

# ccanetwork



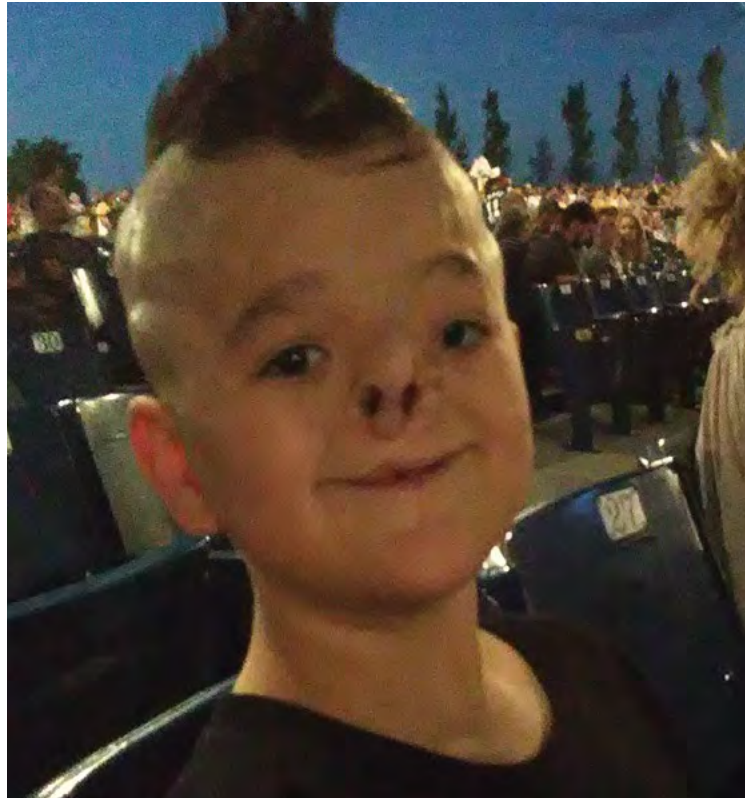
newsletter of the children's craniofacial association

Cher—national spokesperson

2018: Issue 3

## inside

- cca kid  
kent wu . . . . . 2
- cca supersib  
eva wu . . . . . 3
- cca adult  
ben kjar . . . . . 4
- links of love . . . . . 6
- pj's curb your  
enthusiasm donation . . . 7
- donors in the spotlight . . 8
- maigan's motivation . . . . 9
- craniofacial acceptance  
month . . . . . 10
- jonathan seibert  
spreads kindness. . . . . 16
- motorcycle raffle. . . . . 17
- hazen, ND *wonder*  
event . . . . . 18
- birthday club breaks  
records! . . . . . 23
- dfw family night . . . . . 24
- coto for the cure  
tennis pro-am . . . . . 26
- testimonial . . . . . 30
- calendar of events. . . . . 30
- 3 cheers for volunteers. . 31
- 30 stories, 30 faces,  
30 years . . . . . 32



## message from the board chair

**t**hirty years. It is an amazing amount of time for a charitable organization to be serving its community. It is an amount of time that requires effort, excellence, a dedicated staff that is committed to the mission, strong support from volunteers and donors, and a community that finds exceptional value in the services an organization offers.

In 2019, Children's Craniofacial Association will enter its 30th year. Sprouting its roots in 1989, thanks to a small, dedicated group who recognized

see **board chair**, page 8

## the road less traveled

By Danielle Barajas

**t**his year was the first time we attended the annual CCA retreat. This letter is more personal now that we have met so many of you and heard your personal journeys. The warm welcome and unconditional love was just what we needed. Thank you all for how you accepted us.

This year **Conrad** will have his 19th surgery toward his facial reconstruction. We have anticipated this surgery for a couple years, and with so many of you supporting Conrad and encouraging him, he is braver and more confident than he was just a few months ago.

Conrad's cleft lip and palate was a complete surprise. The ultrasound technician made some big errors and did not see any differences. I mention this, because since the doctors were not expecting this, they were not prepared for their reactions or their care plans, and I'm sorry to say

see **conrad**, page 20





# CCAkid



## meet kent wu



In this issue of our newsletter, we'd like you to meet CCA Kid, **Kent Wu**, a busy fifth grader who's into reading, playing video games, and gardening. With his love of books, his favorite class is—you guessed it—reading. His least favorite is music, which is interesting, because he has been playing the cello for the last five years.

After school, when he's not involved with swimming, he can be seen with a book, or playing his favorite video games, "Overwatch" and "Jurassic World Evolution." Kent watches TV, and doesn't have a particular show that he likes, but ask him about

his favorite movie, and he's quick to answer with "*Wonder*."

Kent has been to two CCA Retreats, and has had an awesome time at both. Hopefully, we'll see him at next year's annual retreat in Scottsdale, Arizona.

Over the years, Kent has had about 30 operations as well as an ear reconstruction—a lot for one kid to go through. Yet, throughout it all, he has maintained a positive attitude, and remained optimistic. He tells other CCA Kids these words of wisdom: "Don't be afraid. Don't give up. And don't ever worry about what others think."



# ccasupersib

## meet eva wu

**m**y name is **Eva Wu**, and I am a sophomore at Lubbock High. I enjoy playing the violin, reading the news, playing in my school orchestra, and hanging out with my friends and family in my spare time. My favorite subjects in school are English and history. I also enjoy keeping up and discussing current events. My favorite books include the *Harry Potter* series and *Divergent*.

My brother Kent is one of the strongest people I've met; he never lets his condition stop him from

achieving his goals. Kent is an outgoing, funny, talented and nice person. He also has so much compassion for everyone. One of my favorite things to do with Kent, is playing chess and the Chinese board game "Go" with him. Kent also plays the cello, and I enjoy doing duets with him.

Last summer, my family attended the CCA Retreat in Utah. Kent and I had so much fun at the Retreat. We both enjoyed meeting the kids there, and listening to the talks.





## meet ben kjar

By LaCol Kjar

tonight I am falling asleep, like thousands of others, hearing the words of **Ben Kjar** run through my mind, tears wetting my pillow as I hold him tight. I saw flashes of smiles and tears of thousands of kids that heard him speak the last few days.

A middle school boy said to Ben, “I can relate well to the bully stories you talked about. I am blind in one eye and I get bullied because of it.”

Another girl said, “That girl you pulled out of the crowd today—I am so glad you chose her from everyone! She is going through a really hard time at school right now, some serious things. She loved getting up there.”

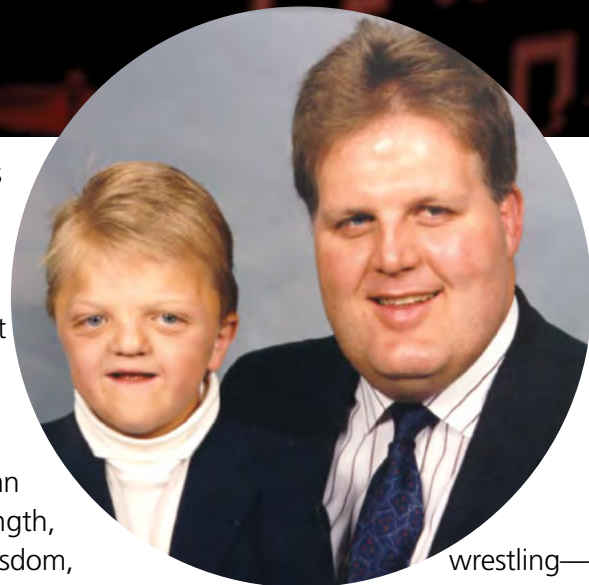
Then there were the two boys in the bathroom who pointed and laughed when my husband walked out (for looking different), minutes before he stood up in front of the school to talk about bullying. (Yes, he did see them in the crowd with their heads hanging—two good boys who know better.)

