

# ccanetwork



newsletter of the children's craniofacial association

Cher—national spokesperson

2019: Issue 2

## inside

- cca kid
- tristen alvey. . . . . 2
- cca supersib
- isabella rae alvey . . . . . 3
- 30 stories, 30 faces, 30 years
- cca adult
- rob gorecki . . . . . 4
- 2019 morgan meck
- invitational . . . . . 6
- thank you, 2019
- cca retreat sponsors . . . . 8
- mason's crawfish boil . . . 9
- harmony for hope. . . . 10
- pjs for pj . . . . . 11
- first-time retreat
- attendee . . . . . 18
- 30 stories, 30 faces, 30 years
- jill patterson,
- a legacy of love . . . . . 21
- north carolina's restore
- opc fundraising efforts . 24
- donors in the spotlight . 25
- calendar of events. . . . 29
- testimonial . . . . . 30
- 3 cheers for volunteers . . 31
- lilly pulitzer . . . . . 31
- links of love . . . . . 32



## message from the program director

### Retreat Recap

“It’s a dry heat!” Does this phrase sound familiar? Let’s just say the heat didn’t stop our families from attending the **29th Annual Family Retreat in Scottsdale, AZ**, June 27th-30th! Once again, we broke records! The 2019 retreat was our largest retreat to date, with 170 families from 33 states and Australia, Canada, Pakistan and the United Kingdom. Of the 170 families, 44 families were first-time attendees.

Our home for four amazing days was the **Hyatt Regency Resort & Spa at Gainey Ranch in**

see **program dir**, page 12

## tyler's story

By Julie Downs

**T** Tyler is one of those kids that everyone knows and remembers, not just because he looks a little different, but because he is a fun, friendly, kind and an all-around great kid!

When our oldest son, **Riley**, was about 2, we decided we wanted to adopt again. We got our paperwork all up to date, had our home study done, and attended the required classes again. Then we waited, and waited, and waited. There were a few close calls, but nothing happened for over 3 years. In February 2007, our caseworker asked if she could show our file to a birth mother who was expecting a child with a cleft lip and palate. We told her that was fine and I didn’t think much of it because our file had been shown to lots of birth mothers. Finally, in April

see **tyler**, page 26





## meet tristen alvey

Having just completed first grade, seven-year-old **Tristan Alvey** has been enjoying summer break. While at school, and like most kids, he loves playing at recess, and field trips are also fun and exciting for him. But writing? Not so much. "It bores me out!" he said.

During the summer, he had lots of extra time for the things he loves, including all kinds of games: "Wii Sports, Mario Kart, Roblox, and Minecraft are a few of my favorites." He also enjoys

spending time helping his dad. "I love helping him with any kind of work he is doing around the house—mowing the lawn, cleaning our garage, and fixing things." You'll also find Tristan riding his bike, walking his dogs, and playing with Legos.

As for music, Tristan likes anything with a good beat that he can dance to, like "Happy" by Pharrell Williams, "Can't Stop the Feelin'" by Justin Timberlake, "Paradise City" by Guns and Roses and

"Celebration" by Kool and the Gang.

*Fireman Sam* is his go-to TV show, as he wants to be a fireman when he grows up, "so I can put out fires, and rescue people from way up high like Fireman Sam." Tristan's favorite movies include *The Good Dinosaur*, *Woody Woodpecker*, *Peter Rabbit*, and *Ralph Breaks the Internet*.

Tristan has Apert syndrome and has had 14 surgeries so far, but thankfully none in the last 3 years. He had an MRI recently to determine if, or when, he might need another cranial surgery. If everything looks good, he will probably have his midface surgery sometime in the next year or two. If **Dr. Fearon**, Tristan's doctor in Dallas, is concerned with the scan then he might have to have a cranial vault surgery much sooner.

The CCA Retreat in Scottsdale was a much-anticipated part of his summer: "I'm

really excited I was able to attend my second retreat." He went to his first retreat last summer in Salt Lake City. He had never met someone else with a trach before, and said meeting lots of kids like him was really fun, as well as making new friends. The pool party was a blast, he said, and he had a terrific time at the dance party. No doubt Tristan had an equally wonderful time at this year's retreat!

After leaving Scottsdale, Tristan and his family drove to Utah to stay with his "Oma" and "Opa" for most of his summer. He rode horses, saw most of his 21 cousins and spent lots of time riding in the mountains on his Grandpa's Ranger. "It was awesome!"



# ccakid



# ccasupersib

## meet isabella rae alvey

**m**y name is **Isabella Rae Alvey**, but my friends and family just call me **Bella**. I am 9 years old, and I am in 3rd grade. My favorite things about school are playing with my friends, and running into my little brother, **Tristan**, in the hallway during the day. My favorite subject is reading, and even though I do well at just about everything, I think I am best at science. Writing is my least favorite subject. The only thing I don't like about school is waking up early. My mom thinks that's funny because I always wake up before my alarm, even when there is no school.

Outside of school, I love to play Minecraft, and read. My favorite book is the one

I'm currently reading, *Dog Tags*. I love to spend time with my family by going on walks with our dogs, playing games, hanging out at the lake, and watching movies. My favorite movie right now is *Sgt. Stubby*. I enjoy playing in a basketball league, and last season my team, Frisco Cavaliers, placed 3rd overall, which was a big improvement over 2nd-to-last the season before. Next season I think we will do even better!

I also love hanging out with Tristan. We love to play Roblox together, have dance parties, and wrestle. I really love how sweet Tristan is. He is always thinking of others and he loves making people laugh. Something I wish people understood



about him, is that he is just like everyone else. If they get to know him, they will love him as much as I do.

Last summer my family went to our very first CCA Retreat in Salt Lake City, and we had SO much fun. My favorite activity was Family Night, because we got to see a HUGE snake, and get our faces painted. I also really loved the Pool Party, because everyone was just having so much fun, and we made lots of friends.

I had so much fun at the Retreat in AZ this summer, and swam in all

the pools, and went down the waterslide. I can't wait to see everyone and make even more friends.

After the Retreat, my family spent some time in Utah visiting family. I rode my grandma's horses everyday, which is the best part of the summer for me. I also really enjoy helping my grandma feed and take care of her horses, bunnies, turtle, and dogs. One day, I want to have a job working with animals, because I love them all. They make my world a happier place.





children's craniofacial association

## meet rob gorecki

I'm **Rob Gorecki**. I'm 32 now, but I was two, going on three, when the organization was founded in 1989. Children's Craniofacial Association (CCA) has been a part of my life since before I can remember.

I was born with Goldenhar syndrome which caused a facial cleft that affected my speech and left me with just one eye and one ear. I've had lots of craniofacial surgeries (my mother says she lost



Above: With Cher in Sturgis for the CCA Motorcycle Raffle

Left: Meeting Cher for the first time

reconstructed, though non-working, left ear and I wear a prosthetic left eye.

I was three years old when I met **Cher**, backstage at her *Heart of Stone* tour in early summer, 1990, arranged by my neurosurgeon who was on CCA's Medical Advisory Board. She had become the organization's Honorary Chair/Spokesperson after she portrayed the mother of a boy with a craniofacial



count after a couple dozen), from the time I was an infant through high school, while I was still on my parents' insurance. I have a



Selfie in Amsterdam, The Netherlands

condition in the movie, *Mask*.

