

ccanetwork



newsletter of the children's craniofacial association

Cher—national spokesperson

2019: Issue 1

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brenna

By Robyn Johnston

It's hard to believe that my Sugarplum is an independent young woman. She went through the ringer the first part of her life. But she's a trooper and doing well now. I stopped counting the exact number of surgeries years ago, but she's probably had close to 80, and still a few more to go. Most of her surgeries happened before she turned 9 years old. **Brenna's** situation has been complicated, but we are so blessed with the amazing team of doctors we have. We are currently in the final stages, and so close to being done. Brenna will be getting the last LeFort surgery this next year to finish up the final phase of her surgeries. What a journey this has been.

May 14, 1996, I went into labor. We knew that the baby was breach. My OBGYN tried to rotate her twice unsuccessfully, therefore I had to have a C-section. I went to the hospital to be admitted for delivery. When my doctor pulled Brenna out, she knew immediately something was

see **brenna**, page 18



message from the executive director

Please state the purpose of your application in 25 words or less." I encounter this phrase a lot, as I'm applying for grants for CCA, or making requests for financial sponsorship.

"Please state the **purpose...**" that word, seemingly straightforward, always gets me. *Purpose* is both a noun and a verb; its definition is (n.) "the reason for which something is done or created, or for which something exists," and (v.) "to have as one's intention or objective."

It's such a wonderful word, purpose, but defining the purpose of CCA's programs

see **exec dir**, page 9





meet addie hill

Seven-year-old **Addie Hill** was quick to tell me she will be 8 soon (in July), and the second grader from Texas has already started making her gift list. Littlest Pet Shop bobble heads and accessories made the top of the list, and so did LOL dolls and their magical bottles that change color to show whether the liquid inside is hot or cold.

Addie enjoys school, and just celebrated her 100th day of the school year. Art is her favorite subject. She said that she has been drawing since she was 2 years old, most of her life. She has a great group of friends at school that always look out for her.

After school on Tuesdays, Addie goes to gymnastics. She has worked so hard that she moved up two levels in a single year. And she is looking forward to spring break. She's going on a family vacation, but she doesn't know where—it's a surprise!

Addie lives with her mom, dad and older brother as well as four dogs (one is a foster puppy), one bunny, five fish, one lizard, and one cat. She likes watching Disney TV shows and *Bugs Bunny* and *Yosemite Sam* cartoons.

She also has a bunkbed, which has been the launch pad for a stack of quilts and pillows below.

Addie and her family went to last year's CCA Retreat in Salt Lake City. "It was AMAZING!," she said. She met the keynote speaker, **Ben Kjar**, and his wife. The family still keeps in touch with them. Addie also met so many kids and made a lot of friends. "I saw people that looked like me."

She danced with **Jacob Tremblay**, who starred in the movie *Wonder*. She also got up on stage and showed off her gymnastics moves with her new best friend. She's sad to miss this year's Retreat. "I'm having a mid-face advancement," she said.

Addie has Crouzon syndrome and has had six surgeries so far. She has a great attitude about it all, and she has some good words of advice for other kids going through similar situations: "It's okay. They'll take very good care of you." She also suggests taking a stuffed animal with you, if possible, so when you wake up, you won't feel so lonely.

ccakid

ccasupersib

meet bryson hill



my name is **Bryson Hill**. I'm 12 years old, and am in 6th grade at Wertheimer Middle School. I love playing Fortnite with my friends and playing trumpet in the school band. My favorite book series is *Amulet*, and I really love the *Ripley's Believe it or Not* books.

For me, life can be tough sometimes being a brother to someone with Crouzon's. When **Addie** was first diagnosed, I was only 4 and really didn't know how it would affect me. When she had her first surgery at 3 months old, I got really mad at my parents, because I didn't know that the surgery was to help her, not cause her pain.

When Addie was 2, her brain started to get bigger than the space available in her skull, and she had to have emergency surgery, and then wear a helmet afterwards. Even after all of this, she was still smiling and playing and it made me realize that surgeries

didn't make her any different.

In 4th grade, I realized how differently people looked at Addie. I thought that Addie was going to get bullied coming into Kindergarten, so I was ready to defend her from that. I love her dearly and never want anything bad to happen to her. Luckily, all my worries went away, and my hope for her making friends, happened. Boy did she make friends; she has a TON of them!

Now that we aren't in the same school, I hate not being able to be there, in case something happens, but I know that she is so strong, and able to handle it. She has a big surgery coming up in April, where she will have to wear a RED device for 3 months. I want her to know, that even if she doesn't want to see anyone else, I will always be there, by her side.

meet jaz gray

At 30-years-old, I imagined I'd have this entire being "different" thing on lock. Until recently, all the experiences I went through as a kid, teenager, and young adult felt like obstacles in my past that I just "got over," in one way or another. I survived being misdiagnosed as a child, having surgeries with a hack doctor looking for fame by treating a rare condition, finally being diagnosed correctly with Arteriovenous Malformation at 10-years-old, having me and my family's world turned upside down by over forty surgeries to date, being laughed out of malls, rejected from job opportunities, botched procedures, side effects, paralysis, pain, stigma, and stress.

Yet, I graduated at the top of my high school class, and was one of 20 students selected to the join the 2010 *USA Today* All-USA College Academic First Team. I received full academic scholarships to undergraduate AND graduate school to study

journalism, and production. I've interned, freelanced, or worked with—and for—newspapers, TV networks, and film studios.

I've traveled on the company's "dime" in search of films released around the world, and premiered my own documentary at the Chinese Theatre in Los Angeles. My nonprofit, **Jaz's Jammies Inc.**, has donated over 6,000 pairs of new pajamas to hospitals, hosted pajama parties for sick and displaced children, and provided volunteer opportunities for over 2,000 people. Now, I am currently pursuing a Ph.D. at the University of North Carolina at Chapel Hill, where I'm combining my love of storytelling, and my passion for health, as a researcher and professor.

Now that you know my bio (joking) and how blessed I am (all kidding aside), I hope you don't mind if I get real. Considering everything I've been through, I always thought, "I have a great outlook on life (smiles to self). I have high self-esteem (sticks chin in air).

