Inside

cca kid
lynzae perez ..........2

cca adult
kristin bartzowkis ....3

cca supersibs
joely and ben perez, jr ...4

miles for cca ..........5

all the way for cca. .......6

morgan meck
invitational ..........8

first-time attendee ...10
donor in the spotlight. 11
cher's birthday funder ...11
nick's network car raffle. 12
kindness dance ........13
mrs. friend's third grade class ..........13
retreat raffle ..........22
testimonial ..........22

calendar of events .......23

gerard family
lemonade stand ........23

atkins family
lemonade stand ........24

Love Me, Love My Face

By Jono Lancaster

I was born on October 31, 1984 in the United Kingdom, with Treacher Collins syndrome. My TCS was caused by sporadic mutation, so I came as a complete shock to my birth parents.

They made the decision 36 hours after I was born that we were to go our separate ways. Social Services then had the task of finding someone to care for me; they approached a foster caregiver, Jean, who cared for kids with disabilities. Jean tells me that all the early conversations with social services were about my face.

“He looks different.”

“Be prepared for the way he looks.”

This went straight over the top of Jean’s head… she just wanted to meet me.

And when she did, she thought I was beautiful (obviously) and when she held me, she felt an instant connection and instant bond. She asked when she could take me home. So home I went with Jean when I was 2 weeks old.
Twelve-year-old Lynzea Perez is having a wonderful summer. Not only is she going camping, enjoying lots of swimming and helping around the house (okay, her mom is enjoying that), she went to her first-ever CCA Retreat! Since last December, she and her family were counting the days until they headed to Reston, Virginia. The retreat was very close to Washington, DC, so they were hoping to ride the Metro into town to check out all the museums and monuments before making their way back home.

During the school year, Lynzea is pretty busy. She’ll begin Seventh Grade in the fall and likes her Language Arts class a lot. After school, she runs cross-country and has been competing with other schools for the last four years. She also said that she and her sister are really into making slime. And when she’s not running or making an icky, gooey mess, she plays with her “awesome-but-somewhat-naughty” German Shepherd, Cujo.

Lynzea listens to all types of music: hip-hop, rap, country, old-school music—you name it, she likes it. She’s also into scary movies. She saw Rings recently and loved it, although she had to hold her hands over her eyes during the super scary parts.

Something really cool that Lynzea started doing recently is Native American dancing. She wears traditional Menominee regalia, most of which her community donated. “I love it,” she said. She even speaks a little of the native language.

Lynzea has had 25 reconstructive surgeries so far, with the last one being just this past March. She’s gone through so much, and tells kids going through something similar that everything will be ok. If she were there right next to them she would talk to them, and reassure them that they’ve got this and will be just fine.
My name is Kristin Bartzokis. I was born with Treacher Collins syndrome in 1982, a time before CCA existed. Because there was no widely accessible support for craniofacial families at that time, my parents raised me in the only manner they knew how.

They emphasized all the ways in which my life was ordinary and taught me to live without setting limitations for myself. This allowed me to thrive. Of course, I knew that my friends didn’t wear hearing aids or have surgeries, but I just thought of those little nuances as being pieces of my life, not the very things that defined it. I wasn’t Treacher Collins; I was Kristin.

While my parents always taught me that I could succeed in anything I chose to do, it was my involvement in competitive gymnastics that led me to believe them. In gymnastics, I was unbeatable. In fact, I was the first person in the state of Florida to receive a perfect ten in a state competition. I found myself being recognized by other competitors for my talent and not for my face, an unusual feat for someone with a facial difference. Gymnastics instilled in me a confidence I’m not certain I would have found otherwise, at least not at such a young age.

Over the years, I have endured ten reconstructive surgeries. Although everyone who meets me thinks that is an enormous amount, I know it pales in comparison to so many others with craniofacial differences. Still, each of my operations left behind scars, both physical and emotional, and I had to learn to combat those wounds somehow. My positive attitude and mental fortitude became my lifeline, something I needed growing up since I didn’t have that direct connection to others with TCS.

A few years ago, I decided that it was time to open up to my family and friends about how my syndrome affected me. Until that point, I never really spoke about it. I began a blog and it truly changed my life. That blog led to a book, Diary of a Beautiful Disaster. That book has allowed me to not only be a voice for those with craniofacial syndromes, but also for anyone struggling to find confidence and acceptance.

I’ve only recently become acquainted with CCA, but I’m proud to be part of this community. I’m grateful to connect with others who have had similar life experiences and I’m beyond thrilled to offer messages of hope to those who are just beginning their journeys with facial anomalies.

My advice to all of you is to know who you are. Never forget who you are. Never quit and always, always choose strong. That has made all the difference in my life.

