child will be transitioning, you will need to fill out an authorization for release of health information at the "pediatric" provider's office. You can request for your child's records to be provided to you or for them to be forwarded to the next selected provider. Historical dental records can be voluminous! You can also request a case summary from your child's provider to make things easier.

8. What does the future of transitional dentistry look like?

The dental profession is striving to provide a dental home across the lifespan of a patient. Patient advocates are championing better coverage for oral health services by dental insurance carriers. Dental educational institutions are incorporating competency in providing care for differently abled individuals across all ages and stages of life. Dentists are utilizing contemporary technology such as telehealth into their practice. This enables dentists to receive consults from experts to provide evidence-based care for their patients.

9. What's the most important tip you can give to parents to prepare AND the most important things for adults who weren't prepared?

"An ounce of prevention is worth a pound of cure." Limiting sweetened foods and beverages, brushing twice a day with fluoridated toothpaste and flossing every night is the best way to prevent getting cavities or gum disease. Regular preventive oral health visits are important to screen and diagnose problems early. It is never too late to start practicing these good oral care habits. If you face challenges in finding a provider to transition to, ask the members of the cranio-facial team for help.

development recap , continued

feature on page 24) and with his nightly “Couch Tour” and raffle, hosted by 5 Points Realty and Briley Burris, he raised \$22,050 for CCA!

A special friend to CCA is Master Gem Cutter, Denny Bradley. We have been the incredibly lucky recipient of his beautiful gem-stones and this year he donated an exclusive nearly 30-carat citrine necklace to be a part of our 2020 Gingertown Holiday Fundraiser!



We cannot thank NorthPark Center’s, RJ Reissig, enough for working so hard to come up with a creative solution to our [annual Gingertown tradition and partnership with NorthPark.](#)



More info will be out soon, but RJ’s love for CCA has warmed our hearts up more than a tray of fresh gingerbread, just out of the oven.

Without you all, this life-changing work would not be possible. Thank you for all the creative ways you have helped us in such a trying year. As we head into the “Giving Season,” we hope CCA remains at the top of your list to support. We are still feeling the heavy effects of a large dip in donations and the loss of our big fundraisers. Every gift truly counts. Help us end the year with the momentum to continue our amazing programs which so many of you love very much.

-Christine Andler
Director of Development 

meet the foley's

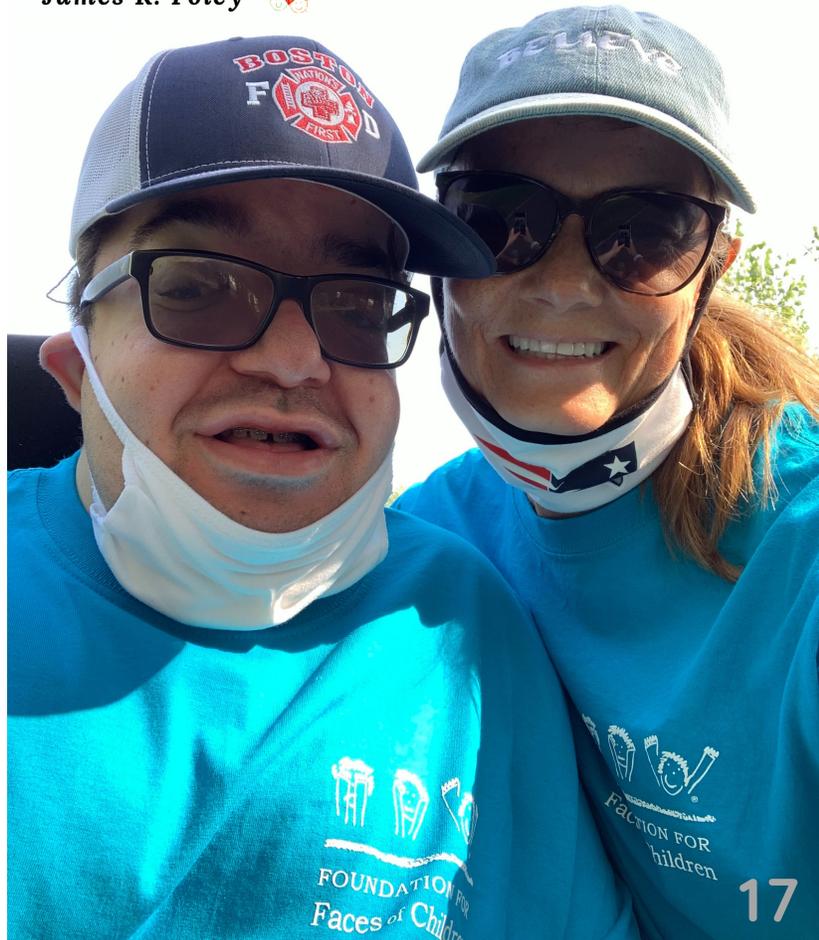
CCA wants to thank Karen and JR Foley from Boston, MA, who are featured as 2020’s Year End Appeal Family. Read an excerpt from JR’s letter and look for our mailed version in your mailboxes this December.