I'm very well-adjusted (pats self on back)." I had survived my challenges largely unscathed, or so I thought. However, I've learned that twenty years of trauma doesn't just go away quietly... at least not in a completely healthy way, that leaves no internal scars (to go along with this disfigured face).

I wish I could say I grew up seeing a therapist regularly. Aside from a few sessions during a particularly bad season of depression, it's been mostly trial-and-error. I have started traveling down uncharted avenues toward my own well-being, moving and mounting dirt in order to pave a sustainable path forward for my life. It is an all too familiar journey towards emotional health for many coming of age in our community. It never occurred to me (or my parents) that my past experiences, though triumphed, would linger in my life—so subtle, so inconspicuous, that it would take years for me to realize the extent of their impact.

Little clues would spurt to the surface every now and then, showcasing how my subconscious mind tried to cope with what my conscious mind could not.

For example, my trouble keeping eye contact. When I was thirteen or fourteen, I remember talking to a teacher at the front of class while staring at the dry erase board behind his head.

I remember his puzzled expression as he moved his face into my line of vision to exclaim, "Hey, over here Jaz!" Maybe he was simply amused that his otherwise bright, outgoing, talkative student would speak to him confidently without looking at him directly.

Sometime later, my grandmother was much more blunt. Leaving her house one evening, I remember gazing at the silky sheen of her blouse as I went in to hug her. After her warm embrace, she took her soft, sturdy hands, placed them on each side of my face, and said, "Look people in the eye. You are beautiful. There is nothing wrong with you."

Honestly, I had no clue I had been avoiding eye contact (or insert whatever unhealthy coping mechanism you might have). There is something about the undeniable truth expressed through this nonverbal exchange though. Looking through these "windows to the soul" made me sad at times. It drained me, and it took work (and sometimes still does). On a good day—when I am feeling comfortable in my skin, feeling like a "normal" human being—the last thing I want to do is have to watch someone's facial expression change during a conversation. As they struggle to hold back shock, stay focused, not stare too long, etc., I am reminded of my "otherness."

ccaadult



Years later, I have started to study the types of stigma and body-shaming phenomena we all have experienced at one time or another. Now, I realize that over time—over compounding hurtful encounters and cosmetic disappointments, it grew easier for me not to look people in the eye than to internalize their expressions.

Granted, my faith and family have truly anchored me. My family protected me as much as they could, and comforted me when they could not. They have supported every unreasonable goal (a girl with a facial difference succeeding in Hollywood!), and never allowed their own fears to clip my wings. It is my relationship with the Most High that has birthed the beauty of a redeemed life from the ashes of an ordinary existence I wanted desperately, but thankfully, no longer desire.

However, my support system has not excused me from the spiritual work of confronting all the lies and half-truths I have unconsciously told myself that do not serve who I am now, and who I am evolving into. These are the pitfalls that come along with our purpose. Not dealing intentionally with the former will derail the later. They say beauty is in the eye of the beholder. But what

happens when the beholder is you, and in the mirror, your own beauty can't be found? You must learn to see anew. With fresh eyes and a new perspective.

To parents: Your kid is indeed strong enough to handle this fight. Protect them when you can, comfort them when you can't. Most importantly, be excited about the amazing person they are becoming.

To my fellow survivors: The day you no longer desire to be "normal," embrace all of who you are, and properly process what you have endured—your world will transform. How you see yourself, your purpose on this earth, and the life you want to lead will never be the same.



ginger town 2018

On December 3, 2018, the world-renowned **NorthPark Center** in Dallas, Texas held its **9th Annual Gingertown Event**. And, for the 9th year, CCA has been the lucky beneficiary of this powerful fundraiser. Architects, engineers, and even electrical companies from around DFW come together to build a giant gingerbread village to be displayed all holiday season in one of America's most highly visited shopping centers.

Each team spends weeks creating a design and concept to match the theme of the village. This year's theme was a colorful candy village. Each

team had a certain candy they had to weave into their design. Some were subtle, and some were very obvious!

The entrance fee into the build each year is a monetary donation to CCA, and the team with the largest donation wins the coveted title, "Mayor of Gingertown." For this year's build, the event raised **\$26,249.39**. It was the largest to date!

Jono Lancaster, Craniofacial Advocate, and founder of **Love Me Love My Face** from the UK, kicked off the build with a meaningful speech about the importance of a supportive community, like CCA, and his own journey

to self-acceptance and love. Every single person was fully engaged in every word of his speech. He even had bystanders stopped

in their tracks to listen to his powerful message. The **Nasher Family**, who graciously sponsor the Gingertown event, were





also in the audience to hear Jono speak. They were moved by his words, and personally came up to him to thank him. The staff was also able to engage with the family and they were so complimentary on the organization, and excited to have our relationship develop further.

Christine Andler, Director of Development and **Khadija Moten**, Outreach Director, personally thanked each participant as they set off to work on their builds. Each team member received a CCA #ChooseKind beanie, and many of them were sporting them by the end of the night. They were so popular—we even ran out before any could be sold to the public! Thankfully, we are restocking them online now.

Annie Reeves, Program Director, welcomed CCA Families and DFW families

spectating this amazing event. A special thank you to the **Greer Family** for coming out to the build, and staying until the end, to see the village placed together. The teams loved meeting you all!

It was a beautiful night of kindness and holiday cheer! One young man, who had no idea what was taking place, stopped Christine to hand her a **\$200** check after hearing Jono speak! Wow! We are looking forward to making the event even bigger next December, as it will be the 10th anniversary. Stay tuned for details in the fall for CCA Kid participation at next year's event.

A big thank you to the **Nasher Family**, who make this whole event possible, and to **RJ Ressing** and **Pamela Mitchell** from NorthPark Center, who execute such a perfect event each year!





cher crewz

a cruise together, but not before giving back to our kids. The night began with some drinks and dancing at the bar, surrounded by the bright lights of New York City, and Cher fans from around the world. Later, Chad Michaels sang a few Cher tunes complete with a number of elaborate costume changes, just as the diva herself would do. Next, Candi Stratton performed for the crowd, stepping out into the audience to dance and interact with everyone in the club. To close out the performances, parent and former CCA board member, **Paula Guzzo**, spoke about the impact that CCA had on her family after the birth of their son **Scott Guzzo**, 34 years ago. Scott was the CCA ambassador for the Cher Crewz that departed the next day.