My mother and I were among families gathered by the organization to attend a special event the following September. We addressed a Congressional hearing focused on insurance coverage needs and toured Washington D.C. together. The event featured a fundraising dinner and auction with Cher, who also went with us to the White House. We kids were invited to spend private time with Cher later in her hotel room and the moms joined those of us too little to be

alone. They shared with her how wonderful it was to be able to relax among the other families while touring the city, exposing our facial differences to the usual staring and whispers of passersby. **None of us were even conscious of any of it while in the group of about ten families; we were insulated because we were together.**

It was Cher who suggested we gather again for some sort of camp or retreat in order to feel that supportive strength at least once a year. Yes, **Char**

30 STORIES 30 FACES 30 YEARS



**Smith** was there too, and she only needed to hear that once. The very first retreat was the following June in Orlando, Florida, and I am still friends with most of those families we first met in Washington D.C. Some of us also appeared on the *Maury Povich Show* with Cher the following year and still participate in CCA activities, especially the Retreat. **The Annual Retreat is really like a big family reunion.**

I've also liked motorcycles for as long as I can remember—maybe because I live in the Milwaukee area, home of Harley Davidson. Every year, the Retreat weekend became our family vacation. I would get to visit the local Harley-Davidson dealership in the different retreat destinations, in order to add to my pin / patch collection for my “biker” vest.

Because my “biker” aspirations were well-known, in 2000, when CCA started a motorcycle raffle, I became the charity representative, the “poster boy,” for the event. In the



With Robbie Knievel, riding for CCA through the Black Hills of South Dakota

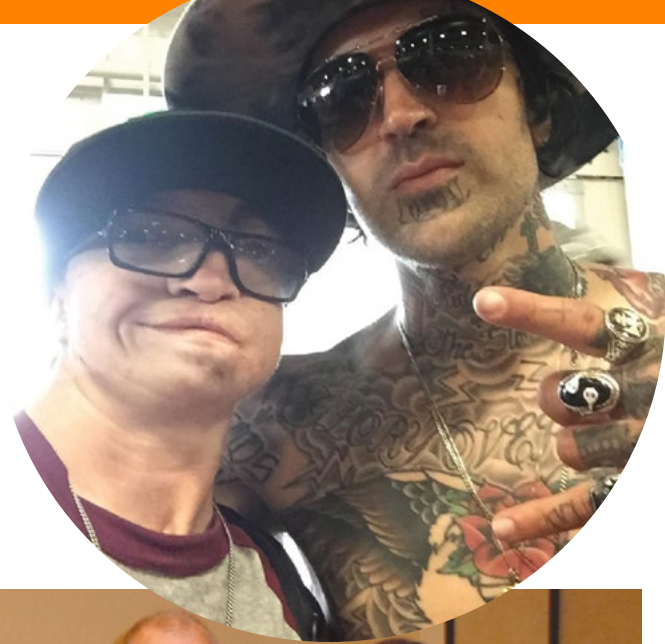
five years we traveled to Sturgis, South Dakota, for the raffle during my teens, I met a lot of famous people and made a lot of friends in the motorcycle industry. I even learned to ride a motorcycle and was gifted my first bike out there. Those connections I made through the organization inspired me to travel across the country to attend MMI (Motorcycle Mechanics Institute) in Phoenix, Arizona after high school graduation.

I also attended Cher Conventions every other year from 2000-2008 with another longtime friend, **Scott Guzzo**, and we met many Cher fans who were

Rob and Scott Guzzo; lifelong friends, posing at CCA Retreats



Meeting rapper, Yelowolf



At Retreat with Ed O'Neill, and the Bordonaros, friends since 1990

raising funds to benefit Children's Craniofacial Association in her honor. I was happy to represent CCA there and at many other fundraising events through the years.

The Cher fans still know and support me as friends today, almost 20 years later.

I think having CCA's support while I was growing up made a big difference in my life. I've only missed one Retreat, I met other kids like me, and my entire family found comfort in knowing we aren't the only ones

dealing with some of the common problems we share living with facial differences.

Knowing I had that “extended family” from CCA through the years bolstered my resolve to just be myself and to go out and live my life. I've traveled all over, twice to Europe, once by myself; with confidence that I can do anything any other average person does. **I am not afraid to go out into the world**, and I hope I inspire any younger kids facing similar challenges to do the same.

# 2019 morgan meck invitational

**O**n March 27th and March 28th the **Mecklenburg family** hosted the eighth annual **Morgan Meck Invitational benefitting the Children's Craniofacial Association**. There were 40 golfers from across the country and approximately 70 people who attended dinners and participated in a significant way. The guests also had the pleasure of meeting the adorable **Keegan Strogatz** and hearing an incredibly inspirational speech by **Ben Kjar**.



It is not often you hear 60 adults shouting their commitment to standup and standout at the top of their lungs, while their leader stood on a chair demanding more volume... Keegan and Ben gave our participants the opportunity to appreciate the lifecycle of CCAkids, from an active and engaging toddler to a highly accomplished CCA

Adult who demonstrates the meaning of striving to embrace the life of a victor rather than allowing any difference in life to make one a victim.

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

**Morgan** welcomed all participants, and thanked them for continuing to support Children's Craniofacial Association, for helping all her friends from CCA, and then encouraged them to "spend more money for her friends at CCA!"

**Erica Mossholder** and **Ben Kjar** truly moved the group with their personal accounts attesting to the amazing work CCA does for CCA kids and families.

First time participants, **Scott Vickers** and **Mark Rogondino** won the overall championship, while **Lou Pugh** and **Russel Newman** captured the most highly contested Ladies' Championship in the history of the tournament; however, the true champions of the tournament were our CCA Kids who inspired this small group of friends, corporate sponsors, and auction

participants to contribute **over \$85,000** to benefit Children's Craniofacial Association.

A special thank you goes out to our **Platinum Level Sponsors: Crum & Forster Insurance, Bobby & Kristen Baillargeon, EverGuard Insurance, SES Insurance, Westchester Programs, Blair & Shelley Schrum, and QBE North America. Gold Level Sponsors: Maria Amelio, Greg & Donna Bonnell, Robert & Karen Reader, and Kevin & Jennifer Trapani**. A special thank you is also deserved for **Shawn Craig** and **Holly Jaenichen** for providing incredible golf and hotel experiences for the auction, along with **TaylorMade Golf** for allowing CCA to benefit from its **Charity Purchase Program**.

**Coto de Caza Golf and Racquet Club** was the host venue and all out-of-town participants stayed at the **Laguna Cliffs Marriott Resort & Spa** in Dana Point, California. Private dinners were held at **Hanna's Restaurant and Bar in Rancho Santa Margarita** and at the **Laguna Cliffs** overlooking the Pacific Ocean in Dana Point and transportation



was provided by **ACCESS Destination Services**.

CCA and the Mecklenburg family would like to thank all of the volunteers, participants, contributors and auction item donors who have made this a memorable and meaningful event.









a big thank you to our 2019 Annual Family Retreat & Symposium sponsors! Because of you, we are able to allow more and more families the opportunity to attend Retreat each year. Your sponsorship dollars, symposium booths, and in-kind donations make the experience for all our families so special. We look forward to seeing y'all in Austin for 2020! Our sincerest thank you from the entire CCA Board and Staff!

# Thank you, CCA Retreat Sponsors

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# mason's crawfish boil and rib rumble for cca kids

This April, our San Antonio friends celebrated CCA with **Mason** and **Vanessa Leibham**, for **Mason's Crawfish Boil and Rib Rumble for CCA Kids**.

Thanks to the local real estate industry, they gathered up their closest friends and family for one of the best foodie challenges of the year, and kicked off Fiesta 2019!

While the delicious competition raged on, our favorite home inspector **JJ Henson**, with **HHI Home Inspections & Pest Control** jammed on stage and with some of the best local Texas country music performers, including **Mario Flores**, **Nick Lawrence**, and **Rex McNeil**!

In addition to music, games, food, drinks and

spirits, **Mayor Mary M. Dennis** spoke to the crowd and named Mason the **Crawfish King!** This exciting moment was celebrated with **Greg** and **Jill Patterson**, huge Mason fans, who helped represent CCA at the event, with Executive Director, **Erica Mossholder**.