My name is **LaCol**, and I am the fortunate wife of Ben Kjar. (I hope you don’t mind, I took over Ben’s assignment, as he was having a hard time writing about himself. He’ll probably never make that mistake again!)

Ben was born with Crouzon syndrome, the only one in his family “blessed” with it. I cannot speak

much for his childhood, as I was not present for any of it, but I do know that I thank God every day for a man of such strength, kindness, wisdom, humor, and patience. Above all, I thank God for Crouzon syndrome. I know most of his qualities stem from that, including his attractive face!

Ben had three major surgeries related to Crouzon (along with a few other minor ones) at ages 1, 5, and 20. He chose to put off that last surgery a handful of years, because he chose to follow his passion of contact sports, particularly



wrestling—even though doctors told him he would never do contact sports. He was not going to let that surgery interfere with his love for sports, although he knew he would be more easily marked as “different” during his teenage years.

I hear many stories about him growing up, how hard it was at times dealing with bullies, and how his parents were his anchors. They are



a big part of why Ben has a “Victor Mentality” in life, then and now. His father, **Scott** is Ben’s best friend, idol in business and life. He describes his mother **Stana** as a “Fairy Godmother.” They made it a point to never treat him differently from his six other siblings growing up, and allowed him to chase his passions and what he excelled at to help build confidence. Ben always advises parents to follow that same style.

After Ben’s last major surgery, he served a two-year service mission for our church after he graduated high school, where he was able to serve and teach the gospel to the Latino community. Ben learned how to speak Spanish fluently and has a great love for the people. His faith is his foundation, and it will always continue to be central in his life.

Ben and I first met as college athletes and went

to a luau on our first date. I told my roommate that night, “I think I’m in love!” The rest is history! We have been more than happily married since January 2009.

Ben continued to wrestle at Utah Valley University after we were married, where he became UVU’s first NCAA Division 1 All-American wrestler. He graduated with his bachelor’s degree in business management, with an emphasis in entrepreneurship. He then traveled around the world competing in the Olympic Sport of freestyle wrestling and placed fourth at the 2012 Olympic Trials. His “fun” goal is to shatter the Guinness Book of World Records for most knuckle pushups and regular straight pullups in under a minute. (Yup, this guy LIVES BIG!)

Together, we love staying active, playing basketball, softball, racquetball, and



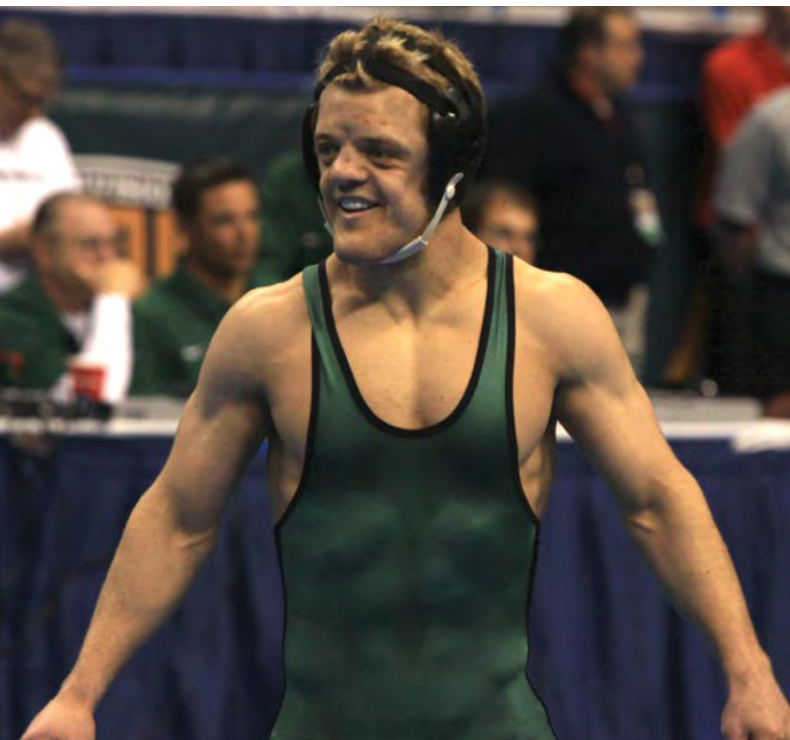
soccer, as well as roller blading, ice skating, running and hiking. We live by the quote **“Travel: The only thing you buy that makes you richer!”** Together we have explored the unique cultures of 30 countries!

Ben has been blessed to really love his career. He is the founder of a real estate group which invests in all levels of real estate assets and education. On the side, he is an inspirational speaker for youth and adults. He’s a thought leader in assisting people to live their potential, stand up and stand out, victor over victim mindset, and becoming a champion in life. His audience has ranged anywhere from one to 10,000 people. Ben is currently part of an anti-bullying coalition, where he

is able to speak to hundreds of schools and share his story.

Lastly, a quote from Ben: **“As you choose [to be a] victor, as you step outside yourself, that’s when you start living. That’s when you’re not the victim of difference, but you’re the Victor of making a difference.”**

To everyone within the sound of my voice, let it be known that I, LaCol Kjar, LOVE being married to a man with a craniofacial difference!





# 11th annual links of love golf tournament

The 11th Annual Links of Love Golf Tournament came in under par and over expectations this year, thanks to the hard work of our new staff member, **Christine Andler, Director of Development**. With her work to organize an exciting raffle, and the true kindness of our loyal golfers and new friends, we raised **over \$14,000** for CCA Kids! We held the event at **Firewheel Golf Park** in Garland, TX, and it was a lovely day celebrating acceptance and awareness.

This year, the players were greeted with an array of overflowing raffle baskets to bid on, including a Yeti® cooler stuffed with goodies, men's and women's Armani watches worth over \$1,000 each, and the hotly coveted Whataburger-for-a-Year basket. Players grabbed their box lunches while being fitted for golf gloves sponsored by **Credit Union of Texas**. The players then loaded into their carts, and rode off for a fun round, with challenging contests along the way. On the course, players enjoyed **Real Ale** brews, thanks to **Ben E. Keith Beverages**. On one of the holes, CCA Staffer **Annie Reeves** and longtime volunteer, **Jana Peace**, took photos and served as unofficial cart girls with refreshments.

Back at the clubhouse, staffers **Khadija Moten**

and **Erica Mossholder**, helped reset after the morning's registration for the post-tournament activities at the Firewheel Pavilion. That's when our special guests, **Brittany Brown** and her sweet children, **Allison** and **Michael**, arrived. They were slated to be the morning's kickoff speakers, but they got stuck at a four-hour doctor's appointment for Michael, 2, who has Treacher Collins syndrome. All the CCA parents out there can relate! We decided to swap them to the end and after a leisurely round of golf, the players gathered back at the clubhouse for a dinner of delicious **Spring Creek Barbeque**, and to hear Brittany speak. She moved the crowd, explaining how when Michael was born she was totally in shock. Her mom, **Doreen**, also in attendance (with her father and brothers who played in the tournament), encouraged Brittany just minutes after Michael's birth by saying, "We got us a special one." And Michael totally showed how special he is offering up fist bumps to every single person in the crowd! Those in attendance were moved by Brittany's fearless commitment to bringing awareness and kindness into the community. We are so grateful for her willingness to be a



spokesperson for CCA Kids.