Many talented and generous people were kind enough to donate items to the silent auction. Artist and friend of CCA, **Scott Clarke** donated a number of his Cher-related artworks. A signed Cher T-Shirt, poster, backstage passes and a hotel stay at **Hilton's Millenium New York Downtown**, were all ripe for the bidding during the evening's festivities.

More performances would await the Cher fans

once they boarded the Norweigan Cruise Line ship, Escape. An additional **\$7,382** was raised through tips donated by both Candi and Michael, more auction items won, a very generous donation by the Guzzo family rounded out the fundraising on board the ship throughout the week. Their donation was matched by Bob's employer, **Bristol Myers Squib**.

Throughout the week-long voyage, the Guzzos took the opportunity to speak to group of Cher fans and other cruisers about CCA, and what it does for our families. Scott, Paula, and **Bob Guzzo** made this cruise a rousing success!

Many people were involved in the logistics



of the cruise, most importantly, **Ralph Martinelli** and **Robert Ryan**, of R and R Travel. We cannot thank them enough for considering us as benefactors for this year's Cher Crewz. Many thanks also go out to Rise Bar NYC, who played gracious host to the VIP event on Saturday, November 3rd.

Excellent work! We love you all!



an incredibly successful fundraising event took place on the high seas, netting Children's Craniofacial Association **\$11,782** in just one week! The **Cher Crewz** began in New York, and set sail on board a **Norweigan Cruise Liner** thanks to the coordination of **R and R Travel** and dedicated **Cher fans**.

At the beginning of the week, Cher enthusiasts descended on **Rise Bar** in New York City, to raise money for CCA kids, enjoy performances by **Chad Michaels**, winner of **RuPaul's Drag Race** and **Candi Stratton**, **Miss Trans USA 2019**, and bid on silent auction items during the first week of November, 2018. Thanks to ticket sales and silent auction items, CCA raised **\$4,400** at this one-of-a-kind event.

This diehard group of Cher fans were headed on



exec dir, from pg 1

and services is incredibly difficult to do.

Generally, people—especially grant makers—want data. Numbers. Percentage point improvement over time. Statistics. Graphs, for goodness sake!

But I struggle on just how to explain the purpose of CCA in those terms.

To me, the purpose of CCA is life. You see, our kids are born into an era of amazing surgical techniques and improved health outcomes. They have parents laser-focused on providing the best nutrition and wellness, all to ensure they are ready for surgery, ready to heal, able to grow and thrive physically. This physical health is certainly the baseline for which life is measured, but once you've ensured survival—once the basic needs of sight, hearing, breathing, and eating are secured—the next step is to make sure

that life you saved feels worth living.

Life is not just survival. In fact, I hear it more often than I'd like to admit, "I just don't feel like living this life anymore." Let that sink in. This precious life, so fought for and prayed over, doesn't feel worth living? Combatting that phrase is our purpose.

So I come back to this question, and answer "The purpose of CCA is community." Nothing can replace that feeling of sharing a raw, overwhelming emotion you've had with another person who emphatically says, "me too." That bond transcends simple understanding. It is validation, reassurance, hope, and faith. CCA offers that tangible, organized, motivated group of people who completely understand what it is like to walk the unique journey of living with a facial difference.

We all have communities of origin, and many times

they are the most loving, supportive friends and family that we grew up with. They were there to start the journey with us (and undoubtedly are traveling their own), and they provided us love, nurture, and fulfillment. They were the ones who ensured all our needs were met, even if theirs were not always met—or even considered. The purpose of CCA is not to *take away* from our immediate family and local friends. In fact, it is precisely to *give* our community of origin that lifeline of support, too.

Just as a person with a facial difference may never feel fully understood by a parent or sibling with a typical appearance, a parent or sibling may never feel validated by their peers outside of the craniofacial world.

It's not every day you meet another mom on the playground who's handed her baby over in his first year of life for skull surgery. It's not many dads that have neurosurgeons on speed dial. It's not many brothers or sisters who have had to call down the big kids at the arcade for sneering in your general direction. And there are not many people who understand what it's like to hear another Grandma in the community take one look at your toddler and proudly proclaim, "She

looks just like you!" Now that's a joy both the parent and the child feel, because we don't hear that enough.

I have read it takes between 5 to 7 positive comments to outweigh one negative one. So there's some data for you... where else can you go to hear 100s of positive comments in one short week that will help combat a year's worth of negative ones? And to be in a community that genuinely means every one because they live it, too? Nowhere.

That's the purpose of CCA. Because we all need a role model, a confidant, that person who doesn't judge the dark spots on your heart, but gently wipes them clean with the magic eraser of shared experience.

The purpose of CCA is life: a life understood, celebrated, and valued. A life of love and kindness that cultivates joy, and even social change, measured in hugs, high fives, talent show performances, cannonballs in the pool, "Happy Birthday" texts, cross-country playdates, and FaceTime calls.

So, thank you for keeping our purpose alive... for 30 years thus far, and hopefully for many, many more.

Erica Mossholder
Executive Director

brooklyn's way golf fundraiser

By Angela Wojtyniak

The inaugural **Spreading the Love for CCA; it's the Brooklyn Way Golf Tournament** exceeded any expectations that I could have had. Thanks to the hard work, commitment, and love of so many individuals, we had an amazing day celebrating acceptance and awareness while raising **\$17,054** for CCA!

The event was held on Sunday, August 5th at

Fox Creek Golf Course in Livonia, Michigan. Each hole was sponsored by a company or individual, yielding \$100 per hole sponsorship. We had 41 various individuals or companies sponsor holes, which was absolutely incredible. **Merlo Construction, Sunrise Family Dental, The Craniofacial Anomalies Program at the University of**



Michigan, Chas Sinelli and Sons, are just a handful of organizations that sponsored holes.