The thing that I want folks to know and truly understand is that people who have craniofacial differences are people, too. No one should ever, EVER judge someone by the way they look. Look at the entire person. Don’t go up to someone and just stare at them, which frankly, I find seriously uncomfortable. Look at what they have to offer and give to this wonderful world we live in.

Being a member of CCA is such a blessing for me and I’m so very grateful to know so many folks who have the ability to show the world what they have to offer just like me.

We, as a community, can make a huge impact on other folks whether they have craniofacial differences or not.

- James R. Foley 





by Kara Jackman

meet jeannelle

Jeannelle Rivera, a resident of Grand Prairie, TX, loves to dance Salsa. Influenced early on by her mother’s cool Salsa moves, she began dancing with her to learn the steps. “My mother introduced me to Salsa dancing. It is in our blood! We could not afford to take lessons when I was younger. I remember my mom would dance while she was cooking, and I would follow her steps. When I was about 7 or 8 years old, I remember asking for a tape player for Christmas. I would lock myself in the room and dance in front of a mirror and dance away for hours.”



The Rivera family immigrated from their home in Puerto Rico to Texas so that Jeannelle could receive care for Pfeiffer syndrome

They may have moved to the mainland, but their Puerto Rican roots were always on display when the family hit the dance floor. Every time Jeannelle attended a wedding or party she had the opportunity to show off her skills. “Coming from Puerto Rico, I have loved to dance Salsa since I was a child. It brought me lots of joy and took my mind off doctor appointments and surgeries.”

As an adult, she recalls how she encountered a new style of Salsa, “Once I turned 19, my brother and I went to a family restaurant. We watched this man dance Salsa a little different than what we grew up dancing. We became intrigued. Now, I was very shy. Yet, I was so intrigued by this new style of Salsa dancing that I called my mom from the restaurant, telling her all about it and asked if it would be ok to dance with the man. So, I did! I did not get to dance the same steps that he did. But, thankfully, he later announced that he had just moved from New York and was going to start Salsa On2 (Mambo) Lessons.”

Thanks to this chance encounter, Jeannelle and her brother took mambo lessons from **Agustin Guzman**. Guzman is “the pioneer of New York Style Salsa, or “dancing On2 in the Southwest region,” reads the Sandunga Dance Company website. She says, “My brother and I were hooked! We learned so much about Salsa On2 and gained wonderful friends who we consider family.”

Salsa dancing On2 is characterized by different timing. Dancers move to the beats ‘1-2-3, 5-6-7.’ Salsa On2 has a more suave feel and complex turn patterns, too.

The love and dedication that went into these lessons gave Jeannelle much more confidence that she began dancing on stage and performing for large audiences. She says, “I started taking Salsa On2 (Mambo) lessons, to learn for fun. Little did I know that I was going to become a dancer and perform on stage!”



Jeannelle, continued from cca athlete

“All of this was totally out of my comfort zone at the time, but I am SO glad that I did it! I trained with an amazing group of dancers. We performed across the Dallas metroplex, Houston, and many other venues across the country.” Shining brightly in Texas, her dance team went on to perform at the World Salsa Congress in her home Isle of Puerto Rico in 2001. Jeannelle shares, “We were the first Salsa Dance Company from Dallas, TX to perform at the World Salsa Congress in Puerto Rico in front of over 2,000 guests.”

Her heart and her toes are in love with all forms of Latin dance, and she is open to other forms of this popular performance art.