First Place winners, Team Lavender

Christine Andler announced the winners of the tournament, with First Place going to **Team Lavender** again this year!

A special thanks to the **Browns**, the **Andlers**, and the **Reeves**, who helped us load up after the fun

was all over. Thank you all for making this day a huge success for CCA Kids.







# pj's curb your enthusiasm donation



**Enthusiasm**, which we were able to auction on **CharityBuzz!** We want to thank **Kristin Alcalá** for helping us with this process as we were able

**W**e had the pleasure of meeting **Crystal Kouri Reynafarje** and **Paul Reynafarje** last April when they organized an epic cirque event to raise awareness for their sweet, new baby, **PJ**, who was born with Treacher Collins syndrome. PJ's condition was a total surprise to his parents, so part of their journey was jumping into action to rally their community for a cause.

**Nathalie Yves Gauthier** and her all-youth professional cirque company based in Los Angeles, California, **Le Petit Cirque**, performed "The Magnificent," a charity fundraiser for PJ and other families affected by craniofacial conditions.

As part of her efforts, Crystal secured one of the most amazing donations CCA has ever received—a walk-on role to **Curb Your**

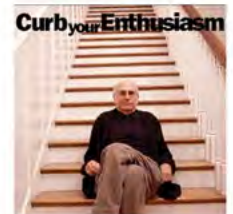
to raise a jaw-dropping **\$51,000** in the auction!

This incredible gift will help fund our financial assistance program, which has experienced a surge in requests this year. Even though we exceeded our budget in October, with special fundraisers like this and the faith of our board, we are continuing to provide this critical funding to families like PJ's, who face staggering medical bills.



Walk-On Role For You and a Guest on the HBO Hit Series **Curb Your Enthusiasm** in LA Plus a Meet & Greet with **Larry David**

Your donation supported: Children's Craniofacial Association



Overview About the Charity Rules & Regulations Shipping

Donated by: The Cast And Crew of Curb Your Enthusiasm  
You and a guest will EACH receive a walk-on, non-speaking featured extra role on HBO's hit series, **Curb Your Enthusiasm**, as well as a brief meet & greet and photo with **Larry David** in Los Angeles.



**board chair**, from pg 1 the need to support individuals and their families who were living with facial differences, CCA has grown into an organization that impacts tens of thousands of individuals around the world each year. From our humble beginnings of an organization run from the Executive Director's garage, to the wave of support that started to grow from Cher's role in the movie *Mask*, all the way to the novel *Wonder*, by R.J. Palacio in 2012 and the movie adaptation in 2017, CCA has become the premier nonprofit focused on emotional and social support for individuals with facial differences.

For three decades, CCA has provided critical programs and services

including financial assistance, educational materials, family retreat, peer networking, public awareness, family support, and the first stop for information for a family with a newborn with a facial difference. The impact of this can be seen in what our CCA Kids have accomplished.

Our first generation of CCA Kids have now grown into CCA Adults, and the world is benefitting from all that they have to offer as doctors, nurses, artists, engineers, retail employees, child care specialists, parents, volunteers, and many other roles that have a positive impact on the lives of others. Not only are these young adults making an impact in their communities, they are serving as role models

for the next generation of CCA Kids, and are a sign of hope to young families who are learning to navigate life with a facial difference.

In the community, CCA Kids of all ages and their families have brought the Choose Kind message to the forefront all over the United States, sharing their stories in schools with thousands of students. The recognition that no one can tell your story better than you, is a powerful form of empowerment to our CCA community. And when others are excited to hear that story, it is even more powerful. This program provides important perspective to students about embracing differences, and helps them to recognize that we are all much more alike than

we are different. CCA Kids make a difference every day by sharing their story, and proudly showing who they are.

As an organization, CCA's plan is to be here for many generations to come, and continue to enable CCA Kids to become thriving members of our society who are valued, respected, and accepted for who they are, not how they look. The Board of Directors and Staff are focused on providing the highest quality programs and services, and continuously improving what we provide to our community with our CCA Kids inspiring us to strive for excellence.

Here's to the next 30 years!

**George Dale**  
Board Chair



## donors in the spotlight

Thank you so much to the **McKesson Medical-Surgical** team, **Jeff Bowman**, **Kenneth Stansberger**, and his wife, **Amanda**, **Toby Wilson**, **Danielle Timmons**, and **Justin Rice** for coming to the CCA office, and making an incredible **\$5,000** donation to our programs and services. Then, **Alyssa Kelliher Kent** of **MSD Healthcare Solutions** contributed an additional **\$2,500!**

The inspiration for these generous gifts came after Toby met **Juliana Wetmore** while providing medical products that she uses in her daily life. Her family nominated CCA for this gift, and we could not be more grateful. Thank you all for sustaining our work.



# maigan's motivation to give back

By Maigan Baker



When our daughter, **Hannah**, was 4 months old, we noticed a ridge on the top of her head. We inquired about it at her 4-month visit but no one was concerned. We were clueless to what it could be, so just trusted it was ok. At 6 months I pushed again at her check up and they said they'd run X-rays. We did that right after her appointment and the next day we learned about Craniosynostosis for the first time!

It was confirmed that her X-rays looked concerning. We had the choice of seeing someone locally who was a neurosurgeon who didn't specialize in kids or to go to **University of Michigan**, which is 2 hours away. We immediately said U of M, knowing we wouldn't be satisfied anywhere else.

They were able to get us in 2 weeks later, and the surgeons confirmed that she had Craniosynostosis. She had surgery on Valentine's Day 2017 at 8 months old.

While it was terrifying to wait during the surgery, and to see her after with her head wrapped and face swollen, we had faith in the surgeons. She ended up needing a blood transfusion during the surgery, and also that first night. After that, things improved a lot.

Hannah's eyes swelled shut, as was expected. When her eyes opened back up on Saturday, this girl was happy, and ready to crawl around and be her normal self. This absolutely terrified us! It's crazy how their little bodies bounce back so fast after such a big surgery. She was all smiles after this, except she would get mad at us when we wouldn't let her do stuff. The next two weeks my husband and I took turns working from home, both lucky to have jobs that would allow this. After those 2 weeks my mom

came to stay with us for the next 2.5 months, until Hannah was cleared to go back to daycare. We were so lucky to have that help! I don't know what we would have done without her.

Fast forward 7 months later, and you would barely know by looking at Hannah that she had surgery! Her hair mostly covers her scars and she is still a strong little girl who has no clue what she's been through!

While we were in the hospital, I signed up to sell **Usborne Books & More** as a fun side gig, as I already work full time. I figured if I didn't like it, I could just stop—no harm, no foul. I knew I loved the books, and I love being social, so I knew I'd probably love it. I had my launch party and donated all of the reward books to **Mott Children's Hospital**. They got over \$400 worth of books! We dropped them off at Hannah's 3-month check up. In June, I held a party where all the rewards went towards **Cranio Care Bears**, an amazing organization that sends care packages to kids who are about to have surgery for Craniosynostosis. They received about \$200 worth of books (my incentive period was up

so I couldn't offer double rewards like I could for my first party). Then in September, since it is **Craniofacial Acceptance Month**, I knew I wanted to do something for an organization that helped kids like Hannah. So I decided to hold a **Cards for a Cause** party, and donate the funds raised to Children's Craniofacial Association. I posted on social media to my friends, family, co-workers, and Usborne VIP page that I was selling boxes of cards with 30 cards in them for \$30, and told them where proceeds were going. I ended up selling 20 boxes of cards! I am super excited to be able to help an organization that helps kiddos with craniofacial abnormalities.