I was in absolute awe of pretty much everything the entire day. I have witnessed the kindness of so many people; from strangers, to our closest friends and family, who have shown that they believe and want to be a part of the mission of CCA; for all individuals to be accepted for who they are; not how they look. And above all, to CHOOSE KIND.

This outing came together after months of planning, and as I watched all 152 golfers depart on the morning of the outing, I took a minute to myself, and thanked God for surrounding my family with so much love and support.

Players were greeted with welcome bags containing items from CCA, golf tees from **Carl's Golfland** in Plymouth, Michigan, and a CCA koozie donated by **Michael Tomczyk** of **Paramount Appraisals**.

Players also got their first peek at over 60 amazing raffle items, and 25 silent auction items to bid on. There was a Star Wars Millennium Falcon LEGO set, VIP Wine Tour at **Chateau Chantal Winery** in Traverse City, MI, a Shinola watch, and so much more. Local businesses, friends, family, and countless others contributed to the items for the raffle and silent auction. Family, friends and the **National Honor Society of Stevenson High School** in Livonia created an absolute dream assortment of baked goods ranging from cookies, brownies, muffins, cupcakes, cake pops, etc. for players to take with them on the course, or enjoy afterwards.

On the course, there were fun challenges for the players to be a part of. **John MacFarland** of **MacFarland and Company Home Sales** led a longest drive



competition on one of the Par 5's, awarding prizes to the longest drives, male and female. Madonna University golfer, **Jackie Green** raised close to **\$500** on a par 3, by challenging players to use her shot, instead of their own. Fox Creek organized a putting contest as well, to test players skill, and raise more money.

Throughout the 18 holes of golf, all teams posed for pics with an amazing photo prop picture frame made by former Stevenson High School students, **Clare Bunton** and **Megan Argenta**. The photo prop was a unique touch that many participants said they enjoyed, and will remember. Players also loved seeing **Brooklyn** riding around and taking pics during the tournament! She truly was at the center of the planning, implementation and overall spirit of the event.

Here is a quote from **Al Newton**, who helped tremendously, every step of the way, in making the day a success. "It was a B kind-of day; everyone chose kindness. And because of B, we choose kind every day; for that choice makes us better people. So does loving her. She lives through others, like others live through her. Lucky are we to be in her wake, to see **Ang's** imagination



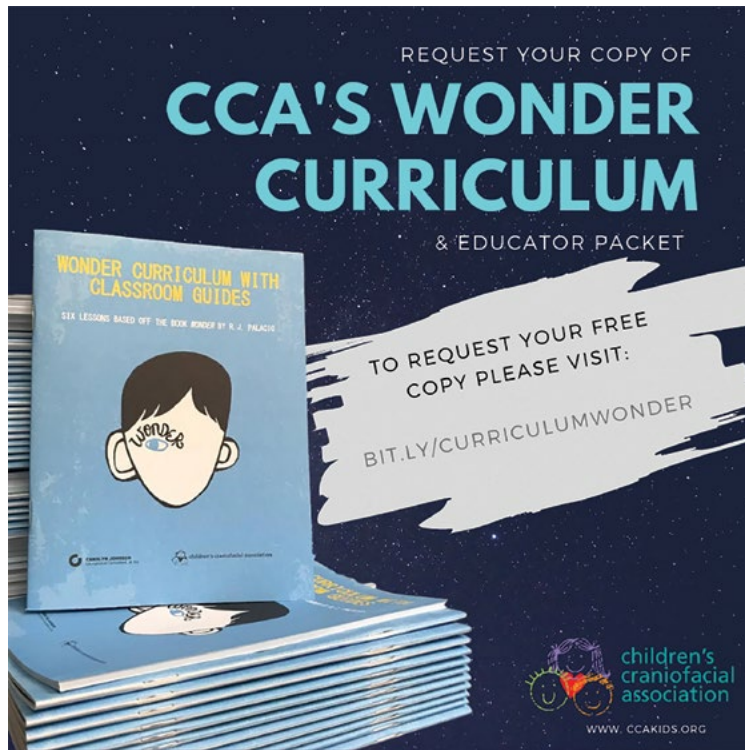
and **Brent's** determination make her into the B she is today, and the one she'll continue to grow into every tomorrow. August 5th, 2018 was another reminder of how beautiful life can be through the eyes of a child full of wonder."

George Murphy's at the Creek is the restaurant/clubhouse in which players were provided lunch at the turn, as well as a delicious BBQ buffet dinner. The staff of both George Murphy's and **Fox Creek** couldn't have been more accommodating and helpful to make the event a success.

My heart is full, and I have so many people to thank. I can only hope you all know who you are. My life took a different direction when Brooklyn was born, and despite my worries and apprehension, it changed for the better. Let's just say, I found my purpose, and I couldn't be more grateful. Looking forward to next year's outing on August 10, 2019!!



our #choosekind initiative is growing



Twenty eight was quite the year for many firsts. CCA was able to take our existing *Wonder* curriculum developed by **Carolyn Johnson, M.Ed.**, and professionally print them for distribution to educators across the world. Since May 2018, we have distributed roughly **700** hard copies of the *Wonder* curriculum—this number does not include the number of digital downloads and international requests from countries all over the world, such as Australia, Canada, China, Egypt, Palestine—Israel, Singapore, and the United Kingdom.

The curriculum has been an amazing avenue to get teachers and students across the world to start the conversation towards awareness, acceptance, and kindness, not only towards our own CCA families, but humanity as a whole.

We are so happy and honored to announce the launch of two additional curriculums to our #ChooseKind Initiative. Last summer we partnered with **Born a Hero** to create our ABC Kind PreK-2nd grade curriculum and with **KiCam Projects** to create our High School Discussion Guide.

ABC Kind Curriculum with Classroom Guides for grades KG-2nd

Gerry Ghanooni, Born a Hero's Creative Team Director and ABC Kind Curriculum Developer, and **Carolina Sommer**, CEO and Founder of Born a Hero, believe that people learn to be kind, appreciate diversity, and to like and believe in themselves when they are very young. This very thought process created the foundation for the ABC Kind curriculum.