You can read more of my writing and learn more on my website, http://kristinbartzokis.com/
My name is Ben Perez Jr. I am Lynzea's older brother. I am a sawyer with the Menominee Tribal Enterprises. I like to go fishing, hunting, playing basketball and hanging out with my friends and family in my spare time.

I love that my sister is outgoing. She never lets her condition stop her from doing anything and everything she wants. Lynzea and I like to just chill out and listen to music. I like to help her out with a few dollars, now and then, so she can go to the store and get her favorite chips, Dynamites.

I know my sister is a very beautiful and strong young girl. I cannot wait to see what she grows up to be. She makes me proud every day. I love you Lynzea Brooke Perez!

My name is Joely Perez. I'm in the Seventh Grade at Menominee Tribal School. Lynzea is my younger sister. We are really close. We enjoy making slime together a lot. We jump on the trampoline, and always walk to the store together. We love hanging out together.

Lynzea is so brave that she can sing in front of people if she wants to. She isn’t shy like I am. Lynzea has a lot of friends—a lot more than I. She likes to go out with them to public events. Lynzea loves her friends and family so much!

Schools have bullies. If somebody bullies her, she will stick up for herself, for me and anybody else that is getting bullied. Lynzea is so strong and has a big heart. Sometimes we don’t get along, but we do have a lot of stuff we like doing together.

We are very proud of you Lynzea. You are amazing! We love you.
June 10 was this year’s date of our annual “Miles for CCA Kids” ride in Dallas, TX, spreading awareness and raising over $5,000 for CCA. Event organizer, Pastor Lewis Boykin, rallied the help of Stephanie and Darren Pollack, Katherine Jones, Gen White, Lori Hinkley, Scott and Laura Reynolds, Robert Page, and Greg Patterson to hold another successful run for Children’s Craniofacial Association.

Each rider was given a CCA Kids’ photo in a lanyard so they had a CCA Kid “riding with them” along the course.

Sponsors were: Leaders Of The Pack; Acacia Insurance Managers, LLC; Adkerson, Hauder & Bezney; Dickweed Motorcycle Club; Laucius & Associates; Law Offices of Stephen Smith, Ekvall & Byrne; Cole Investigative Agency; and Bikerlawyer.com; Road Captains; Maverick Harley Davidson; 2nd Sunday Biker Church; Praise Hymn Fashions; Redneck Heaven; End Zone Sports Bar-Little Elm; Nick’s Sports Bar; II Brothers; and End Zone Sports Bar-Plano.

The event raffle had many great prizes from generous donors including Stirr, Dallas; Marbles Blow Outs & Makeup; Midia; Bone Daddy’s; Chuys; Rock ‘n Brew; Towers; Craft House; Katy Trail; Hula Hut; Pak Pao; Kona Grill; Kenny’s Restaurant Group/Burger Joint; Smoke House & East Coast Pizza; Homewood Suites Addison; Spirit Grille Irving; Terillis Italian Restaurant; Via Real Las Colinas; and Lone Star Leather–Denton.

Special thanks go out to the group, Mega Chief for playing our after party and rocking out for CCA Kids! The band members were so kind to donate their talent to the cause.

Thank you all.

We hope to see everyone at our 2018 Miles for CCA Kids on May 19, 2018 in Dallas!
They say “Everything’s Bigger in Texas,” and All the Way for CCA never fails to disappoint.

The Texas CCA Mom Trio of Lisa Bock, Jennifer Kilmer and Becky White hosted their 5th Annual Golf Tournament and Luncheon on April 28th, 2017, with Title Sponsors, LBC Tank Terminals and Empowering Motivated Women at Wildcat Golf Course in Houston, Texas.

They brought big crowds, big prizes and big results for the Children’s Craniofacial Association. John Grimes of LBC Tank has personally committed to growing this event each year, and with 164 golfers raising $107,000, “All the Way for CCA” is one of the highest grossing family fundraisers in CCA history. Thank you to Mr. Grimes and your team, consisting of Alisa Shelton and Heather Russ, for your dedication to raising awareness for individuals diagnosed with craniofacial conditions. Special thanks to Ms. Shelton who has passionately devoted her heart to children and adults with craniofacial diagnoses,

**Sponsors**
- LBC Tank Terminals, Title Sponsor
- Empowering Motivated Women, Title Sponsor
- Allan Calloway and Maxcon, LLC
- Roy and Celeste Craeger with F.I.R.S.T.
- Dr. Payne and The Craniofacial & Plastic Surgery Center of Houston
- J.J. Shelton and Shelton Services
- The Women’s Hospital of Texas Pediatric Center
- Stephen Sproat and Hufco
- Epic Health Systems
- Helfman River Oaks Chrysler, Jeep, Dodge and Ram
- Republic Harley-Davidson
- Gus Salinas Photography
working year-round to ensure the success of this event and engaging with families by attending events such as CCA’s Annual Family Retreat and Symposium.