# 14th annual craniofacial acceptance month

This year marked the 14th year CCA observed September as **Craniofacial Acceptance Month** across the nation. CCA families, friends, volunteers, and related support groups widened the circle of acceptance for individuals with facial differences.

Several of our amazing CCA families were able to get their local newspapers to feature them in the paper, and we mailed out around 100 Craniofacial Acceptance Month packets to 20 states, and even had a request all the way from Australia! And, for the eleventh year, CCA held **National Picnic Day** in September as part of Craniofacial Acceptance Month. CCA families across the nation held picnics in **California (2), Michigan, Minnesota, New Jersey, Ohio, Pennsylvania, Texas, and Utah.** For

the second year in a row, **The Craniofacial Center and International Craniofacial Institute** joined us, and invited their patients for our local DFW picnic here in Texas.

CCA would like to send out a special thank you to the following families for hosting picnics!

- Watkins Family**
- Vysocky Family**
- Quinonez Family**
- Dowd Family**
- Merrill Family**
- Grubbs Family**
- Seitz Family**
- Donahue Family**
- Bowers Family**
- Kearns Family**
- Sutton Family**

We would also like to thank **KLS Martin** for their continued generosity and support, year after year, as well as all the CCA families who attended the picnics.





TEXAS



MICHIGAN



TEXAS



MICHIGAN

MICHIGAN

TEXAS



MICHIGAN

MICHIGAN





MINNESOTA



OHIO



NEW JERSEY



NEW JERSEY



OHIO



NEW JERSEY



OHIO





OHIO



OHIO



PENNSYLVANIA



PENNSYLVANIA



OHIO



PENNSYLVANIA

see **cam** page 14





UTAH



UTAH



SOUTHERN CALIFORNIA



SOUTHERN CALIFORNIA



SOUTHERN CALIFORNIA



SOUTHERN CALIFORNIA





UTAH



SOUTHERN CALIFORNIA



UTAH



UTAH



UTAH



# jonathan siebert spreads kindness across the world

hello! My name is **Jonathan Siebert**, and I have been talking to students in the United States of America, and around the world, about the book *Wonder* since January. I share with them my real-life Auggie Pullman story. I have talked to students in all **50 States**, as well as **Pakistan** and **Australia**.

One night, I had an amazing idea to spread awareness about how to choose kind, to stop bullying, and to educate others to accept people's facial differences.

The feedback I've been getting is that I am changing people's lives.

It was a good way for me to get through a tough time, since my father passed away in March. I have also talked to classes in person, which has created memories I will never forget. One of my favorite experiences in the classroom was teaching Zumba after telling my story. I am a certified Zumba instructor. *Wonder* has changed my life, and I pledge to #ChooseKind, and hope you do too. What inspired me to do this, and to continue doing it, is Auggie Pullman from the movie *Wonder*, as well as my dad, who I lost in late March.



I was lucky to find these classrooms from teachers with whom I connected online. When I talked to students via Skype in Australia and Pakistan, I was able to use the same message, since the children spoke English. The only difference between us

was the time zones! I had so much fun talking with them, and hope to do Japan and China one day! My next goal is to get my teacher's certification, since I love working with kids. I also want to be a Disney cast member!





# MOTORCYCLE RAFFLE

WIN A CUSTOM BIKE FROM LEGENDS CUSTOM BIKES



- Pro Taper Tracker Outlaw Handlebars, with a Pro Taper Outlaw 2.5" Riser
- Burly Stiletto Rear Shocks
- Freedom American Outlaw 2-into-1 black exhaust
- Burly MX-style Footpegs
- LePera Bare Bones Solo Seat
- Quick-Detach Black Fender Rack
- Headlight Stone Guard
- Avon Custom Contour Grips
- Black 2-Slot Clutch and Brake Levers
- Trail Tech Mount System
- 21" 40-Spoke Black Front Rim
- 16" 40-Spoke Black Rear Rim
- Knobby Tires, Front and Rear
- Custom Legends paint, valued at \$3,500
- Custom Front Skid Plate
- This motorcycle required over 30 hours of build time



## ORDER RAFFLE TICKETS!

CUT HERE

Quantity \_\_\_\_\_ x \$25 each = \$ \_\_\_\_\_

Mail stubs to: \_\_\_\_\_

CCA will award a motorcycle from **Legends Motorcycles** in Springville, Utah. This incredible bike is **valued at approximately \$19,000 USD.**

Order at [ccakids.org/motorcycle](http://ccakids.org/motorcycle) or use the form at right.

Include this coupon and your check or money order made payable to "CCA Kids," and mail to 13140 Coit Rd., Dallas, TX 75240. We will send your ticket stubs, and you will be entered in the raffle. **All orders must reach our office on or before February 11, 2019.**



# hazen, ND *wonder* event

Our friends in North Dakota celebrated **Craniofacial Acceptance Month** with a screening of the movie *Wonder* on September 9, 2018 at **Cinema Flix** as part of their annual HarvestFest celebration. The film provided an opportunity to raise awareness about facial differences during CCA's 14th Annual Craniofacial Acceptance Month, and help two local girls, **MacKenzie Berger** and **Makena Heier**, feel some love, too.

Sixty people attended the screening sponsored by the **Hazen Chamber of Commerce** who teamed up with Cinema Flix, showing the film at no cost. A number of *Wonder*-themed displays filled the lobby of the movie theater, showcasing CCA's *Wonder* curriculum, Craniofacial Acceptance Month posters, coloring pages, crossword

puzzles, and syndrome booklets for the audience to explore. Information was available for all ages. Mackenzie, born with Apert syndrome, attended the movie with her siblings shortly after recovering from surgery.

Makena was nearby working at the movie theater while her mother, **Antoinette Heier**, watched the film for the first time. Antoinette said, "I had tears throughout the entire movie. I kept picturing our own daughter."

Viewers responded positively to the film with kind words and deep pockets. The sixty people who came out to see *Wonder* that day donated a total of **\$323** to CCA. Antoinette tells us that, "One viewer kindly said 'Bless you for bringing in this movie. We love you!'"

Other members of the community came out thanks to Antoinette's article in the local newspaper. Thanks to the newspaper's wider readership, a young mother brought her three daughters to the event to watch *Wonder* for the second time. Another couple came because they wanted to "help the girls we saw in the newspaper."



People came out to meet Makena and Mackensie who have been involved with CCA for years. Makena is the face of CCA's syndrome page for facial palsy. The Heiers' have been hearty advocates for CCA since Makena's birth. Thanks to the Heiers, the Bergers were overwhelmed with support, too.

The display of CCA's booklets and posters remained available for the public to view at Hazen

City Hall. CCA is so very grateful for Antoinette's and Makena's interest and willingness to raise funds as a community. In closing, Antoinette says, "I am very proud of our community and county for their support. Choosing kindness is so easy for all of us to do. If we managed to educate one person, through our showing of the movie *Wonder*, well, that's a win."