"I am convinced that if we expose children at a young age to differences, then there won't be a difference, because that will be their norm.

We want to teach children that differences are not only okay, they are good. We want to make them realize that we are all different. When they can understand that, and find the beauty in other's differences, it means that they are accepting themselves and the things that make them unique."

– **Carolina Sommer**

The lesson plans approach many social and moral issues by addressing three specific themes: **Appreciating**

Diversity, Believing in Yourself, and **Choosing to be Kind**. Together, these themes encourage practicing acceptance, kindness, and anti-bullying. The guide contains eight individual lessons based off of eleven children's books that reinforce the themes mentioned. The lessons include an art activity that works on developing the student's fine motor skills, and a song to reinforce the values discussed in the book. Early literacy is also integrated seamlessly within the curriculum, by including one-to-one matching, letter and sound identification, as well as sight words, and new vocabulary. The lessons conclude with discussion points for the class to discuss and focus on to initiate the conversation back to the ABC theme.

"On my first day of first grade, I looked up, and on the walk way, I saw a girl whose mouth looked different. It was hard to understand her. She had a cleft lip. In my ignorance, I looked at her and quickly looked away, I was afraid. I feel guilty about my reaction, but it was something new for me. In my years of teaching

extraordinary children, I learned a valuable lesson; we all need to help educate our children with experiences, so that we have a kinder world, and in a school's curriculum it can be done in tandem with literacy goals. I believe this!" – **Gerry Ghanooni**

Diary of a Beautiful Disaster Discussion Guide for high school educators

KiCam projects headed the development of the high school discussion guide based on the book *Diary of a Beautiful Disaster*, by **Kristin Bartzokis**, an author and CCA Adult with Treacher Collins syndrome. KiCam hopes that through reading the book and working through the discussion guide, students will learn to embrace their own unique gifts... and is inspired to embrace the gifts present in every individual.

The discussion guide encourages critical thinking, and having uncomfortable conversations by opening students' eyes to individual differences, respecting others, and the dangers of bullying. The discussion guide consists of three lessons based on the themes: **Respecting Others, Empathy, and Making Choices**. Students

are encouraged to place themselves in hypothetical situations to come up with possible solutions they may apply, or encourage those around them to utilize, if the need were to arise. The lessons not only walk students through understanding and learning about individuality, but empower them to step up against harm, and intervene to help those around them.

"KiCam Projects' mission is to use great stories to help change the world, so it's been an honor for us to partner with Children's Craniofacial Association, which is also changing the world, and making it a more caring, compassionate place. We're proud to have *Diary of a Beautiful Disaster* in classrooms across the country, and we, in partnership with author Kristin Bartzokis, hope Kristin's story challenges and educates readers of all ages." – **KiCam Projects**

Contact Outreach Director, Khadija Moten, kmoten@ccakids.com, to request your free educator resources.

CCA'S 2ND ANNUAL ART CONTEST

The competition is open to all those in America between the ages of 1 to 16 years.

THEME: KINDNESS MATTERS

For official rules and to sign up follow this link:
bit.ly/2SJ7SGa
case sensitive

DEADLINE: August 1st, 2019

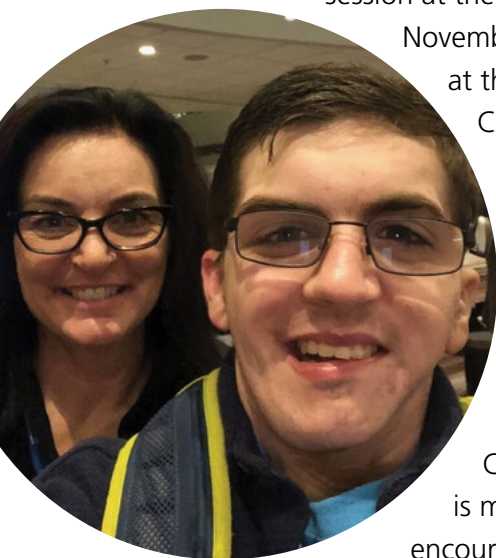
naes conference

We want to extend our sincere thanks to the National Association of Episcopal Schools, who hosted Dede and Peter Dankelson at their Biennial Conference this past November.

CCA's *Wonder* curriculum was shared in a keynote session at the Conference on November 7th. All attendees at the session received CCA's special-edition copy of the book, *Wonder*, and our exclusive educator materials. **Dede** and **Peter Dankelson** spoke about the positive impact that CCA's *Wonder* program is making in schools by encouraging students to be kind, and inclusive. Peter shared

how he brings the story to life by presenting his true *Wonder* story to the audience. Teachers were invited to contact CCA and book a CCA Speaker to connect with their students after reading the book.

For more info about our educational resources please email Khadija at kmoten@ccakids.com.



motorcycle raffle

Congratulations to **Mike Schon** of South Carolina who won our motorcycle raffle, drawn by **Lily Walker**! Many thanks to **Rick Salisbury** of [Legends Motorcycles](#) of Springville, Utah, for donating this custom bike—an incredible show of support—and to the entire **Walker family, Tasha, Nathan, Josey and Mark, Tanner, Lily, Xander**, plus their extended family and friends for being a part of this wonderful dinner month. A special thanks too, to **Jennifer Munson** for taking photos. We appreciate everyone who bought and sold tickets and we wish you the best of luck in our next raffle!



full psycle for cca



It's hard to beat blasting calories and pumping motivating music on a Saturday morning, but there is one way to really take your workout to the next level – make it an event with the team at **Full Psycle!**

Jessica Wilcox reached out to CCA in honor of her niece, **Keegan Strogatz**, and at the prompting of her uncle (and Keegan's grandpa) **Burt Strogatz**. She said she loved Keegan so much, and appreciated her and her mom, **Brooke's**, involvement with CCA so much, that they were moved to get involved.

So a **Cycle for CCA** event was planned. It was nothing short of a raging success! The room was packed, since the studio graciously told regular members that there was a benefit today. We cannot overstate our gratitude for the amazing turnout. A full room of folks riding in honor of our kids was a beautiful, sweaty sight!