“I love dancing Salsa On1, Salsa On2, Bachata, and Merengue. I am open to learning anything.” She suggests others that want to get started dancing to search for dance studios, or go to a local restaurant, like she did, to find her dance teacher! She implores budding dancers to “let your voice be heard.” And her advice for instructors is to be more inclusive in their studios. “If you are a dance instructor, open your heart to adaptive dance. You have no idea how much music and dance affects one’s soul. It brings peace and so much happiness.”

Jeannelle encourages others to do what makes them feel fulfilled. Dancing helps Jeannelle change her mood from gloomy to

sunny. “I love to dance because it makes me happy.”

During the day, she is an elementary school technology teacher for Mansfield Independent School District in Mansfield, Texas. In her role as educator, she hopes to “someday incorporate adaptive dance to inspire and encourage others to dance, too.” 🎉



Post-Surgical Craniofacial Rehab Soft & Liquid Diet Feeding Oral-Motor Therapy Devices



OraStretch® Press Jaw Motion Rehab - TRISMUS CARE AND JOINT DYSFUNCTION

The OraStretch Press jaw motion rehab system is a jaw exerciser and stretching device to rehab after joint surgery, and treat trismus. It stretches the jaw for easy, safe therapy to achieve and maintain a functional opening.

Oral-Motor Therapy & Microstomia Prevention Appliances

The Tonguometer™ device provides measurable biofeedback and strength and endurance exercises of the tongue and lips. The Facial Flex® device prevents & treats microstomia, and provides resistance for oral motor control exercises.

NutriSqueeze™ Specialty Diet Bottles - Liquids, Thins, Thicks

4, 8 and 16oz bottles with various straws to assist in hydration and feeding for alternative diets and unique patient needs, including bite resistance. We will work with you to address your needs!

Additional Therapy and Rehabilitation Options

- CryoJaw™ cooler system for improved craniofacial surgical recoveries.
- TheraPacer™ mobilizer provides intensive TMJ therapy for the prevention of jaw ankylosis.
- OraStretch ROM & MIO scales for tracking jaw motion and therapy progression.



CranioMandibular Rehab, Inc.

We specialize in therapies for head, neck, mouth & jaw.

CRANIOREHAB.COM

1-800-206-8381

HELPING PEOPLE SAY AHHHHH!



OraStretch, TheraPacer, Salvate, & NutriSqueeze are trademarks of CranioMandibular Rehab, Inc. Tonguometer and Facial Flex are trademarks of their respective owners.

an international welcome

by Erica Mossholder

CCA is proud to have partnered up with **Small Big Hearts Foundation**. The organization helps bring families from Poland to Dallas for craniofacial surgeries and they provide assistance while they are here on medical travel.

Due to COVID-19, these families were forced to quarantine for two weeks in a hotel before surgery could happen. The President of Small Big Hearts, **Remi Sejwa**, reached out to CCA to see if we could help him locate suitable rooms for his families. CCA assisted with booking rooms for them at the **Residence Inn**, where CCA families stay when they are in Dallas on medical travel. We love these rooms for families because they have kitchenettes and a bit more space when extra family members are traveling along, too. CCA receives a special discounted rate on rooms and Small Big Hearts provided the funding for the hospital stays. Our coordination and collaboration assisted 4 Polish families, so far!



We know how difficult any surgery is, and with the added stress of international travel during a pandemic, we wanted to make their stay as comfortable as possible, so Program Director, **Annie Reeves**, packed up some “supersize” care packages for the families and delivered them - contactless - to the Residence Inn staff, so they could place them in the rooms for the families when they arrived. We hope these simple items helped make their long stay a bit more enjoyable, and we are overjoyed with this



partnership, which we hope to keep going.

Special thanks to Remi Sejwa, for sharing photos with us. You can learn more about their work at smallbighearts.org.



donor in the spotlight

by Kara Jackman

Creative, resourceful, thoughtful and determined - All words that come to mind when we think of the **Bowers-Alters Family**. In 2020, they took head on the challenges and made it a mission to help CCA - even as going as far to forgo gifts and suggest donations instead for their COVID-impacted wedding this summer.

During two weekends in August and September the Bowers-Alters hosted not one but two huge yard sales that raised over \$3,000 for CCA! The yard sales were not all about raising funds, they were also about sharing and owning your story. **Madisyn** and her family were able to share their story with the many people who shopped.

"We had the opportunity over the past 2 days to meet some 'AMAZING' people & share Madisyn's story and surgical photos about having a cranio-facial difference. There was 'LOTS' of work involved, AKA a labor of love, but it was a triple benefit...people got good deals, we purged stuff we didn't need, and CCA is getting a donation! We were also able to maintain safe social distancing."