The events consisted of a brisket taco breakfast including Bloody Marys and a selection of cigars sponsored by Evergreen Environmental and Specialty Tank Services; and a boudin/sausage booth sponsored by Stronghold. Two Harley-Davidson’s offered by Republic Harley-Davidson were up for grabs on hole 8 on each course. Following the last golfers off the course was a BBQ lunch. During lunch we had raffles, a silent auction and a very exciting live auction. Highlights of the live auction were an original artwork by CCA adult Mary Elizabeth (M.E.) Sanders that went for $1,000 to JR Haack, Shelton Services, and a certificate for a pair of custom-made western boots that went for $10,000 to Ben Sheppard, owner of Cannon Industrial Services.

Deepest gratitude and sympathy for Ben Sheppard who lost his life on June 4th, 2017. We will forever be grateful for years of support and your generosity for our craniofacial families.

CCA Kids Ashley Bock, Jakob Happ and Wade White along with John Gorman, M.E. Sanders and Wesley Sanders were in attendance to represent those served by Children’s Craniofacial Association. CCA Super Sibs, always supportive of CCA, were Destiny Carlisle, Antasia Hart, Jessica Bock, Haley Lucas as well as Monica Shelton and Maggie McCloskey. Executive Director, Erica Mossholder, Board Members Tate Gorman and Haley Streff were also in attendance.

We appreciate the efforts of our incredible volunteers Wade White, Darlene Wright, Heather Russ, and Teresa Postel.
On April 4th and 5th, the Mecklenburg family hosted the 6th Annual Morgan Meck Invitational in Southern California benefitting the Children’s Craniofacial Association. We enjoyed catching up with our loyal group of participants this year and adding some new friends into the fold.

We are so grateful for our committed friends and neighbors who pitch in to help prepare for and attend this two-day event that continues to raise the bar each year. Morgan welcomed all participants and thanked them for their continuing support, encouraging them to “Not think about winning, but think about the children and grown-ups you are helping!” She also gave a rousing speech at dinner the second evening, proving that like her father, she shines with a mic in her hand.

The theme of the evening was truly family. Both of Morgan Meck’s grandmothers were in attendance this year, Debbie Mecklenburg and Karen Condino, who won First Place in the Women’s division!

Erica Mossholder, Executive Director, was also fortunate to have her parents, Andy and Melanie Yarbrough, in attendance and they volunteered on the course conducting the Game of Chance. Celebrating the importance of family continued as CCA Dads Bill Mecklenburg, Darin Dankelson, and Russel Newman shared personal reflections during a lovely dinner attesting to the amazing work CCA does. Darin Dankelson spoke about the powerful work his sons, Peter and Jacob, are doing as a team. He spoke of the diligent effort that his wife and CCA Mom, Dede Dankelson, has put into managing an extremely busy school visit and Skype session schedule. In addition to preparing for Peter’s 2017 major surgery, she also created a full website, PetesDiary.com, and social media pages to manage school visit requests and to showcase Peter and Jacob giving these presentations to schools across the country. One of those schools where Peter and Jacob did a return assembly is Ladera Ranch Middle School. This school has truly integrated Wonder into their curriculum and Chris Jones, the head of the English Department there, makes sure Wonder creates a lasting impact on the hundreds of students who participate.

Russel Newman delivered a moving appeal and spoke about the journey his family has been on for the past several years. Not only has his son Nathaniel endured over 60 surgeries related to CCA Dads Bill Mecklenburg, Darin Dankelson, and Russel Newman shared personal reflections during a lovely dinner attesting to the amazing work CCA does. Darin Dankelson spoke about the powerful work his sons, Peter and Jacob, are doing as a team. He spoke of the diligent effort that his wife and CCA Mom, Dede Dankelson, has put into managing an extremely busy school visit and Skype session schedule. In addition to preparing for Peter’s 2017 major surgery, she also created a full website, PetesDiary.com, and social media pages to manage school visit requests and to showcase Peter and Jacob giving these presentations to schools across the country. One of those schools where Peter and Jacob did a return assembly is Ladera Ranch Middle School. This school has truly integrated Wonder into their curriculum and Chris Jones, the head of the English Department there, makes sure Wonder creates a lasting impact on the hundreds of students who participate.

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Treachter Collins syndrome, but his wife **Magda**, has also been battling cancer, all while he and his younger son, **Jacob**, have been a rock for the family (and tearing it up on the lacrosse field!). The Newman family opened their home and hearts to the author of *Wonder* and the production team of the film to use their stories and experiences as a resource for what it’s like to live life as the “real” Pullman family. Their willingness to share helped shape this powerful story into the raving success it is today.