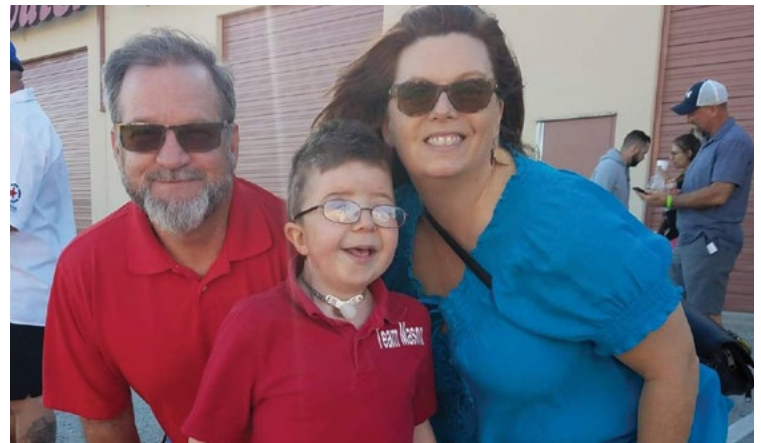
A very special thanks goes out to **Shannon Lopez** of **One Guard Home Warranties** for her work organizing this event, and to **Quartermain's Pub** for hosting us! We'd like to thank our sponsors: **Wells Solar & Electrical Services**, **City of Live Oak**, **One Guard Home Warranty Shannon Lopez**, **Rezerexion Woodworking Billy and Carrie**, **OMG Sounds**, **George Jasso Sound & Stage**, **Mitchell Realty**,

**Prime Lending**, **Jeanette Slaughter** and **Jerry Kostroun**, **Scott Haby** and **Cindy Keller**, **State Farm Insurance** **Kim Haby** and **Scott Haslam**, **CUTCO Joseph Rodriguez**, **My Insurance Guy**, **Stephanie Moore**, **JPAR Realty**, **Meemos Bakery**.

We also know this awesome event couldn't have happened without **Heather Haby**, of **HHI**, and of course, **Team Mason!**



It is such a wonderful community of friends who put on this very special event in honor of Mason, to support all of our CCA Kids. Thank you and viva Fiesta!







## harmony for hope

Thank you to the students of **Lake Zurich Middle School North** in Hawthorn Woods, IL. **Pete’s Diary** gave a #ChooseKind assembly at their school for 715 middle school students, who had all read the book, *Wonder*. The students did more than read and listen to **Peter**

and **Dede Dankelson** speak, they took action too, compiling items for surgery care packages, and hosting a fundraiser at their local **Barnes and Noble** store. CCA is grateful to North Zurich’s thoughtful **PTO** that organized all of these efforts to help our kids. The money will be used to help CCA Kids gain access to medical care for life-changing surgeries, families to network at our Annual Family Retreat, and provide educational materials to new students.

The good vibes continued as CCA and Lake Zurich Middle School North, widened the circle to include **Harmony 4 Hope (H4H)**, a local Illinois-based nonprofit, whose mission

is “using music to fuel scientific discoveries in rare disease, educate medical students, and unite people for rare disease.” **Kerry Hughes, H4H Executive Director**, lives in the Lake Zurich school district, so it only felt natural to be part of the festivities at the middle school. H4H encouraged students to submit songs for a #ChooseKind playlist dedicated to CCA Kids. The playlist was posted to **Spotify**. You can listen to it for yourself at [bit.ly/H4Hkind](https://bit.ly/H4Hkind).



The students hope these songs might help you get through a difficult day, lift your spirits, and provide inspiration.

Many thanks to Lake Zurich Middle School North and Harmony 4 Hope. We are honored to have all your donations, care packages, and Spotify playlist.

Keep **#ChoosingKind!**

**H4H Choose Kind Playlist by Lake Zurich Middle School North**  
[bit.ly/H4Hkind](https://bit.ly/H4Hkind)





## pjs for pj

By Crystal Kouri Reynafarje

### **n**ew Hope Christian Academy in

Columbus, Ohio has been following PJ's story on social media, because **Principal Allison Catlos** has been following my makeup career. We have never met, but have become friends through social media.

Last year, Principal Allison organized a school-wide fundraiser to help raise money for PJ's medical expenses called, "PJs for PJ." It was a pay-to-play concept, where the students were allowed to come to school in their pajamas instead of their uniforms in exchange for

a small donation to PJ. They even added PJ to their school yearbook as an honorary student!

To keep the kindness going, we, in turn, sent them an engraved inclusion bench—"PJ's Bench." It sits on the playground, so if anyone feels alone or sad, they can go sit on the bench, and it's a signal to others to come and join them for friendship and support. It is a lovely way to share kindness with our attention and time.

Principal Allison has decided that the school will continue to do the "PJs for PJ" fundraiser every year, and donate the proceeds to a different charity. In 2019, they chose CCA Kids! We are very proud to have

started this tradition, and traveled to Ohio for the second annual "PJs for PJ" fundraiser, benefitting CCA!

We spent a full day at New Hope Christian Academy visiting all 187 students in their classrooms, grades K-12. With everyone gathered in their pajamas, we spoke about kindness, inclusion, differences, and acceptance. There were a lot of emotions as we saw "PJ's Bench" in the courtyard, and were introduced to these wonderful children/teachers/parents that raised money for a family they had never met.

The following day was the big event! We had many prizes to raffle off, a full concession stand, and

seating for 1,000 people to gather and watch the movie *Wonder* with us! **Erica Mossholder** joined us as a guest speaker, and we raised **\$3,300** for CCA!

We would like to thank our sponsors for this event:

**New Hope Christian Academy, Heritage Nazarene Church, Principal Allison and her lovely family, CCA, Mary Phillips, Kristine Studden, Crystal Kouri, Stilazzi Cosmetics, A Return To The Fold Books, and Gerda Spillmann Cosmetics.**

Together we are making the world a kinder place, and we could not do it without community support and a lot of nationwide love!



**program dir**, from pg 1



**Scottsdale**, and it didn't disappoint. The hotel had big majestic cacti all around the resort, the largest pool we've ever seen, breathtaking mountain views and the most kind and generous staff we could ask for taking care of our families all weekend.

One thing I heard throughout the retreat was "We are friends on Facebook and have known each other for years but haven't met in person until today." Thanks to social media, these families are able to "meet," but coming to the Retreat and actually meeting one another in person is the icing on the cake! Seeing kids run up to each other after waiting a year to see their friends or hugging that new friend for the first time is the cherry on top!

Once again, this year we had expert speakers in the field of craniofacial

research and medicine hold sessions for our families during the 11th Annual Craniofacial Symposium. We would like to thank the following team members and volunteers from **Phoenix Children's Hospital, Barrow Cleft & Craniofacial Center, Children's Hospital of Los Angeles**, and **Neuro Health, LLC.:** **Pedro A. Sanchez, MD, MSCE, FAAP, FACMG;** **K. Drorit Gaines, Ph.D.;** **Dr. Davinder J. Singh, MD, FACS, Division Chief, Plastic Surgery;** **Dr. Cynthia Monheim-Janns, PHD, Clinical Psychologist;** **Dr. Carolynne Garrison Howard, PhD, Clinical Psychologist.**

We would also like to thank our Keynote Speaker, **Jono Lancaster**, from **Love Me Love My**

**Face Foundation**, as well as **Ben Kjar**, Motivational Speaker and Wrestling Champ, our very own **Erica Mossholder** and CCA family members **Rasheera Dopson, Paula Guzzo, Lisa Bock, Darryl Dyson, Scott & Stana Kjar, Rose Seitz, Dorina Watkins, Owen Anderson, Jessica Bock, Carson Cooper, Aaron Guzzo, Amelia Sanborn** and **Lea Zaengle** for either holding sessions or participating as panel members. Presenters discussed topics including "The Importance to Love Yourself and Embrace All That You Are," "Living a Victor NOT Victim Lifestyle," "Life After



Surgery, "What's Your Superpower?" and the tool of social media.