Further, the Bowers-Alters family encourages other families to commit to some fundraising too. Lisa says, "I would encourage our network of families to take this oppor-



tunity to do something similar, in an effort to support CCA, in lieu of our Annual Picnic & Gatherings! Even if you're unable to donate ALL your proceeds, every little bit helps."

Forever innovative fundraisers, the family hosted a spaghetti dinner at the beginning of the year that spread awareness, fun, and built connections with CCA members new and old. The dinner and donated auction items raised a whopping \$7,000 thanks to the hard work of Seneca Valley

student **Maddie Karchut**.

In addition, they also raised funds for CCA by collecting change in penny jars and as previously mentioned, having donations sent to CCA in lieu of gifts for their wedding. The picture featured here is from this special wedding day for the Bowers-Alters family on June 20, 2020!

Three cheers for you: Thank you, Madisyn, Lisa, Dave, and Nancy for all you do for CCA! 🍷🍷🍷

meet musician josh daniels

by Kara Jackman

North Carolina singer/songwriter, Josh Daniel, sang and strummed his way into our hearts over several months of quarantine with his “Couch Tour,” and has turned his personal pandemic pivot into an incredible opportunity to raise funds and awareness for nonprofits, like CCA.

In the middle of March, after many of Josh’s road gigs were canceled, he started singing and playing a set each afternoon on his porch or in his backyard. He called these two hour, daily concerts, **The Quarantine Sessions**. Hundreds of devoted fans showed up every day for “happy hour” at 5:00pm on Instagram and Facebook Live to watch him play and throw a few dollars his way via Venmo. Thirsty for entertainment, and something to look forward to, the “**Jamily**,” the name given to Josh’s fanbase family, kept the Daniels family afloat as Josh’s tour dates evaporated.

After some three months of shows, and introducing his family, including wife, **Kellie**, daughter, **Maddie**, and son, **Sonny**, to the Jamily, Josh wanted to find a way to give back. In June, he raised \$5,000 for **Levine Children’s Hospital** where Sonny receives medical treatment. Then in July and August, they auctioned off a guitar on Ebay, and all proceeds went to CCA.

After learning more about CCA and with the momentum of the Jamily, Josh and Charlotte-based **5 Points Realtor, Briley Burris**, got together to fill a YETI cooler with gift certificates, experiences, and locally-sourced goodies that were raffled off on Josh’s website. He advertised the raffle each day during his daily, Facebook Lives. Meanwhile, Briley asked local businesses in and around Charlotte to donate items to place in the cooler to sweeten the deal. The total value of the cooler and the items in it, reached a whopping \$3,500 value.

Ticket sales raised over \$10,000 for CCA. During the final weeks of ticket sales, **Geoff Endlich** matched the total amount raised to bring the final donation total to a jaw-dropping, ear-popping \$22,050! All this love was in honor of the Daniel’s son, Jackson “**Sonny**” Daniel. Sonny was born with Apert syndrome which is characterized by fused cranial sutures and fused bones throughout the body. However, his diagnosis does not keep him from being a shining star, like his dad!

Charlotte-based businesses such as **SunHeist Eyewear, Legion Brewing, Salon Piper Glen, Common Market, Letty’s on Shamrock, the Kube**, among others, contributed items to the cause.



We love how major-match-maker **Geoff** put it, “**Let’s do our best to make other people’s lives better. Happy to throw a small rock in a lake and help make some kids smile and be confident!**”

From the bottom of our hearts, we want to thank you, Josh, Kellie, Maddie, Sonny, Briley, Geoff, and the entire Jamily, for this enormous act of generosity. The love from the people of Charlotte will be felt by families nationwide. Kids like Sonny will be able to gain access to life-changing surgeries, students will be educated about how to prevent bullying, and CCA will continue the work of making the world a kinder place one neighborhood at a time!

Learn more about Josh’s music by visiting his [website](#) and watch him go live every day on [Facebook](#).