The studio also generously offered a 20% donation to CCA for any merchandise and packages purchased on that day. While everyone cooled down after an intense ride, they shopped, mingled, and enjoyed mimosas!

All in all, we raised **\$500** for CCA Kids! Thank you so much!

We had so much fun, and we encourage all our Texas friends to stop by your local Full Psycle studio and experience a high energy workout for yourself!



alex and ani



On October 5th, 2018, **Christine Andler**, Director of Development, held a shopping night at **Alex and Ani** in Scottsdale, Arizona. It was a great turnout of new and old CCA Families in the Phoenix metropolitan area. In between looking at fabulous jewelry, there was lots of chatter about how everyone is getting excited to welcome the rest of the CCA families to their sunny home state in June!

A special thank you to **Evonne Bowling**, Christine's mom, for donating bubbles and wine to the sip and shop! And a big thank you to **Lori Takeuchi**, Program Coordinator at **Barrow Cleft and Craniofacial Center** for inviting their families and supporting CCA. We cannot wait to see what they have in store at their booth at this year's Retreat!



In all, the event brought in 10% of sales for the night which resulted in a check of **\$350** to CCA! We look forward to more local events with our CCA families throughout the year.

lilly pulitzer

CCA celebrated the holidays all month long at **Northpark Center** in Dallas. In addition to the 9th Annual Gingertown build and display, **Lilly Pulitzer** held a **Shop for CCA Day!** 10% of all sales of their classy and fun styles



went to benefit CCA Kids on December 8th. Shoppers raised **\$532** for CCA Kids.

The Northpark Lilly team went above and beyond, even after our shopping day, by passing out Northpark Trains tickets and VIP Santa passes to CCA Families who got to experience the magic of Christmas, due to the kindness of our Northpark Center friends, including **Nancy Nasher**.

We especially want to thank **Deborah Cuzalina**, the Events Manager at Lilly Pulitzer, for her loyal support and continued assistance setting up and promoting our shopping days and facilitating more festive fun for our families.

join us for a shop & share in partnership with Lilly Pulitzer



children's craniofacial association

CHILDREN'S CRANIOFACIAL ASSOCIATION

CCA is headquartered in Dallas, Texas. Nationally and internationally, CCA addresses the medical, financial, psychosocial, emotional, and educational concerns relating to craniofacial conditions.

10% OF PROCEEDS DONATED

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levine academy



We are so grateful to **Levine Academy** students, faculty and staff who welcomed us to their **Shabbat Rocks Friday** morning celebration. CCA Kids were invited to be the recipients of the monthly **Mitzvah Mensch** by **Ms. Stephanie's** and **Ms. Brenda's** Pre-K Class.

This recommendation came from CCA Board member, **Steven Weiss**, and his wife **Petty**, whose

twins, **Blake** and **Claire**, attend Levine Academy. On January 11th, CCA Staff joined their morning Shabbat with **Brittany Brown**, and her children **Michael** and **Allison**, along with nurse **Angela DeVaul**. Brittany and Steven spoke to the families there about the impact CCA has had on their lives. Then, we all sang songs together, and celebrated acceptance and kindness.

Amazingly, the class raised money for CCA Kids amounting to **\$1,118!** WOW! That is enough to send a CCA Kid to Retreat. What a very special Mitzvah Mensch.

We want to extend our biggest thanks to these kind-hearted students, and their generous school community.



brenna, from page 1



not right. Off she went for the first of very many X-rays and CT scans. She was then put into the ICU until she stabilized. We had a hard time feeding her, because she couldn't breathe through her nose. The nasal passages were too small. We finally found a specialized bottle that would work for her. Brenna was always very small due to such a hard time breathing and eating at the same time. As a baby, we had to supplement her milk to give her much needed calories. I've always called her my Sugarplum from the moment I got to hold her for the first time. She was a sweet baby, and is now a beautiful and wonderful young lady, and my daughter.

After we left the hospital, we went to a genetics clinic here in Eugene, OR.

A specialist from Portland came down to help diagnose her. We knew it was craniosynostosis, but they gave her the diagnosis of Crouzon's syndrome. We also were given an article about Crouzon syndrome early on. The prognosis was not good. We had no idea what we were dealing with. We were advised to go to Portland to receive the medical care. So we started all the trips to Portland and back. I tried to resume my career managing a recreation facility for the City of Eugene. I tried to put Brenna into daycare for a while, but she began to fail to thrive. She was just so hard to feed and couldn't get in enough calories. She began to lose weight. I eventually chose to leave my career, and take care of her full-time. My husband at the time had a good career, so we were blessed that I could do this. Instantly, I went to the Internet to find as much information as I possibly could about this condition. There were several wonderful websites/groups where people could talk about everything relating to this new lifestyle. I'm very thankful I had that support. It helped

me figure out the right directions to go, and the right questions to ask. So many parents of children with craniofacial issues became online friends.

When Brenna was around six or seven years old, I hosted a small weekend gathering at my house. I live beside a small lake in the country. We swam, boated, and had a nice BBQ. We drove over to the Oregon coast the second day, and played, and hung out on the beach. The third day, we went swimming, and picnicked at a local swimming pool.

It was wonderful to actually meet several other families who had similar lifestyles. Many of us are still friends online, and continue to chat and support each other, even

though our children are mostly grown-up now. That's also how we found CCA. We've been to three fantastic retreats, and met up with our online friends once again, plus many new friends were made! What an incredible organization!

In the beginning, after Brenna was a little more stable, she had her first surgery at four months of age. Her ENT doctor was trying to open her nasal passages to help her breathe and eat. He put in breathing stents in her nose to try and help her breathe. They needed to be suctioned regularly to keep them clear. We were very blessed that our local pediatrician's nurse volunteered after work, to come help me do this. It was so overwhelming. She



helped me clean out the nasal stents daily.

Her second surgery was at six months to expand her skull. Unfortunately, that surgery did not go well, and the doctors broke the forehead bone in half. They had to patch together bones from the back of her skull to replace the broken bones. I was absolutely devastated. I'll never forget that wonderful ENT doctor

why they were necessary, not just cosmetic. She needed surgery to help her function in life. I requested a case manager for her. We were approved to start seeing doctors in Seattle. I remained in close contact with that case manager for many years.