We also had exhibitor booths again this year and would like to thank them for being part of our Educational Symposium: **Barrow Cleft & Craniofacial Center, Phoenix Children's Hospital, Med-EI Corporation, Stryker, KLS Martin, TMJ Concepts, UC Faces of**





**Hope, ConnectMed, and the ACPA.**

And last but not least, a HUGE thanks goes out to all of our amazing families who volunteered their time during the symposium, registration and retreat:

**Sharon Allbright, Dave & Liz Anderson, Owen Anderson, Chris & Chole Andler, Suzanne Ashby, Taylar Aumann, CJ & Bette Barbalaci, Kristin Bartzokis, Lisa Bock, Jessica Bock, The**

**Eric & Jennifer Lucas, Nancy Merrill, Johnny & Jessica McMahan, Harlena Morton, Jenna Ottow, Eric Papadeas, Jill Patterson, Emily Paulson, Michael Piacenza, Bobbie Quiroz, Denise Rast, Erin Richmond, Amelia Sanborn, Erika Scamehorn, Jonathan & Robbie Seitz, Rose Seitz, Patricia Simon, Char Smith, Meg Storie, Haley & Samantha Streff, Heather Sutton, Kevin**



offering this important service to our families.

We kicked the retreat off Thursday evening with a Fiesta Night. Families indulged in yummy nachos while announcements and welcomes were being made. The highlight of the night was our strolling magician! We heard he was a little hard to find in the giant crown, but we aren't 100% sure that wasn't a part of his disappearing act! Just kidding, he was truly buried by a crowd around him filled with laughter and amazement at his tricks the entire time he was with our group. We even had a few of our own CCA Siblings show him a trick or two which was fun to witness!

Friday morning started with breakfast, and then the families gathered for Group Meet-Ups, one of our most popular additions to the Retreat in recent years. It's so popular, we extended their time

together during these groups this year. What takes place within these small groups is priceless. Families were able to meet other families with like or similar syndromes/craniofacial conditions as well as others around their same age. It was so wonderful to watch the families circle up and visit with one another in a more intimate setting and to see what icebreaker each group will come up with. We have some creative parents and we thank everyone who helped with these group meet-ups.

After the Group Meet-Ups the families went to enjoy lunch on their own and came back to the ballroom for our Talent Show, or as I like to call it "CCA's Got Talent!" This year there was dancing, taekwondo, singing, gymnastics, instrument playing and more! Our families have some amazing talent and



**Bowling Family, Brittany Brown, Lia Burton, Jerry & Virginia Carchi, Carson Cooper, Stephanie Cooper, Liz Cox, Kelly Cunha, Kristine Dale, Tommy & Cody Dale, Emerald Demor, Rasheera Dopson, Whitney Dunn, Darryl & Deena Dyson, Colleen Fallon, Nate Finch, Stephanie Fray, Michelle Gonzales, Tammie Trude Gonzalez, Aaron Guzzo, Paula Guzzo, Ed & Amy Kern, Jennifer Kilmer, Ben Kjar, Scott & Stana Kjar, Jono Lancaster,**

**Irvine & Karen Tamley, Courtney Vysocky, Tasha Walker, Dorina Watkins, Megan White, Andy & Melanie Yarbrough, Lea Zaengle,** all of our raffle ticket sellers and everyone who brought raffle items/baskets.

For the second year in a row, CCA held "Camp CARE" which is a counseling opportunity that takes place during the retreat. We would like to thank **ConnectMed International, Cashel Gaffey, MSW, and Dana Howorth** for their time



**program dir**, from pg 13



to raffle! These baskets always blow me away! Our families truly go above and beyond and their generosity shows in what they bring yearly! This year our **basket raffle raised \$3400** for CCA!

It is because of the awesome baskets our families bring that we're able to raise these funds, a tradition the staff started with the help of **Rose Seitz** many years ago!

While parents were buying raffle tickets with the hopes of winning one of the fabulous raffle items, the teens were swimming together in the HUGE pool and making new friends and catching up with those they already knew. Teen night wouldn't be possible without our amazing chaperones. Thank you to **Lindsay Condefer**,

**Colleen Fallon**, **Jan Perkins** and **Patricia Simon** for helping out this year!

Saturday morning a group of early risers headed to a super fun and intense Zumba session from CCA Dad, **Jerry Carchi**. I personally



attended his session and was wondering why on Earth I scheduled it for 7:00 AM. Let's just say after we were finished, I understood, because I was wide awake and ready for another fun-filled day! Everyone had a total blast and we can't thank Jerry enough for volunteering his time!

After Zumba, everyone gathered in the ballroom for a group photo! It's quite a task gathering over 600 people for a group photo but with the help of our amazing videographer and photographer, **Trip Owens**, and the direction of **Andy Yarbrough**, we got it done and it's such a powerful photo! Seeing everyone together in one spot is quite impressive. We keep growing as a group, and it gets harder and harder to fit everyone in, so we are so grateful for the organized manner in which everyone cooperated to get it accomplished!

Following the group photo, everyone ate lunch and enjoyed a fun-filled afternoon of swimming, playing volleyball, going

down the slide and lounging. This year's pool was probably the most amazing pool we've ever encountered. It had something for all ages, including a sand beach!

Saturday evening, after an afternoon of some fun in the sun, everyone came together for our most popular event...the Dinner/Dance. Before kicking off the dancing, we showed a video that Trip & Faith Owens had magically put together for us as well as a slideshow from the past 30 years, put together by **Char Smith** and **Jill Patterson**.

The video highlighted some of the events from our Retreat and the slideshow showcased 30 years of CCA's existence and highlighted some of the significant things that have happened over the years. After everyone was finished eating, it was time to boogie! Let's just say the dance floor was packed the entire night. For the third year, CCA has been fortunate to have the amazing **DJ Matt Figueroa** at our Retreat. He knows how to keep the





crowd going and kept the party going all night long!

Sunday morning is always bittersweet and comes way too fast. There were hugs being shared, photos, laughter, tears, social media friend requests being made and a sense of belonging like no other. To top it all off, a local news station, KTVK 3/CBS 5 came to highlight the event for the news program, Arizona Family. Thank you to **Eric Papadeas** for making this visibility possible! Spreading

## Annual Family Retreat & Educational Symposium

which will be taking place in **Austin, TX, June 25th-28th!** Be sure and register before all spots are filled! We hope to see "y'all" there!

And be sure to read about a first-time retreat attendee, **Dana Fernando**, and her family's experience.

**Annie Reeves**  
Program Director



the word about Retreat is one of our favorite ways to share our stories with the world.

Thank you all for coming and for being such a bright spot in my life. I hope each and every one of you had the **TIME OF YOUR LIFE!** Until next year...

Speaking of which, **registration is officially open for CCA's 30th**













# cca retreat: a first-timer's perspective

## what it's like to feel normal: moments of reflection

by Dana Fernando

Ten years ago our Goldenhar son, **Kiran**, made his entrance into this world, and what a ride it has been thus far. We've done our best to navigate the psychosocial and medical journey, which has included eight months of NICU life, 16 surgeries, 60+ hospitalizations, and endless hours of PT, OT, speech and feeding therapies. There has always been a piece of me that felt alone, despite our army of doctors, nurses, therapists, friends, and family to help us along the way. That as much as everyone wanted to, they would never completely understand

what it was like to walk in our shoes. What it's like to emotionally brace yourself every time you leave your house; hoping you have the strength not to get angry, or worse yet, cry when faced with the inevitable stares and comments from strangers. What it's like to see your child endure invasive procedure after procedure to simply live. What it's like... to raise a child with a craniofacial difference.