# Boot Sale

## Exclusive Offer!!

Mention this AD and get your *Wonder* boots at a discounted price of:



Available\* in  
USA Kid Sizes  
10 - 3

To order email:  
kmoten@ccakids.com



\*While Supplies Last

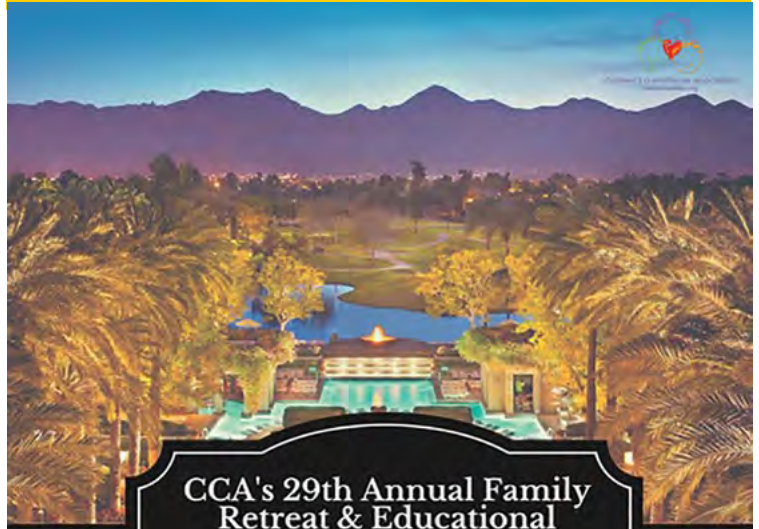
## You've reached a milestone...



### Can you now provide a stepping stone?

IRA Rollover Gifts are a unique way to avoid large tax penalties and fund the future for CCA Kids.

Please contact our office or your financial planner to learn more about why this gift is an awesome option if you are living the golden life in your 70s and beyond.



### CCA's 29th Annual Family Retreat & Educational Symposium

Scottsdale, Arizona

June 27 - June 30, 2019  
Hyatt Regency Scottsdale Resort & Spa at Gainey Ranch

Registration for the 2019 retreat is officially open. Please note the scholarship deadline and NEW registration deadlines below.

Scholarship Registration Deadline	December 31, 2018	No Fee
Early Bird Registration Deadline	January 31, 2019	\$100 per Family \$75 per Individual
Final Registration Deadline	February 28, 2019	\$125 per Family \$100 per Individual

For questions or concerns please contact Annie Reeves, Program Director, at: areeves@ccakids.com



**conrad**, from page 1 that this paved a way and created a pattern for us for quite some time. As I am writing this, I realize that many of you have experienced these same things. The reactions to



facial differences and the uncertainty of some care providers is not uncommon for the CCA family. These are things that we are still learning how to gauge and navigate.

When Conrad was born, the doctors would not let him leave the NICU or hospital until he showed them that he would be able to eat. One day old and already being challenged, Conrad, with a cleft lip and palate, latched on and looked at the nurses with eyes filled with determination and accomplishment. We were able to leave the next day. The nurses sent us away

with a stack of online print outs and baby formula.

Looking back, I should have known how inadequate the medical community was there.

Nursing ended as quick as it came, and I was pumping to give comfort and relief to my newborn baby. I was also reading all the printouts the hospital sent home with us. I had to find a special baby bottle that we squeezed to shoot the milk out of instead of him having to suck. All of this was very challenging, and when we finally found an amazing bottle they unfortunately cost \$20 to \$30 each!

Without any real guidance, I was desperate for first steps. A distant relative who is an oral maxillofacial surgeon called my dad and told him the road will be hard and long. So, to add to my stack of papers, my dad sent me more website links, this time with lots of surgery pictures. This was painful, but it gave me an idea where to start.

Taking a shot in the dark, I took my infant to an OMFS doctor and expected to be set up for something like a lip repair. The doctor took one look at Conrad and told us we had one option in our city, or we could go to UCLA

and meet an expert. We obviously chose to go to California. When we got there, we saw lots of wonderful before and after pictures. This doctor had an amazing portfolio. He was the first to separate conjoined twins and knew his stuff. He was also the first doctor we saw who wanted to take pictures of Conrad and who ordered a CT scan for us.

I still can't believe that we had to drive to California to have a doctor order a CT scan. We were terribly disappointed to learn that UCLA wouldn't take our insurance, so there we were, back at square one. I decided to have the CT scan done and sent back to the doctor in California anyway, and I am so glad I did. Conrad was eight months by then and would cry constantly. The only time he would stop, was to eat, or if he was being bounced. When the doctor saw his image, he informed us that Conrad had hydrocephalus. He also gave us our first referral and it was to a brain surgeon. I already felt alone with finding a way to help Conrad with the cleft, but now something with his brain!

I went to see the doctor we were referred to, and we were set up for surgery immediately. The doctor told us that his brain fluid does not drain on its own

and a shunt needed to be placed in his skull. This was very sudden, and happened fast. The surgery was hours long, and that's when I first felt that terrible feeling of handing over my baby and watching him go behind the operating room doors. I don't feel the need to go into detail here, because I know each CCA family knows the feelings I felt in that moment.

Conrad has a cousin who is three weeks older than he, and every month I was watching him hit milestones. He started lifting his head during tummy time, and Conrad would not. He started sitting up, and Conrad wouldn't. His cousin was up on his knees and Conrad didn't even want to hold his head up on his own. Literally, the morning after the surgery, Conrad grabbed the crib bars and pulled himself up to a sitting position, and for the very first time, right up on to his feet. He had the biggest smile on his face, and we had tears in our eyes.

We never had an easy surgery. His upper jaw bones had to be broken to be put closer together, his cleft was so wide that his skull had to be rotated closer together, and his lip had to be done multiple times, because it would fall apart. They finally sewed his bottom lip to the top,





and kept his mouth sewn shut for a few weeks. I would sit behind his chair and pour Ensure in his feeding tube while we watched good 'ole *Sesame Street*.

Everything changed when Conrad started getting an infection on his face between his eye and nose. The doctors called it a dermatoid cyst, and had to surgically remove it. But, it kept coming back, and the doctors couldn't figure out why. It got so constant that the doctors wouldn't do any reconstructive surgery, because if an infection were to occur, it could ruin it.

Confused that the doctors were at a loss, I sat down and brainstormed. If everything was fine, and Conrad was without all these special needs, what would I do? I decided to prepare to homeschool for kindergarten, and take him to a dentist for his first dental check up. I had become a dental assistant the year before Conrad was born, and knew he would require a very experienced dentist. I didn't know one, and decided to go see the OMFS who removed my wisdom teeth. He knew where to find one.

Just when I felt defeated, because all the doctors

didn't know what to do for Conrad, a door opened. Literally, the OMFS doctor walked us to the back of his office to a door, and walked us through it. On the other side was a beautifully painted children's dental office. This was the first experience with a doctor who really loved and cared for children. This was the beginning of our journey to Salt Lake City.

The dentist knew of a talented and kind doctor who knew how to help us, and worked at a children's hospital. The next day we received a personal phone call from the crainiofacial

surgeon in Salt Lake City. His call was informative, and most of all, genuinely compassionate. This was not what we were used to at all.

Those couple of weeks were a whirlwind. Conrad had once again developed an infection, and this time it was getting really bad. Usually, we could put warm compresses on him, and it would drain. This time was different though. It was hard, and causing a temperature. It got so bad, we had to go to the ER in the middle of the night because of the fever. The doctors gave us antibiotics and Tylenol, and sent us home.