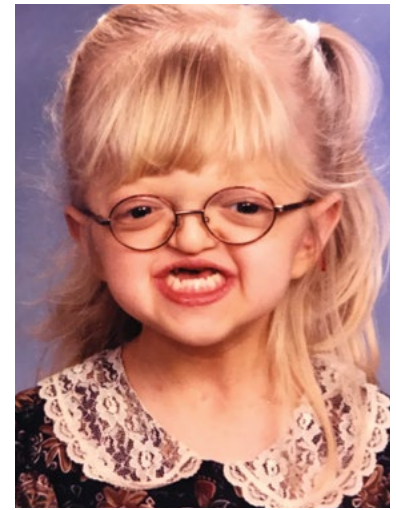
So, on our first trip to Seattle, we got a wonderful relationship established with one of the best teams

would do a large surgery to fix for forehead using rib bone graphs. More CT scans were taken, and the neurosurgeon did not have good news for me. There were two screws from the bad surgery that had gone into her brain. (This was before absorbable screws were used). So we set a date and back to Seattle we went with a plan.

The neurosurgeon removed the screws, but there was a little bit of damage to the front part of her brain. The reconstructive surgeon repaired her forehead and upper orbits. That surgery took most of the day. When he came out and show me the pictures of the screws going into her bone and brain, and all the complications, I was horrified.

When he left, all I could do was hit my head on the wall, and cry "Why?" As she was in ICU, I noticed her nose was always wet underneath. It started getting worse... Brenna sprung a leak because she had underlying hydrocephalus, so a temporary shunt was put in for a few days to monitor the leak. A few days later, a permanent shunt was put in. Unfortunately, because of the leak, contamination occurred in her new bones.

She was put on several heavy antibiotics. One had to be flushed into the



brain. It was just crazy! The forehead came back off, not to be replaced until she was stronger. We decorated her hospital room with all kinds of artwork, as she was now in isolation due to the infections; we were going to be there a while. This is one of the longer stays that we've had—several months.

They always sent a volunteer to her room to play/be with her for a couple hours, so I could go for a run—to take care of myself while trying to take care of her. It was crucial for me to get a daily break. Seattle is a beautiful city! I love the hills overlooking the harbors and mountains.

When she healed, Brenna was sent home with a pink helmet that we decorated with as many stickers as we could. I noticed that her motor skills and coordination were not very good. More scans revealed she had something called Chiari malformation. The

see **brenna**, page 20



in Portland who suggested that Brenna should be seen by a regional craniofacial center from that point forward. This is when I had to step up my game, and be a strong advocate for my daughter. Our insurance company at the time refused to let us go out of state. At this point I knew there was no other option than to go see a regional team of craniofacial doctors. So I proactively created a very involved informative journal about Crouzon's, Brenna, and what we had been through to date. I also explained about the surgeries, and

in the nation. They were so kind, and listened to me, and actually diagnosed Brenna also with acanthosis nigricans as part of her syndrome. She has some dark, tougher skin on areas of her face and body. That has also been a challenge at times. We met with close to 10 specialists. Each of the doctors checked out their area of expertise, then we all sat in a room and made a plan together. She was very complicated, and because of the bad surgery in Portland, this was not going to be easy. We were told to wait until she was two years old, then they

brenna, from page 19 bones in the base of her neck were very malformed and running right through her spinal cord. This caused a syrinx, which is a bubble in the spinal cord. So, back to the table we went to get these bones taken out of her spinal cord, so the fluid could flow more normally. Her neurosurgeon had to design an operating table specifically for her, since she has no forehead bones to rest on the table. So he designed a table with a donut shape, so her face could be down for surgery. That surgery was a success! Everything came out perfectly; she had an easy recovery, with no infections this time! Brenna still did not have a forehead, so once she became strong again, we went back to fix it for the third time. Once again, ribs were grafted, and this time it was a success! She needed one more surgery in the back of the brain to hold everything in the proper place. Her doctors designed a sling for that. Due to the bones in her face being so small, she was also plagued with ear infections, her tonsils were removed twice to make room to breathe. Her eyes were also probed several times because they did not drain properly. These are all little surgeries, in my opinion, but she's had so many—it seemed like we lived in Seattle. It was very



hard on my family, by this point. We had two other boys, **Caden** and **Perry**. It was very hard for me to be away, but I just had to do it!

By this time, I had put a lot of miles on my car going back-and-forth for the 5 1/2-to-6-hour trip. One of our doctors suggested we look into a program called **Angel Flight**. It is the best thing that ever happened for us with all these medical trips. Volunteer pilots fly you to and from medical appointments. That was such a huge blessing when all this craziness was happening. This actually allowed me to be home with my family a little bit.

At this point, we were gearing up for the RED

distraction. Brenna finally had a good forehead to attach the distractor onto. And then she had to have a palate distender to widen her upper jaw several millimeters. So in the summer after second grade, when she was eight years old, we once again mostly lived in Seattle while we were lengthening the bones in her face forward and sideways. Before we did this we had to tape oxygen over her mouth at night to breathe, because her sleep apnea was so bad. So I knew the distractor would be a very hard experience, but I wanted her to just be able to breathe normally. She was still very small from having to work so

hard at it. We almost got away with a successful RED procedure, but in the final two weeks I noticed that the device was starting to slip, and then I saw a place near the screws that was looking infected. It had to come off two weeks early and once again... back on antibiotics.

After this infection cleared up and we were given the green light, Brenna started really thriving finally. She was able to breathe at night now, without struggling so hard. Her airway was finally opened! She finally gained a little weight. And we got a break from all the surgeries, for a while. She even played soccer in high school.

The last few years we have been trying to work on her upper jaw, getting it ready for the last phase of her repair.

Brenna has been in braces for several years, trying to align the teeth. She cannot bite effectively, as the teeth don't line up together. She has a significant gap between the top and bottom teeth. We met with her doctors recently, and now we're waiting for her next surgery to be scheduled, sometime this year.