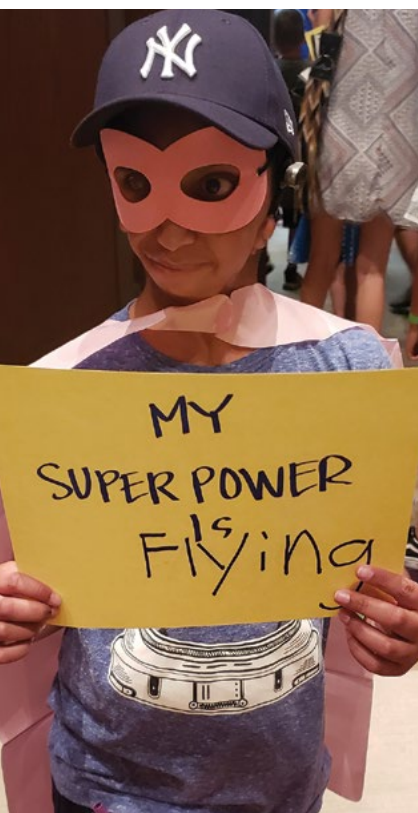
So when **Dina Zuckerberg**, Director of Family Programs at **myFace**, selected our family to be sponsored for this year's CCA Retreat, I was thrilled! Kiran's face lit up when I shared the news that we were going to Arizona to spend time with families like ours. For several weeks, he proudly told anyone he met about our upcoming trip. My husband, **Sharontha**, and I were looking forward to connecting with other experienced families, especially for guidance on how to handle obstacles we faced with Kiran's schooling, nursing care, and feeding therapy. Friends who attended previous retreats shared in our excitement as they

knew firsthand what an impact this weekend would have on our family. The "cherry on top" were the welcome emails we received in the weeks leading up to the event from **Annie Reeves** and **Kristine Dale**.

I don't think anything could have prepared me for the myriad of emotions I felt on day one, and perhaps that's why I spent the entire time teary-eyed and in awe of everything around me. Approximately 600 people were in attendance; the largest retreat yet, and we were one of forty-four new families. For the first time since Kiran was born, we were able to blend into a crowd and that feeling of peace was truly indescribable. Sharontha and I were able to veer away from our usual "heightened alert mode," and allowed our kids the unprecedented freedom to wander a bit as we relaxed in our safe environment. Veteran CCA families went out of their way to make us feel comfortable, and forewarned us that each day at the retreat gets better than the next, and that we would be leaving here as family.



Dropping Kiran and his seven-year old brother, **Caleb**, off at daycare was surprisingly harder than I expected. Both kids expressed how nervous they were, and it dawned on me at that moment how overwhelming this experience was from their perspective. Kiran was concerned that everyone would stare at him, and I almost chuckled while reassuring him that this was probably the only place he would not have to worry about that. Caleb, our self-proclaimed "shy" child, continued to glance around the hallway noticing the different faces around him. I reminded him that it is ok to ask questions (and to be kind while doing so), and that each of the kids in that room were just like Kiran and him. With some hugs







and kisses, they were off to play, and we anxiously made our way to the symposium sessions.

I had been looking forward to the Symposium from the time I received the agenda, and it did not disappoint. As we strolled around the vendor tables, and listened to the morning presentations, I was inspired by the research, technology, and devices that are advancing the way we medically treat our children. **Jono Lancaster's** keynote speech was equally moving, as he bravely shared his challenges this past year and how he

continues to forge ahead. It gave comfort knowing that Kiran has role models to turn to when life gets tough, and that he will have peers to guide him in a way that we as parents cannot.

My emotions reached a crescendo during the afternoon sessions. It was nearly impossible to hold back tears while listening to the siblings discuss what they loved most about their craniofacial sibling, and what they liked least about their situations. It was a good insight into what my own son could be thinking and feeling, though

these words haven't been expressed yet. I know this life will bring Caleb unique challenges, and it was eye opening to hear "from the mouth of babes" what it is really like for them.

As if I wasn't teary enough from that session, then came the parent panel. That one hour sitting next to Sharontha, with his arm around me while tears streamed down my face as I listened to others talk, was truly cathartic. I usually reserve those vulnerable moments when we are alone at home, but I felt unabashed knowing I was with people who just "get it." I was able to ask a question that has been on my mind for years, given the statistics of divorces amongst families with special needs kids: "How do you keep your marriages strong in light of all the challenges we face? I know we've been to Hell and back, so how do you do it?" Apparently, that was a loaded question as many of the panel and audience

members chuckled, and let out a heavy sigh. It was comforting having other couples share their experiences, provide guidance on various topics, and reassure those of us self-doubting that we are not alone on how we cope with our situations.

I wasn't sure what to expect next, but it was true—each day got better than the last. By day two, we found our comfort zone, and by day three, we were in the groove. We started running into more familiar faces, and getting to know different families simply because our kids were playing together. The boys were more at ease with their surroundings, and eagerly sought out the friends they made so far. There were so many fun activities to keep us entertained, and to create more bonding opportunities: group meet-ups (by age and by syndrome), talent show, raffle, Zumba, group photo, pool party, and the

see **first-timer**, pg 20







**first-timer**, from pg 19

final dinner dance, which sent us all home with a bang.

Time sure does fly when you're having fun, and Sunday arrived before we were prepared to go home. It was hard to say goodbye, so we shouted

"See you in Austin!" to lessen the sadness we felt; the planning for 2020 CCA retreat was underway in our minds. As we made our way back to NJ, I replayed the events of the last three days in my head, and I couldn't help but smile at the amazing time we all had. In that moment, a wave of grief hit as well, knowing that we were on our way back to reality, and life would not be as carefree. But at least we had those three outstanding days where we could feel like a typical family: no stares, no comments, no drama.

Retreat. The memories of Kiran being surrounded by faces as beautiful as his, Caleb finding instant friendship with an adorable boy (who just happened to have Treacher Collins), Sharontha connecting with other fathers will be permanently imprinted in my heart. We are sincerely and whole heartedly grateful to myFace and CCA for this unique and

priceless experience. We look forward to next year's retreat where we can once again just stop... and breathe... and feel normal.



It's been a week since we returned home, and I'm finally able to fully process the thoughts and feelings that overwhelmed me during our first CCA





# a legacy of love: jill patterson



Not only is a Jill a tireless advocate, still advocating with CCA, she is also a devoted mother to her own CCA Kid, **Rob**, who is featured in this newsletter as well (see page 4), and his SuperSib, **Erick**. She also met her husband **Greg**, through CCA.

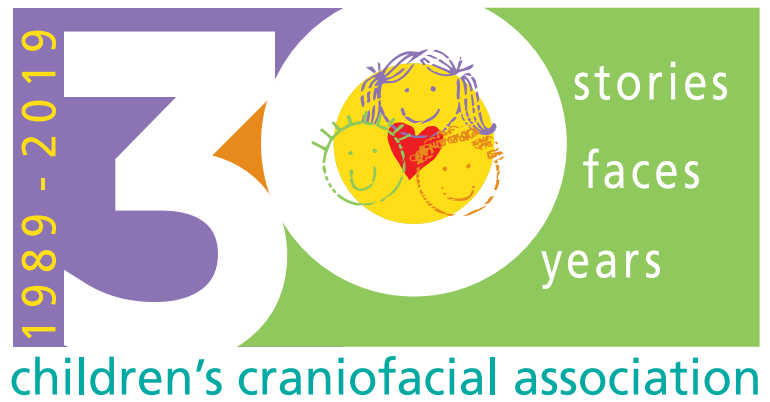
Together, they have all been a part of volunteering and fundraising for CCA for decades.

**Jana Peace**, longtime CCA supporter and former Program Director, says, “Jill taught me a mother’s love for her child. She worked as our Development Director at CCA, but her first—and most important—role was mother to Rob, who had his own craniofacial anomalies, that gave Jill compassion for helping families raise money for hospital stays. She was a fierce momma bear! I don’t think her work is what shaped her character; I think it was her motherly instinct. She was vulnerable, she was scared, but she gave 100% in advocating for her son and I think that’s why she connected with the families. She walked in their shoes.”