After another day passed, I called the surgeon's office and asked if I could speak to Conrad's doctor. The office was surprised, but allowed it. I told the doctor everything that had happened, and how Conrad was doing. The doctor was clearly upset, and raised his voice to me, and asked why on earth would I go to the ER where they don't know anything, instead of calling him?

I have run this so many times in my mind, and I still feel that I did the right thing for my child. I was so shocked to be yelled at, that I hung up on him, and never spoke to him again. I immediately called the doctor in Salt Lake, and

see **conrad**, page 22



**conrad**, from page 21 they told me to get there as soon as I could, and they would have the doctor come to see us, no matter what time it was.

The doctors cleaned the cyst and scheduled us for a surgery to remove it, once and for all. (These doctors did it right and, five years later, it hasn't come back).

We stayed at the Ronald McDonald House, and searched for housing and employment, because we decided to move to Salt Lake City. Conrad's dad found a job, and we packed up our home, and said goodbye to our family and friends. We didn't know where we were going to live, but by faith, we just left. We knew we could never be that far from good health care again. The hospital is equipped, and they know how to treat children and families. Conrad's doctors have had to do things to repair and improve prior surgeries, but we are headed in the right direction.

A mother of a friend of ours knew a pastor whose church had an inn. After weeks of worry, driving, packing, more driving and so much uncertainty, it felt as if though I fell into the pastor's arms when we arrived. It was comforting. Conrad was healing, his dad was working at a job he really enjoyed, and I was driving around a winter

wonderland looking for an apartment. We have found so many good people, and the seasons feel wonderful. Even though we still have challenges, we feel like God has us in His hands, and led us to the right caregivers.

I still homeschool Conrad. He is learning to play an instrument, and is the most friendly and caring person I have ever met. He is growing so much physically and mentally.

Conrad is learning how to follow his heart without letting the hard times knock him down, and tries to be positive. Conrad's light shines bright in a dark world, and attracts the best kind of people. I am very honored to be his mother, and we give each other strength. Life can be hard, but it is also so beautiful, and there are many things, every day, to be thankful for.

I'm grateful Conrad has met so many of you from all ages, and at different stages in life. Conrad loves CCA, and got to make some friends his age (even famous ones), and older ones who can be very positive role models. Thank you so much for being like family to us.





# RECORD-BREAKING BIRTHDAY CLUB 2018!



It's a lot more fun to celebrate when you know it makes a difference! This year has been an amazing success for our birthday club. We are so very grateful to all of you who hosted fundraisers, and to those of you who supported your friends' birthdays with contributions to CCA. This year was record-breaking as YOU raised **over \$61,000** in birthday gifts!

Now that's worth a party! Happy birthday—and here's to many more with you, our friends.

Kenny Alford-Mays  
Meghan Aline  
Sharon Allbright  
Falina Alvey  
Flor Anchondo  
Peter Anthony  
Carol Ardelean  
Macey Atkins  
Stacey Atkins  
Taylar Aumann  
Rhea Beach  
Simon Bench  
Autumn Hancock Berte  
Catherine Blain  
Ashley Bock  
Lisa Bowers  
Madisyn Bowers  
Farahnaz Boyzan  
Arlene Brambila Contreras  
Joe Brooks  
Ryan Broome  
Cathy Broz  
Sara Bullen  
Maricela Burns  
Danille Caincross  
Alana Carroll  
Amber Carruth  
Emily Conneway  
Brandon Cook  
Avery Cooper  
Emily Crabtree  
Lynn Folwer Crawford  
Arienne Damrow

Drew Davis  
Kimberly Davis  
Lew Davis  
Genny DeLong  
Markie Dew  
Katia Dos Santos  
Mark Elzey  
Erica Faircloth  
Sarah Fishkind  
Skye Flores  
Kira Frederick-Douglas  
Marco Garcia  
Khashad Gillespie  
Katie Distelrath Gold  
Rob Gorecki  
Jaz Gray  
Lupita Meza Green  
Fran Griffin  
Zoe Grossfeld  
Christina Hahn  
Sarah Hall  
Pam Hamill  
Alyssa Hamilton  
Melissa Harmon  
Torey Harrah  
Nikki Hemmerich  
Nicki Hinson  
Debbie Holmes  
Theresa Hospodka  
Janelle Howell  
Shauna Huddleston  
Layna Hunter  
Kevin Irvine

Kara Jackman  
Jazmyne Jezowski  
Rachel Fabre Johnson  
Ticia Kay  
Tiffany Kerchner  
Amy Kern  
Jennifer Kilmer  
Pete Klaus  
Bruce Klein  
Ahslie Kristine  
Diana Kuenzli  
Christina Landes  
Thomas M. Lee  
Brenda Long  
Allison Lupton Cho  
Ava Martin  
Amanda Maves  
Alan McAllister  
Kate McAllister  
Darnell Menard  
Emily Merrill  
Tamarah Milne-Myazoe  
Isa Moreno  
Dawn Morgan  
Jayme Morrill  
Stacy Needleman-Klein  
Kayde Grace Newman  
Eva Foxon Nicholas  
Robert Paige  
Michael Piacenza  
Pamela Piacenza  
Eloise Priest Thome  
Ashlyn Prom

Allie Quinn  
Kyleigh Quinn  
Annie Reeves  
Krystle Rizzo  
Kristen Dolan Roberts  
Sarah Shay Robinson  
Katherine Rooney  
Jaci Samhammer  
Mark Sanborn  
Kim Spears Sarsi  
Josiah Sean  
Fred Seitz  
Rose Seitz  
Kiersten Kai Sell  
Therisa Sesvold  
Carrie Shaw  
Ariadna Silveira  
Pat Simon  
Savannah Simon  
Mike Sinelli  
Char Smith  
Christie Smith  
Coach Smith  
Francis Smith  
Lacey Ann Smith  
Mary Kate Smith  
Vicki Smith  
Wayne Smith  
Jennifer Spiegelberg  
Brittany Stevens  
Meg Storie  
Mindi Anderton Stowe  
Lauren Brennan Strauss

Brooke Strogatz  
Keegan Strogatz  
Karri Strogatz Jones  
Sarah Suwalski  
Dava Mackey Swafford  
Becky Taylor  
Tash Thibodeaux  
Radhika Thorn  
Tanya Tiger  
Crystal Uerz  
Kris Vaughn  
Viva Veedo  
Christian Vestman  
Courtney Vysocky  
Alyssa Wagor  
Nathan Walker  
Stina Warner  
Dorina Watkins  
Susan Cunningham Werner  
Casey Weston  
Katie Whicker  
Jessica Wilcox  
Chloe Willett  
Tammi Willett  
Stephanie Loe Williams  
Miranda Leigh Williamson  
Shelli Wiser  
Stacy Barksdale Woodruff  
Kristal Younger  
Lauren Zekas



# double the fun: dfw family night

CCA families came together on a sweltering August night in **West Village** to celebrate one another and strengthen our Dallas community!

We owe a huge thanks to **Araceli** and **Matt Kimberlin**, and **Petty** and **Steven Weiss**, who rallied their families and friends to show up in force at CCA's **Family Night Out in the West Village** on August 16th.