Image Source:
joshdanielmusic.com

Need a Gift for the Holiday Season?!

we got you covered



& more on our [webstore](#)

financial assistance testimonial



meet the Tandazo family

by Ludivine Tandazo

Our family went through life changing events as we were approaching Paolo's birth. My husband lost his job one month prior to Paolo's being born. We discovered at birth that Paolo has Apert syndrome. Our family was overwhelmed with all the unknowns ahead of us. The CCA Kids' website provided us with initial resources, including a list of qualified craniofacial centers. But the lack of a second income, in addition to unforeseen ongoing medical bills for Paolo's care, was an additional stressor - which CCA Kids alleviated. It was a huge relief to know that we could travel for medical care that he needed and have financial support for those expenses; may they be travel, housing, or food. We are

extremely grateful CCA Kids made this possible for us twice already, within a year, and took some of our worries away so we could focus on Paolo's care and recovery. As we continue our journey, we feel blessed to be part of this new family that CCA Kids represents. CCA is an ongoing resource for us - educational, financial, and learning about other families' stories. It helps us feel we are definitely not alone in this journey and are stronger parents for our little Paolo.

To learn more about our financial assistance program visit our website at: ccakids.org/financial-assistance

or email CCA's Program Director, Annie, at areeves@ccakids.com

GIVING TUESDAY

DECEMBER 1ST, 2020

AS FOR MANY OF YOU, 2020 BROUGHT MANY CHALLENGES. DUE TO THESE CHALLENGES, DONATIONS HAVE DROPPED BY 40%. WE ARE ASKING FOR YOUR HELP TO BRIDGE THE GAP. YOUR GIFT, WHETHER \$5 OR \$500, MAKES A DIFFERENCE!





GIVING TUESDAY

children's craniofacial association
www.ccakids.org

#GivingTuesday was Dec. 1, 2020 this year. #GivingTuesday is a global generosity movement unleashing the power of people and organizations to transform their communities and the world. #GivingTuesday was initially created in 2012 as a simple idea: a day that encourages people to do good.

Over the past seven years, it has grown into a global movement that inspires hundreds of millions of people to give, collaborate, and celebrate generosity.

This year CCA set a goal of \$15,000 which was \$5,000 more than 2019's set goal. We are so

humbled and grateful to say that we surpassed our goal by over \$12,000 and \$12,875 more than 2019's raised amount!

We are continuing to see donations come in through individual check donors and Facebook Funders in honor of #GivingTuesday. In a year full of challenges for many we are so grateful for a generous community who continues to give.

On the day and leading up to #GivingTuesday we also saw the kindness of strangers through social media by sharing our posts, videos, TikToks, and stories to encourage their own followings to support CCA.

#GivingTuesday was not only a huge win for CCA's Development but for CCA's Outreach in all of the new virtual connections who are now aware of craniofacial differences because of your shares! We hope the awareness translates in to our mission of a world where everyone is accepted for who they are and not how they look. Additional funding

and awareness then feeds in to our programming to allow more families to know, they too, have a place within the CCA family.

We truly thank you from the bottom of our hearts! Thank you for being our silver lining during this roller coaster of a year.

And thank you to our celebrity friends for helping us create our first ever #GivingTuesday promotion video.



thank you to our 2020 facebook fundraisers:

names are listed in alphabetical order by the fundraiser campaign owner

- | | | |
|---------------------------------|----------------------------------|--|
| 1. Abby Daniels | 51. Jennifer O'Neil Arnold | 100. Petty Helou Weiss |
| 2. Adam Pratts | 52. Jennilyn Helms | 101. Rachel Fabre Johnson |
| 3. Alayna Christine | 53. Jeremy Stowe | 102. Ray Merenstein |
| 4. Alayna Ventimiglia | 54. Joan Nielsen Lloyd | 103. Rebecca Sathre |
| 5. Amanda Mason | 55. Joe Brooks | 104. Robb Gorecki |
| 6. Amanda Simpson | 56. Joel Brusik | 105. Robyn Emily Lewis |
| 7. Amber Carruth | 57. Judith Kemler | 106. Rose M. Solic Seitz |
| 8. Amelia Sanborn | 58. Kara Jackman | 107. Roxanne Morris |
| 9. Amy Rule-Thomas | 59. Katie Carter | 108. Ryan Corrigan |
| 10. Annie Burt Reeves | 60. Katie Hartke | 109. Sam Miller |
| 11. Becky Hartman Hendrix | 61. Katie Whicker | 110. Samantha Faulkenburg
Corbett |
| 12. Bobbie-Jo Theriault | 62. Kayde Grace Newman | 111. Sarah Suwalski |
| 13. Brock Hale | 63. Keith Miller | 112. Shauna Abbott
Huddleston |
| 14. Brooke Strogatz | 64. Kelly Cunha | 113. Stacy Needleman-Klein |
| 15. Candi Oldfield | 65. Kelly Turbeville
Lemmonds | 114. Stephanie Watt |
| 16. Carrie Davis Church | 66. Kelsie Fletcher | 115. Tammi Trude-Gonzalez |
| 17. Cassie Ayers Linnell | 67. Ken Goodrich | 116. Tammy Pinney |
| 18. Chelsea Buyalos | 68. Kendall Peters | 117. Tiffany Lyn |
| 19. Cheryl Raby-Reeves | 69. Khadija Moten | 118. Torey Harrah |
| 20. Christina Taylor | 70. Kim Mader | 119. Trashica R. Robinson |
| 21. Christine Andler | 71. Kim Morrison | 120. Troy Lynn Hershman
Bettenbaugh |
| 22. Christine Clinton | 72. Kristen Dolan Roberts | 121. Twyla Appleby Sumpter |
| 23. Christine Valdez Potter | 73. Krystle Rizzo | 122. Vanessa VanSile |
| 24. Claire Emily Kouri | 74. LaDarius Davis | 123. Yesica Aragon-Trejo |
| 25. Connie Williams | 75. Laura Weber Kemp | |
| 26. Courtney Vysocky | 76. Leeann Boone | |
| 27. Dana Fernando | 77. Leslie Lively
Cunningham | |
| 28. Darla Kramer | 78. Lindsay H Griffin | |
| 29. Darnell Ann Menard | 79. Lindsay Walters | |
| 30. Deb Wood | 80. Lindsey Mills | |
| 31. Dede Hostetler
Dankelson | 81. Lisa Bowers | |
| 32. Derek Edwards | 82. Lisa Rusinowski Austgen | |
| 33. Dorina Watkins | 83. Maddie Cameron | |
| 34. Edgar Omar Artiga | 84. Maricela Burns | |
| 35. Eduardo RG | 85. Mark Peralez | |
| 36. Elizabeth Marie Pacheco | 86. Mark Sanborn | |
| 37. Emily Rose | 87. Markie Dew | |
| 38. Erica Mossholder | 88. Markus Piaskowski | |
| 39. Erin Williams Richmond | 89. Meg Storie | |
| 40. Heather Angel Williams | 90. Melanie Roder Pipkins | |
| 41. Heather Geroy | 91. Melissa Phillips | |
| 42. Heather Johnson | 92. Michael Piacenza | |
| 43. Horejs Amber | 93. Michelle Marcus | |
| 44. Jaci Samhammer | 94. Miranda Arnold Shrum | |
| 45. Janel Fry | 95. Mitch Maltby | |
| 46. Jason Williams | 96. Nancy Musher Bowers | |
| 47. Jeff Steinberg | 97. Nancy Penelopy | |
| 48. Jeff VanTil | 98. Olivia Wardlaw | |
| 49. Jennifer Kilmer | 99. Patricia Simon | |
| 50. Jennifer Mau | | |

Thank you

help us get to 150 by December

create your own facebook funder

Facebook is a great way to raise funds for CCA Kids. Facebook takes 0% in fees and you can set up your fundraiser with a few quick clicks.

- 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 Fundraiser or CCA Fundraiser, etc
- Enter - tell your audience why you are raising for CCA (We already have a template 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!

upcoming events

DECEMBER 1st

#GivingTuesday
CONTACT: candler@ccakids.com

DECEMBER 11th & 12

Joint event: CCA & ConnectMED's Camp Cosmos
11th - Virtual Wonder Movie Showing
12th - Career Roundtable, Holiday activities, & more
MORE INFO & REGISTRATION... coming soon

MAY 10th, 2021
Southlake, TX
TIMARRON COUNTRY CLUB

6th Annual PAR Premier Golf Tournament
Benefiting Children's Craniofacial Association

CONTACT: candler@ccakids.com

Legacy Giving

Thank you to the late
Rosemary Euphrasia Mitchell



and Ed Shea for their Legacy Giving gift to Children's Craniofacial Association.

Simply put, planned giving enables you to make a meaningful gift to CCA that reflects your beliefs and values while leaving a unique legacy to memorialize those values and beliefs by supporting CCA Kids during your lifetime and beyond.

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