In celebration of our thirtieth year, we wanted to take a special moment to recognize and celebrate one of CCA’s first families, and most dedicated supporters, **Jill Patterson**.

Jill was with CCA from the earliest days, most notably travelling to Washington, DC and meeting with Congress in 1990. There, along with 9 other families, they spoke to Congress about the importance of craniofacial surgery and how it impacts our children’s abilities to survive and thrive, living with craniofacial syndromes and conditions.

From that moment, Jill’s mission in life was to advance the cause. Her heart beats to widen the circle of acceptance and create a world where everyone is accepted for who they are, not how they look.



**Bill Mecklenburg**, CCA Board Member, and one of our most loyal fundraisers, was introduced to CCA via Jill. He says, “When we were informed that our daughter was born with a craniofacial condition, we found CCA. Jill answered the phone, and it felt like God had placed an angel on the other end of the line to bring us comfort and hope. When we started attending Retreats, we quickly realized how many lives a true angel can touch, with every one of us feeling a connection to Jill that is beyond words.

As the development director, Jill taught us to dream and dream big

when she brought us to **Jorge Posada’s Heroes for Hope** gala. That event was the catalyst for catapulting CCA into the major fundraising category that now enables our organization to serve CCA kids and their families in ways we could only dream of less than 10 years ago.”

Like Bill, **George Dale**, board chair and devoted CCA supporter and father, echoes just how integral Jill has been to the CCA family. George says, “Jill is my first memory of CCA. When we walked into the registration area at our first Family Retreat in Washington, D.C. in 2002, she knew us all by name





jill, from pg 21



even powerless. However, for many CCA families, hosting or participating in these fundraising events can bring comfort and healing, as well as a sense of community. The connections she fostered with other families and volunteers in the wider local and regional area created a team of support, even as they were supporting CCA directly.

**Charlene Smith, Executive Director Emeritus**, explained the amazing work Jill accomplished for CCA Kids. She says,

“I met Jill (and Rob) 30 years ago at the hotel registration desk in Washington, D.C. when CCA representatives were testifying before the House Budget Committee. What I didn’t know at the time, was that meeting would forge a 30-year relationship between us as friends and colleagues.

Having Jill in the CCA office was like having a living memory bank! I cannot count the number of times I yelled to the next



office, “Hey, Jill, when did we do this?’ or ‘Which retreat was that?’ or ‘How much did we raise at this event?’

If she didn’t have the answer in her head, it was in archived CCA materials that she’d managed to save through the years, and was able to put her fingers on in no time!

Besides initiating the opportunity to join in the **Jorge Posada** fundraiser in New York, Jill was able to take the Family Fundraiser concept **Darin and Dede Dankelson** started by holding a golf tournament, and cultivate the concept into one of CCA’s top fundraising initiatives that



lives on today.

And, when **Rose Seitz** came to her with the idea of a basket raffle at the Retreat, Jill turned it into a ‘hometown basket’ fundraiser that remains a highlight of the Retreat.

And, did I mention she was an expert at rhyme and alliteration in naming funders?



In the 30 years that have passed since that first meeting in Washington, D.C., we’ve had many long phone conversations, many laughs and some tears, many ‘time of our lives’ Retreat moments, many long nights selling raffle tickets in Sturgis, many long, productive, fun and, at times, stressful days at the CCA office... many moments that will keep us connected for many years to come.”

**Dan Paulson**, another of the “original CCA Families,” says, “Back in the day, I recall Jill with goals to be met and hard-charging to attain them. Jill continues to be a great ambassador for CCA, a wonderful person, and one who is probably unaware of how she quietly made an immense impact on many people.” We love that sentiment so much, because so many people have benefitted from Jill’s passion and love for our community.

Working with Jill is a true pleasure. Jill always brought a fun, playfulness to the office. She used her talents and creativity to





invent beautiful and fun ways to display raffle items, recognize volunteers, and showcase extraordinary efforts. Jill and Greg's home was full of donated, or rescued-from-the-dumpster items that might serve a purpose for CCA "someday." She never turned down free furniture or office supplies! She curated T-shirts from all 30 years for CCA, and recently helped us organize those shirts for a special project we'll debut at upcoming Retreats.



Indeed, it was not just Jill who was committed to CCA, but also Greg, as expressed by CCA Mom, former board member, and ardent supporter, **Paula**

**Guzzo**, who says, "We met Jill and her sons at our first CCA retreat 25 years ago. She has been a constant in our family's life as a CCA parent, CCA staffer, and friend. Whether she was working as a paid staffer or volunteering her time unpaid, Jill's commitment to CCA is stellar. CCA got a bonus with Jill's employment, as her husband, Greg, volunteered untold time, and donated generously to CCA by taking pictures at Retreats, doing whatever was needed at golf tournament fundraisers, attending CCA-related events throughout the nation, and driving CCA merchandise/materials cross country to Retreats and conferences. Jill, thank you and your family for more than I can write in these few sentences."

Friend and fellow advocate, **Diana Sweeney**, parent liaison

**in the Division of Plastic Surgery at The Children's Hospital of Philadelphia** says, "Jill and I have spent many hours supporting all children with



facial differences, sharing stories and lives. We have 'grown up together' in the craniofacial world, and worked hard to change the way the world perceives kids with facial differences.

My friend, Jill, is a front-line warrior in the fight for awareness!"

Jill worked long hours and never thought about "overtime" or "comp time," because truly her life was CCA-centered. Her dedication to this organization is unparalleled, and will be her lasting legacy.

Now that she has retired, she still contributes so much via volunteering on projects at the office, and staying active in the CCA family. Her sense of humor and style is her signature, and she always comes dressed to impress at CCA events.

Transitioning into a new stage of life is not always easy, but Jill has filled her time with travel and family, which most of us aspire

to do when we retire! Through it all, Jill has been an unwavering loyal friend to us all, and put aside the ebbs and flows of fundraising and community organizing to be a pillar for the craniofacial community.

**Thank you, Jill, Greg, Rob, and Erick!**





# RESTORING HOPE & HAPPINESS



CHARLOTTE, NC. L-R : Lindsey Griffin, Stephanie Shumaker, Anna Harris, Mandi Massey, Jamie Lovingood, Bethany Brady



WINSTON-SALEM, NC. Clockwise from top left : Doug Leclair, Mike McDonald, Geof Tibbs, Sarah Eaves

## FUNDRAISING EVENTS BENEFITING CHILDREN'S CRANIOFACIAL ASSOCIATION'S



Last month, we partnered up with Children's Craniofacial Association (CCA) to raise money at City Barbeque Place (Charlotte, NC) and Incendiary Brewery (Winston Salem, NC) - a project spearheaded by our interns, Anna Harris and Sarah Eaves. We used this opportunity to invite our current referral sources, targeted referral sources, existing patients, and community members to get to know Restore OPC and to talk more about how we treat patients.

**We are proud to be from a compassionate organization that pulled together to make both such successful events!**

*Events like this are a great way to remind people that we are patient-focused in our efforts. I am excited about the new relationships we were able to form, and look forward to continuing to reap the benefits of this event moving forward.*

*- Logan Kelley, Area Sales Manager*



donors in the spotlight

# choose kind

**C**onley Smith and Bethany Dougan from Bonham, Texas donated **\$146.13** after hosting a pop-up fundraiser for CCA in honor of **Brisa Dougan**. These budding entrepreneurs sold hot chocolate and cookies to guests at the Dougan's local boutique during a rare, chilly, spring day in Texas.