Araceli, CCA Mom with **Crouzon syndrome**, hosted families on the patio of **Village Burger Bar**. We had complimentary appetizers and a kid-friendly craft activity, called "kindness rocks," where CCA Kids and Sibs painted rocks to leave around town with messages of love. Araceli facilitated conversations about CCA, growing up with a craniofacial condition and also raising her son, **Aaron**—who *also* has **Crouzon syndrome**—and his SuperSib, **Aiden**.

**Steven**, CCA Board Director, and his wife, **Petty**, brought out a record-breaking crowd to shop at the lovely **Kendra Scott** store. Steven always moves the audience with his inspiring account of growing up and dating with a facial difference.

His humor and his love for **Petty** were evident as always, he personally inspired many with his faith and persistence. Their story continues as they raise their adorable twins, **Blake** and **Claire**, who were also at the event.

Both of these hosts provided unique perspective on craniofacial conditions, as both a former patient, and now as parents. Araceli says, "As a child, **Crouzon syndrome** was just something I *had*. I had to go into surgeries for it, and it was just a part of my life. *Having* a child with it opens up a whole new world. All of a sudden, I have become a doctor, advocate, nurse, insurance bill specialist, protector, and so many other things I wasn't when our first son was born."

Further, she feels strongly about CCA and the community we provide. "When we found out that our second son, **Aaron**, had **Crouzon syndrome** like I did, I wanted his experience to be different. I wanted him to have a community where he could feel accepted, and where he would feel like others could relate to him and the issues he was facing."

Steven and **Petty**, too, felt strongly about advocating on behalf of those born with facial differences.



We are so grateful to their dedication to CCA as they both use their leadership and business skills to increase CCA's reach to help more families.

Seven other local CCA families joined us, which made this event a mini reunion! We hope to host more events of this type that fill our buckets with love, and get us through until the next Retreat,

and hopefully encourage some play dates in the meantime! We want to especially thank our summer intern, **Elizabeth Mocek**, who put in an enormous effort prepping and cleaning up for the event.

At each location, the stores donated a portion of the evening's proceeds to CCA. We raised **over \$1,200** for CCA Kids!









# coto for the cure tennis pro-am

Each year we wonder how we will fund another amazing year of growth and serving families. The short answer is faith, but the long answer is the tireless efforts of friends—old and new—who come together, spend 100s of hours organizing events, gather amazing experiences and auction items, and graciously welcome their communities into their homes to serve the greater good.

This year, CCA was the beneficiary of the most successful fundraising event in our 30-year history—the **Coto for the Cure Tennis Pro-Am** event held November 2-3, 2018. CCA was nominated by the incredible hosts of the event, **Peter** and **Shannon Wernemar** who were moved by *Wonder* and CCA's initiatives to

bring the messages of acceptance, inclusion, and anti-bullying to children in Orange County and across the country. The Coto de Caza community has embraced CCA like no other community, and we are beyond humbled that this club decided to bless our families with their incredible annual pro-am tennis tournament.

After CCA was selected as this year's beneficiary, **David Page, Michael Olds, Peter** and **Shannon Wernemar, Chris Jones** and **Val Laguatan** organized an unbelievably incredible night and weekend. The weekend event kicked off with a beautiful cocktail party with over 200 guests, set at the home of Peter and Shannon Wernemar. Our host couple opened their breathtaking home as

the scene for delicious cuisine, music and dancing with **Tim Sacks** spinning the tunes, and a moving speech by **Jono Lancaster**. The funds generated at this event came from the critical sponsorships of **Karma Automotive, Kaiser Permanente, Hayne & Company, Alliant Insurance Services** and **Travelers**, a record-breaking "fund the cause" donate-a-thon, a riotous live auction, and an expertly run silent auction. **Morgan Mecklenburg** and **Madeleine Daniels** commanded the audience as Morgan urged the crowd, "Don't you have love in your hearts? Well, then reach deep into your pockets ... and pull out your wallets!" David Page masterfully worked the crowd, and ensured that everyone truly did dig deep in their wallets.

After smashing all previous CCA fundraising events in our history, the next day sixteen amateurs and sixteen tennis professionals faced off in beautiful weather on the tennis courts. Lively banter and athletic prowess were on display, as well as the stunning **Karma Revero** line of cars, which were available for test drives, with a special thanks to



**Chuck** and **Madeline Russell** and **Dr. Liang Zhou, CEO of Karma**, for being in attendance.

The action on the court was thrilling to watch. Ultimately, **Tommy Haas** and **Bode Miller** (Olympic Gold Medalist) clinched the title, but we thank all our pros, including **Sam Querrey** and **Michael Chang** for the inspiring display of talent and tenacity on the courts along with the love in their hearts!

The outpouring of generosity resulted in **\$182,992** of funds raised to provide medical care for our kids, scholarships to the Retreat, and to spread the message of kindness and inclusion throughout Southern California and the nation, through CCA's *Wonder* Initiative. As an organization, we pledged to steward this money dutifully, to serve families, and go bravely forward, as we envision a world where all people are accepted for who they are, not how they look.





**SPONSORS**

- Karma Automotive
- Peter & Shannon Wernemar
- Coto de Caza Golf & Racquet Club
- EMC<sup>2</sup> Head
- Haynie & Company
- Alliant
- Ryan Getzlaf & Family
- SES Risk Solutions
- Allied Universal
- Travelers
- Asombroso Fine Tequilas
- United Way
- Kaiser Permanente
- Harley Laguna Beach



see **coto**, page 28





seeds Alliant  
**\$172,868**









# testimonial



Just nine short months ago, our son **Moshe** was born. He is our seventh child, and much to our dismay, only after he was born did we discover that he has a rare syndrome called Apert syndrome.

We quickly became experts in many areas—although we were very non-medical before this!—with “trachs” and “syndactyly” becoming part of our regular vocabulary. We’ve traveled all over to try and get the best care for our son. Obviously, with six other children, traveling expenses were not easy to come by. That was when CCA came to the rescue!

Always with a friendly email from **Annie**, CCA has truly empowered us and given us hope. With the financial assistance and resources they provided, we truly feel we were able to give Moshe the best we possibly could. Several of his many surgeries are behind us, and they were all made possible because of CCA.

Thank you for all you have done!

– Sol and Rebecca Fishman

## calendar of events

date event contact

### 2018

Dec 3  
5-8 PM **9th Annual NorthPark Center  
Gingertown Build** [Emossholder@ccakids.com](mailto:Emossholder@ccakids.com)  
NorthPark Center  
8687 N. Central Expressway  
Dallas, TX 75225  
Watch as talented local architects build a sprawling  
Gingerbread town, and hear Jono Lancaster speak!