Brenna has successfully graduated from high school, and is now currently finishing up an associates degree at the local community college. She's also working nearly full-time as a caregiver at an assisted living center. Everybody loves her strong work ethic, and her huge heart! For fun, she loves to write poetry, take beautiful photographs, and just enjoy being creative. She has come such a long way and I am so proud of her! She's a tough young lady, and I love hanging out with her. She will always be my sweet Sugarplum.



testimonial



Lev was born on the 22nd of February, 2018, in California. From the moment he was born, we noticed there was something wrong with his forehead. He was diagnosed with metopic craniosynostosis, and the doctor said he needed surgery. We spent many hours, days, weeks to find a better possible solution instead of the one suggested.

We found out that there are two types of surgeries. One was the traditional method. The surgery took five hours, and required a long hospital stay, and the other one was minimally invasive, took only 50 minutes, and you could go home the next day. We went to two big children hospitals in California, and both of them suggested the traditional surgery, but we did not give up. We knew somewhere there was a doctor who could do the less invasive surgery. Thank God we found **Dr. Jimenez** in San Antonio, Texas. We were able to schedule the surgery within a month. Then we had to fight with insurance for two weeks to get the approval for the surgery, because the network was out of state. In a couple of weeks, we flew to San Antonio, Texas, and had the less-invasive surgery done. Everything went well.

After the surgery, Lev had to wear a helmet for approximately 6-9 months each day, only being able to take it off for one hour. We needed to see the surgeon every 2-3 months for check-ups, and the doctor at the Cranial Remolding Program to get a bigger helmet. There are many travel expenses to fly from California to Texas and back every time. We are very thankful for Children's Craniofacial Association for helping us out in this difficult moment with travel expenses. The treatment is now done, Lev does not have to wear the helmet anymore and we are so happy. We personally want to thank **Annie Reeves** for all she has done for us.



– **The Aliyev Family**

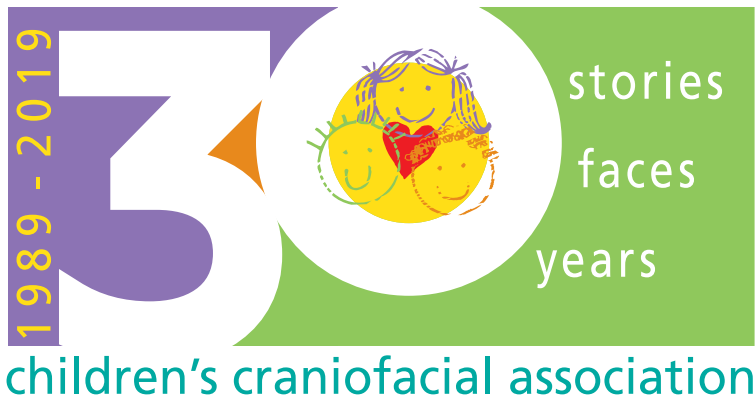
calendar of events

date event contact

2019

March 27-28	8th Annual Morgan Meck Invitational <i>benefitting Children's Craniofacial Association</i> Coto de Caza Golf and Racquet Club Coto de Caza, CA	
April 6 5-8 PM	2nd Annual PJs for PJ Movie Night for CCA New Hope Christian Academy 2264 Walnut Creek Pike Circleville, OH 43113 Hosted by Crystal Kouri-Reynefarje and Allison Catlos	Tickets: bit.ly/pjsforpj
April 16 7 PM	RARE General Meeting – RARE Texas A&M College Station, TX	emossholder@ccakids.com
April 18 3-10 PM	Mason's Crawfish Boil Quatermain's Pub 13920 Interstate 35 Live Oak, TX 78233	Tickets: bit.ly/jjhenson emossholder@ccakids.com
April 27 Noon-4 PM	TOAST to TOTS Fundraiser Incendiary Brewing Company (family friendly with games, silent auction, and food trucks) 486 N Patterson Ave. Winston-Salem, NC 27101 Free, purchases benefit CCA	
Jun 27-30	29th Annual Family Retreat Hyatt Gainey Ranch Scottsdale, AZ	ARees@ccakids.com 214.570.9099 800.535.3643
Aug 10	2nd Annual Spreading the Love for CCA; it's the Brooklyn Way Livonia, MI	Angela Wojtyniak angwojtyniak@gmail.com
September	15th Annual Craniofacial Acceptance Month (CAM) Nationwide	ARees@ccakids.com 214.570.9099 800.535.3643





my passion, and I have been fortunate to work in this field for 30+ years. **Retreat teaches us that we are a family that embraces all differences.**

We are a unique family that connects with others to give hope, compassion, education and unconditional support. Thank you, CCA, for making all this possible!

Diana Sweeney

Diana Sweeney works diligently as the patient liaison at Children's Hospital of Philadelphia, the only parent liaison in pediatric plastic surgery in the country. She blends both personal experience and professionalism together to advocate for her patients and their families. In her own words, "They need a voice," and



she's the woman for the job. She works with works with the craniofacial team to make sure that voice is heard. Diana also organizes events and activities for her CHOP families, and accompanies a handful of them to Retreat each year. Diana knows the value of a strong community, and

works tirelessly to make sure her patients have a place to build, grow, and enjoy that community. She has been a part of CCA since the beginning, and we are so very grateful for her leadership, support, and love.

30 STORIES **30** FACES **30** YEARS

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If you know of someone who would like to be placed on the mailing list please forward to us their name and address.

3 cheers

for volunteers!



We are so honored to have had the privilege to collaborate with **Born a Hero** on the ABC Kind Curriculum for Pre-K to first grade (and adaptable to second grade.) A HUGE thank you to Born a Hero founder, **Carolina Sommer**, and Born a Hero's creative team director and curriculum developer, **Gerry Ghanooni**.

Gerry's knowledge, creativity, and endless hours of dedication have made the final product what it is today. Carolina first introduced us to this opportunity last summer by showing us their amazing display binder filled with colorful art projects, catchy songs, and intriguing discussion points. We are so humbled to have been given this amazing opportunity! We truly appreciate all of your time and dedication, we give Three Cheers for our super volunteers, Gerry and Carolina!