The funds raised will go to CCA Kids in need of travel assistance to access quality medical care, distribution of

educational curriculum, and social support and networking. Thank you Conley, Bethany, and Brisa for donating to CCA Kids. You were a breath of fresh air during a hot day at the office in June. We enjoyed talking to you about your softball tournaments and our #ChooseKind library.

Keep up your fundraising ways, so you can keep changing the world!



L-R: Kara Jackman, Marketing and Communications Coordinator; Brisa Dougan; Conley Smith; Bethany Dougan; Erica Mossholder, CCA Executive Director; and Khadija Moten, Outreach Director



tyler, from page 1



2007, we got the call that we had been chosen for that special little boy to be born in August. We were thrilled!! We met with the birth family and even attended an ultrasound to confirm the cleft lip and palate diagnosis. The specialist couldn't really tell, but we still went ahead and researched doctors for the possible future surgeries. We feel really lucky that we live close to **Primary Children's Hospital in Salt Lake City**, and decided on **Dr. Louis Morales**. We met with him before Tyler was born so we would have an idea of what we would need to do. Tyler was due August 12th, 2007, but his birthmother was being induced on August 3rd. I'll never forget the call that I got at about 5:30 PM that day from his birth grandmother, telling me that our son was born. He

did have a unilateral cleft lip, but not a cleft palate. We were so excited!! He was born on a Friday, we got to see him for the first time on Sunday, and then on Monday we took him home from the hospital. The pediatrician there told us that we would want to take him to our doctor soon because of 3 abnormalities: the cleft lip, his second and third toes on each foot were webbed and he had prominent eyes. My brother is a doctor and came to see us that night. When I asked him about what it could mean, he didn't know (he's an anesthesiologist) but said that when there are 3 things wrong, it could be a syndrome. He suggested that I google "cleft lip, webbed toes and proptosis." Well, that wasn't a good idea because a lot of scary things came up and I felt even more overwhelmed. I did think he probably had Pfeiffer or Jackson-Weiss syndrome. That first month was filled with lots of doctor visits. Tyler was little (5 lbs. 11 oz. when he left the hospital), and wasn't really gaining weight; he just ate enough to maintain his weight. I had to put him on a higher calorie formula and have him weighed



a couple times a week for a few weeks until he finally started gaining what he should. His pediatrician gave us recommendations for an ophthalmologist, an ENT doctor and a geneticist. We had already chosen our plastic surgeon, and it turned out that he was a talented and well-known craniofacial surgeon. We felt really blessed that we had already connected with him. We saw the geneticist

at **Primary Children's Hospital** and Tyler had his blood drawn to be tested at **Johns Hopkins Hospital**. The results were a random mutation of the FGFR2 gene, Pfeiffer syndrome. As is common with these syndromes, Tyler also had craniosynostosis, but only 1 suture was fused, and only half way.

When Tyler was 2 months old he had his first surgery, the cleft lip repair.





At 6 months he had his craniosynostosis surgery, and at 1 year he had a brow advancement. He was actually in the hospital on his first birthday, so we celebrated a few days early. Tyler had his first eye muscle surgery at 2. He wasn't born with a cleft palate, but his palate was very high and narrow. His plastic surgeon lowered it to give his nasal passages more room and help with future surgeries.

When Tyler was 4 his ophthalmologist noticed that his optic nerve was swollen. He had a CT scan and it was discovered that his skull hadn't grown, causing pressure on the nerve, which could cause blindness. Another surgery was soon scheduled to expand his skull. This one was hard because his head and eyes became so swollen!

One thing I learned is that Tyler recovers so much better at home. I pushed really hard to get him released from the hospital as soon as possible.

Even with all of this going on, Tyler was a happy and loving little boy. He wasn't shy, and liked to sing for people. My husband, **Rich**, takes the boys to a local donut place on Saturdays. One week when Tyler was 3 he stood on the table and announced, "Ladies and gentlemen, boys and girls, it's time for the Tyler

show!" He then sang the latest song he learned at preschool with actions.

In January 2014, it came time for his biggest surgery to date: the Lefort III. It was scheduled even though our insurance had denied coverage. The reasons they gave were that Tyler hadn't been on the plan since birth, the surgery was "reconstructive" and not life-threatening. They covered his skull expansion surgery about 18 months



earlier because it was an "emergency" and he could have lost his eyesight, but told us that maybe they shouldn't have. We appealed the decision, and our doctor wrote a letter, but we then received a final denial. Tyler got croup and the surgery had to be rescheduled for May. I

continued working on the insurance, trying to get him another plan, and called about CHIP. The woman there suggested I call the state office of insurance, which I did. They were very helpful, thought the reason for denial was suspect, and suggested I file a formal complaint with their office, and so I did. About a month later I got a letter from our insurance company stating that the surgery was approved. We were so relieved! Tyler got croup again in May, so the surgery was rescheduled for September. Well, he got croup AGAIN about a week before the surgery. The nurse said it would have to be rescheduled for 4 months later (lots of doctors to coordinate), and I told her he seems to get croup every 4 months, so we should try to reschedule for 6 weeks from now. She didn't think that would be possible, but called back a few hours later, and it was rescheduled for October.

This time, Tyler was healthy and ready. He did great! After the long surgery, he was even able to give us a thumbs-up. We were at the hospital for about a week, and then he stayed home from school for 2 months. His teacher would come over on Fridays and bring some work for him to do. He was self-conscious, and didn't

really like to go out, but we did have friends over. He ate lots of applesauce, mashed potatoes, yogurt and other soft foods. Halloween was during this time, and he was so sad that he



couldn't eat his candy. We got a little creative and would put things in the blender: a turkey sandwich, pizza, and even his favorite, a Kit Kat bar. I couldn't believe the dramatic change in Tyler's face! Tyler has had 12 surgeries so far, which isn't as much as many cranio kids. His Pfeiffer syndrome is considered "mild," but he's still one of the toughest kids I know! Next up for him is braces, and then probably a jaw surgery when he's about 17 or 18.

Tyler has been playing baseball every year since he was 4, takes Taekwondo, enjoys playing X-box

see **tyler**, page 28



**tyler**, from page 27 and basketball, watching YouTube videos, hanging out with friends, and will still sing on occasion. He pretty much does what any 11 year old would do, except his dad won't let him go to a trampoline park or play tackle football.

We've been to a few local CCA picnics, fundraisers, and gotten the CCA Network for several years, but had not been to a retreat until it came to us here in Utah. It was amazing! We met so many great people and made many new friends, including another **Tyler** with Pfeiffer syndrome, right here in Utah! We also attended the Retreat this year in Arizona, and hope to now go every year!



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[smile.amazon.com/ch/75-2265649](https://smile.amazon.com/ch/75-2265649)