Dec 8  
10 AM-3 PM **Lilly Pulitzer** [Emossholder@ccakids.com](mailto:Emossholder@ccakids.com)  
NorthPark Center  
8687 N. Central Expressway  
Dallas, TX 75225  
Call in orders welcome! **214.234.0458**  
Please join us for sips and sweets while shopping our new collection.  
10% of proceeds will be donated to CCA

Dec. 11  
5pm - 7pm **Vineyard Vines Shopping Night  
hosted by the Wieses**  
Ross Park Mall  
Pittsburgh, PA  
Call in orders welcome! **412.837.4025**

Dec 31 **Retreat Scholarship Deadline** [ARees@ccakids.com](mailto:ARees@ccakids.com)

### 2019

January 12  
9am **Cycle for CCA** [Emossholder@ccakids.com](mailto:Emossholder@ccakids.com)  
Full Psyche  
2650 N. Fitzhugh Ave. Suite 120 (592.11 mi)  
Dallas, Texas 75204  
\$25 and CCA will get 50% of purchases - including memberships  
and merchandise purchased on the 12th

Jan 31 **Early Bird Retreat Registration  
Deadline** [ARees@ccakids.com](mailto:ARees@ccakids.com)

Feb 28 **Retreat Registration  
Officially Closes** [ARees@ccakids.com](mailto:ARees@ccakids.com)

Jun 27-30 **29th Annual Family Retreat** [ARees@ccakids.com](mailto:ARees@ccakids.com)  
Hyatt Gainey Ranch  
Scottsdale, AZ  
214.570.9099  
800.535.3643

Aug 10 **2nd Annual Spreading the  
Love for CCA; it's the  
Brooklyn Way** Angela Wojtyniak  
Livonia, MI [angwojtyniak@gmail.com](mailto:angwojtyniak@gmail.com)

September **15th Annual Craniofacial  
Acceptance Month (CAM)** [ARees@ccakids.com](mailto:ARees@ccakids.com)  
Nationwide  
214.570.9099  
800.535.3643





# 3 cheers

for volunteers!

author, registered nurse, and cleft lip and palate advocate, **Patricia Simon**, is spreading her message of acceptance and hope across the world. Earlier this year her children's book was translated into Tagalog for kids in the Philippines taking part in a speech camp organized by **Smile Train**. And just recently, at the beginning of September, Patricia delivered the keynote speech at **New York's Morgan Stanley Hospital Cleft Lip and Palate Team Day**.

The road to the keynote address in New York all began with an email. Two parents were interested in her books, *Smile with Simon*, and *Simon and the Buddy Branch*, about a cardinal named Simon that has a cleft beak, who seeks out acceptance and kind friends in both books. The family requested the books, sharing that they were unable to afford to pay for them. Simon sent the books to the parents for free, and enclosed an additional set for their surgeon's office waiting room at Morgan Stanley Hospital. Plastic and reconstructive surgeon, **Dr.**

**Thomas Imahiyero** picked up the books, read them, and wrote to Simon saying, "As someone who has dedicated a large part of my career to taking care of children with clefts, these books really spoke to me. The positivity that they exude and kind stories that they tell are exactly the outlook that I wish for my patients and families to have." Dr. Imahiyero went on to ask Patricia to speak at the Cleft Lip and Palate Team Day.

Morgan Stanley Hospital hosted its inaugural Cleft Lip and Palate Team day this year. It was so successful that they plan to make it an annual event. The goal for this year was to focus on advocacy, outreach, but most importantly, building community among patients with facial differences. To that end, the hospital chose a beach theme with brightly colored tables, a DJ, and leis and Cleftstrong bracelets for everyone. Craniofacial patients and their families were all invited to mix and mingle with Morgan Stanley Hospital medical



professionals including, Dr. Imahiyero, **Dr. June Wu**, **Dr. Jeffrey A. Ascherman**, and **Natalie Tavarez**, **Craniofacial Coordinator**. **Miss New York Teen USA**, **Saige Guerin**, was also present for the event.

Pat spoke from the heart, sharing her keys to success and happiness. She told the audience of 125 people to, "Open yourself up to others and experiences. We are all different and we are all beautiful. Be kind to one another, and accept people for who they are. Yes, there will be struggles and ups and downs. Continue to move forward. Put your cell phones down, look up, and experience life. Realize you are not alone. There are organizations such as CCA and the **American Cleft Palate-Craniofacial Association** that can provide resources and assistance for those affected with craniofacial differences." She let people know about the books she wrote that help carry this message to children with a bright, fun cast of characters, including a

cardinal named Simon, girl named Patty, and Buddy the bluebird.

The crowd responded positively to her words with tears, knowing nods, and smiles. Pat said, "After I gave my keynote speech, a

husband and wife came up to me crying as they were holding their one-year-old daughter. They told me they were deeply touched by my speech, and thanked me for being so positive and transparent in sharing my journey. I was deeply touched, and happy that others got so much from my speech."

Later she signed copies of books that were distributed to each family at the event, and listened to patient testimonials shared during the day spent together. In speaking with patients and families, Patricia talked about everything from upcoming surgeries to the gratitude they each felt in being part of the Morgan Stanley Hospital community.

Way to go Patricia, on spreading words of kindness, hope, and acceptance to these New York families. CCA looks forward to your future writing and speaking adventures as you advocate for all of us in the craniofacial community.



# children's craniofacial association

13140 Coit Road, Suite 517 • Dallas, TX 75240



## Honorary Chairperson:

Cher

## Board of Directors:

George Dale, *Chair*, Corning, NY  
Kelly E. Cunha, Tampa, FL  
Dede Dankelson, Libertyville, IL  
Margaret Lavender, Norman, OK  
Bill Mecklenburg, Mission Viejo, CA  
Russel Newman, JD, Seattle, WA  
Haley Streff, MS, CGC, Houston, TX  
Steven Weiss, Dallas, TX  
Rose Wiese, Mars, PA

## CCA Network Editor:

Kelly Liszt, [copybykelly.com](http://copybykelly.com)

## CCA Network Design and Production:

Robin Williamson,  
Williamson Creative Services, Inc.

## Executive Director:

Erica Mossholder, MBA

## Program Director:

Annie Reeves

## Director of Development:

Christine Andler

## Outreach Director:

Khadija Moten

## Marketing & Communication Coordinator:

Kara Jackman

voice 214.570.9099

fax 214.570.8811

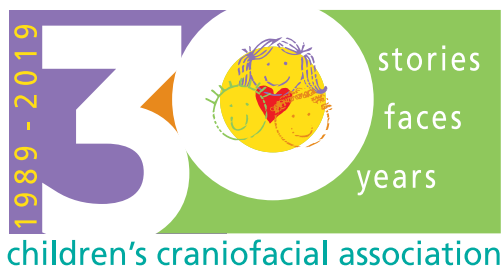
toll-free 800.535.3643

url [CCAkids.org](http://CCAkids.org)

The views and opinions expressed in this newsletter are not necessarily those of CCA.

If you no longer wish to receive this newsletter, please send an email to [AReesves@ccakids.com](mailto:AReesves@ccakids.com) or mail the label to the CCA office and ask that it be removed from the mailing list.

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



children's craniofacial association

**W**e are so excited to kick off our **30th Anniversary** celebration this year! Children's Craniofacial Association will celebrate 30 years of changing lives throughout 2019. CCA began on February 24, 1989. For nearly 30 years, your efforts have truly shaped a generation—growing confident, healthy kids into

kind, motivated adults who are ushering in a new wave of tolerance, acceptance, love for others, and mentoring the

newest members to our community.

As we kickoff this celebration, we will feature **30 Stories, 30 Faces ... some of them in about 30 words.** Each story will honor the legacy of CCA Kids from a unique perspective—patients, parents, volunteers, donors, and professionals. We invite you to follow this journey over the next year, and be

a part of the conversation! You'll see these stories in our newsletters and e-newsletters (so sign up online!), on social media and in videos.

**We invite you to share your story ...** in 30 words (or so) via email:

[contactCCA@ccakids.com](mailto:contactCCA@ccakids.com)

with the subject "30 Stories." Please include a photo! You might see your story featured on our social or print media.

Stay tuned friends, this is a huge celebration for our community! Thank you for 30 years of loyal support ... and here's to 30 more!

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