# calendar of events

## date event contact

### 2019

Aug 10	<b>2nd Annual Spreading the Love for CCA; it's the Brooklyn Way</b> Livonia, MI	Angela Wojtyniak <a href="mailto:angwojtyniak@gmail.com">angwojtyniak@gmail.com</a>
September	<b>15th Annual Craniofacial Acceptance Month (CAM)</b> Nationwide	<a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a> 214.570.9099 800.535.3643
Sep 7 8 AM-Noon: Noon-2 PM:	<b>Colorado Picnic and Walk-A-Thon</b> Hours for the Walk-A-Thon Hours for the Picnic 8201 Colorado Blvd., Frederick, CO 80504	Erika Scamehorn <a href="mailto:e.scamette@gmail.com">e.scamette@gmail.com</a>
Sep 7 10:30A-3:30P	<b>Christmas in September at Santa's Hideaway Hollow</b> 15400 Bundysburg Rd., Middlefield, OH 44062 Bring your family and come visit Santa's Elves, Reindeer and the Village of Shops! We will have a cookout lunch and some Christmas music! You can even sing along! There will be volunteers to direct parking options. Golf carts will be available to transport you from the parking area to The Hollow and are available throughout your visit to help you get around. Our trolley is wheelchair accessible and will be available to transport as well. Please RSVP to Elf Valerie, <a href="mailto:valhurstoh@gmail.com">valhurstoh@gmail.com</a>	
Sep 8 Noon-4 PM	<b>Southern California CAM Annual Picnic</b> 4986 San Jacinto Circle E., Fallbrook, CA 92028 RSVP by 9/1 to Dorina Watkins, <a href="mailto:watkinsfamily1996@gmail.com">watkinsfamily1996@gmail.com</a>	
Sep 12 5-8 PM	<b>Links of Love at TopGolf Dallas</b> 8787 Park Ln, Dallas, TX 75231 CCA Links of Love Player: \$75 Includes: 3 hours of play time , Dinner, 1 Raffle ticket Friends of CCA & Kids 6+: \$30; Kids 5 and under are FREE Includes: Dinner, Putt Putt for kids Kid's 6 and under: Free	Christine Andler <a href="mailto:christine.ccakids@gmail.com">christine.ccakids@gmail.com</a>
Sep 14 11 AM-1 PM	<b>Texas Craniofacial Picnic</b> Mary Heads Carter Park 2320 Heads Ln., Carrollton, TX 75006 Spring Creek BBQ will be providing a FREE lunch for everyone from 11:15am-12:15pm. Entertainment will also be provided.	Annie Reeves <a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a>
Sep 14 1-4 PM	<b>Michigan Craniofacial Picnic</b> Bicentennial Park 35400 7 Mile Rd., Livonia, MI 48152 (Ben Celani Pavilion which is off of 7 Mile east of the Main Park Entrance. Do not enter at Main Park Entrance.)	Kellie Dowd <a href="mailto:kdowd22@gmail.com">kdowd22@gmail.com</a>
Sep 14 2 PM	<b>Pittsburgh's 3rd Annual CCA Picnic</b> 465 Scott Ridge Rd. Harmony, PA 16037	Lisa Bowers <a href="mailto:bowerszoe@zoominternet.net">bowerszoe@zoominternet.net</a>
Sep 14 5-8 pm	<b>Utah Cleft and Craniofacial Awareness Picnic</b> Murray City Park, Pavilion #3 495 E. 5300 S. Murray City, UT 84107 Come enjoy food, friends, crafts, and games. Family introductions and a group photo will be done at 6:30pm. Sandwiches, drinks, fruit, and veggies will be served. Please bring chips or dessert to share. Please RSVP by September 7th to.	Heather Sutton <a href="mailto:heatherjsutton@msn.com">heatherjsutton@msn.com</a>
Oct 5 11 AM	<b>Illinois Craniofacial Picnic</b> Starved Rock State Park 2668 E. 875th Rd., Oglesby, IL Please bring a dish to share and your own drinks.	Amber Harrold <a href="mailto:isabellajune12.ijh@gmail.com">isabellajune12.ijh@gmail.com</a>
<b>2020</b>		
Jun 25-28	<b>30th Annual Family Retreat</b>	<a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a> 214.570.9099 800.535.3643

# RELAUNCH



SINCE 2018

## SPEAKERS' BUREAU

CHILDREN'S CRANIOFACIAL ASSOCIATION

The Speakers' Bureau originally launched in 2018 due to an influx in requests from schools and organizations to hear the stories and experiences of our CCA kids and adults. We wanted to create a Bureau to maintain a cadre of qualified representatives who can not only share their story but also represent CCA in a public setting. Our speakers are ambassadors for our craniofacial community, therefore we wanted to provide access to professional training and high quality resources for all of our speakers.

**Since the inception we have gained 12 members and of those 4 are also certified members! We are now officially relaunching this Fall and accepting additional applicants.**

If you were unable to complete the process the first time around we hope you will be pleased to find the process has since changed to be more accommodating to individual schedules and needs.

For more information and to view our current members visit our website at [ccakids.org](http://ccakids.org).

**We will be accepting 12 Speakers' Bureau applicants for this year starting August 1st.**

**For questions or concerns please contact our Outreach Director, Khadija, at: [kmoten@ccakids.com](mailto:kmoten@ccakids.com)**





# testimonial

On August 13, 2018, our beautiful twin daughters, **Lilly and Ellie**, were born very unexpectedly at 25 weeks. They spent a total of ninety-three days in the NICU at **Morristown Medical Center** in New Jersey. While in the NICU, Ellie was diagnosed with bicoronal craniosynostosis, and it was recommended that we take her to **Boston Children's Hospital**.



During this visit to BCH, we also met with a geneticist who diagnosed her with **Muenke syndrome**.

This appointment was scheduled just three days before Christmas, and we certainly had not planned for these unforeseen travel expenses. As one can

imagine, this was a very scary and overwhelming time for us. In addition to the constant concern for our daughters' health, there was looming concern for our financial stability. We had always worked very hard, and were conscientious, but now found ourselves faced with unpaid leave from work, mounting medical/travel expenses, and new expenses from the home we had just purchased one month prior to the girls'

birth. Lilly and Ellie also have a four-year-old big brother for whom we were trying to maintain some normalcy in the complete chaos that was our new normal.

Right after New Year's Day, we received word that Ellie's surgery would be scheduled for February 4, 2019. We began to make arrangements for our travel, and while doing this, I came across CCA's website. After much browsing, we saw that there was an application for financial assistance.



This seemed like a dream, as our life was feeling so out of control and upside down.

When we received word back that we would be granted assistance for travel to Boston from New Jersey, we felt a weight was lifted from our shoulders. This assistance undoubtedly eased the financial burden of spending a week in Boston with infant twins. Furthermore, it allowed us to focus on Ellie and her needs, instead of worrying about what the trip's expenses were going to be, and how to pay for it. This peace of mind was priceless. Ellie came through her surgery beautifully and gets to wear a cute little helmet to mold her head to the

proper shape for the next six-to-nine months. Then she will be followed by her amazing surgeon for the next five years and additional specialists as needed. Thank you, **Annie and CCA**, for giving us the gift of being present with Ellie when she needed us most, and for all you have done for our family.

– **The DeCataldo Family**





# 3 cheers

for volunteers!



**J**asmine Amini is a CCA behind-the-scenes hero. If you received a care package, ordered #ChooseKind merchandise, or requested curriculum packets in the last five years, there is a good chance that Jasmine fulfilled your order. She became interested in CCA as many have, through close friends and word of mouth.

Jasmine went on to read *Wonder*, and asked if she could volunteer in the CCA office. She loves the culture at CCA headquarters. She says, "it's a friendly environment full of people that are on a mission to make a difference." Jasmine enjoyed the work, too, "It was fun assembling curriculum packets and helping organize things in the office."

She began volunteering for CCA in 2014 while still in middle school. She

gave back while juggling school, extracurriculars, and the rigors of being a teenager. She is an avid ice skater that gets up in the wee hours of the morning to practice before heading to school. Her drive to do her best in all things, paired with her desire to give back, will take her far as she graduates Plano West Senior High School in May 2020.

She says of her work with CCA, "Many people in our society don't realize the resources needed and seriousness of craniofacial conditions. I wanted to give my aid in any way possible to be a part of an organization that is so caring and supportive of others."

In the Fall of 2020, she hopes to attend college. We feel she has a very bright future ahead of her. Thank you, Jasmine for all your help!



Chloe Andler, CCA's Jr. Development Assistant

## lilly pulitzer

**O**n Saturday, June 1st, CCA held a shopping day at **Lilly Pulitzer** in Dallas, Texas. We have partnered with Lilly Pulitzer for their **Shop and Share** events since 2017. The team at the Dallas store is always so kind and welcoming to our organization. Thank you, Lilly Pulitzer team of NorthPark Center, for hosting such a great fundraiser for CCA!

In all, the event generated **\$625** to CCA! **Lookout for our winter shopping day in December—just in time for those holiday gifts!**



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