Winners were announced during the dinner for 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 **more than $70,000**. A special thank you goes out to our Platinum Level Sponsors: **Crum & Forster Insurance, EverGuard Insurance, Praxair, SES Insurance, Maria Amelio, Greg and Donna Bonnell**.

A special thank you is also deserved for **Christine Condino-Mecklenburg, Shawn Craig and Trina Conti** for providing incredible golf and hotel experiences for the auction along with **TaylorMade Golf** for allowing CCA to benefit from its Charity Purchase Program. We are also grateful for **Kathleen Philippi** who took these incredible photos.

**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 **Vue Restaurant** overlooking the Pacific Ocean in Dana Point, and transportation was generously provided by **ACCESS Destination Services**.

CCA and the Mecklenburg family would like to thank all of the volunteers, participants, contributors and donors who have made this a memorable and meaningful event.
When I was expecting my first child, Abby, my husband, Tom, and I received a very unexpected diagnosis: Pfeiffer syndrome. I immediately tried to learn everything I could, but the deeper I fell down the Google rabbit hole, the more overwhelmed I became… until I was connected with CCA. After talking with Annie and looking through the CCA box she sent me, I knew I wasn’t alone, and I started to feel more at peace with the journey ahead of us.

In one of the newsletters she sent, I read about the annual retreat. Even though Abby wasn’t even born yet, I knew I wanted to take her there. However, because of Abby’s surgeries and welcoming two more babies into our family, it took five years to make it happen. Let me tell you—it was so worth the wait! This was our first time in Reston, Virginia, and we all agreed it was an absolutely beautiful area. The beauty around us couldn’t compare to the beauty found in all of the participants within the retreat, though. From the moment we joined everyone on Thursday morning, we knew we were going to experience something special. The atmosphere of love and acceptance the entire weekend is something you just have to feel for yourself; it can’t be explained.

That first morning, Abby joined the other kids (we called it “camp”) while Tom and I attended the symposium sessions. Abby immediately connected with the other kids in the room, especially the girls around her age. Every time we checked in on her, she was happily running around with them, making crafts, and playing games. Meanwhile, Tom and I were connecting with other parents and learning at the various sessions. It was helpful to get example IEPs for students with craniofacial differences, and learning about self-care for caregivers was much needed. My favorites, though, were hearing about the experiences and advice from parents with affected children and from affected adults, especially the keynote speaker, David Roche. Although Roche’s humor kept us laughing, he shared some very poignant realizations. My favorite was, “My face is a gift because I’ve been forced to find the beauty inside myself. I’m lucky because I’ve had a head start with the work that everyone has to do.” I’m fairly certain that I’m not the only one who was touched by his words. I can only pray that my daughter, and others, will come to this conclusion as well.

Especially during the first day, it felt very surreal to meet families in person who I had “known” through social media for the past five years. I think this inner dialogue played on repeat: “Melissa, you may know who these kids are because you’ve watched them grow for the past five years online, but they probably don’t know you. So don’t run up and squeeze them! Chill out and introduce yourself like you’re not crazy!” Seriously, though, it was hard to control myself. I felt like I was meeting celebrities!

Being able to meet and develop friendships with other families was, by far, the best part of the retreat. Abby had never met another child with Pfeiffer syndrome, and suddenly, she was running around with a handful of Pfeiffer
At the start of my senior year at Falmouth High School, I knew that I would have to decide on a senior project; something that encompassed the rudimentary foundation of what I had accomplished thus far in high school, while alluding to what I wanted out of my future. Naturally, I chose to raise money and spread awareness for CCA Kids. Growing up around a close family friend who was heavily involved in this nonprofit, I saw the degree to which CCA was able to help individuals through personal and meaningful support, both monetarily and emotionally. Over the past 9 months, I was involved in numerous fundraisers, including a cocktails for a cause night, multiple bake sales, and the use of local sponsorships. Additionally, I spoke to numerous groups of people (most notably the entire freshman and sophomore class of my high school) in an effort to spread CCA’s message of choosing kindness and translating the universally beneficial values that resonate across the organization. Throughout this experience, I made sure to emphasize the messages and morals that CCA is founded on rather than simply focusing on the monetary goals I set for myself. This process not only made me a better person, but truly gave me a cause to be passionate about for years to come. Thank you CCA.

~ Dex Dremann

Cher’s fans, known as her “CherCrew,” held their annual fundraising effort to benefit CCA Kids in honor of Cher’s 71st birthday throughout the month of May until her actual birthday on May 20.

We’re so very grateful to Doug Wemple for gathering Cher’s “chickadees” together virtually and in person, and to his “meme team,” Lori Jerome and Terri Hughes, for creating easy ways to spread the word on social media.

The group encouraged participation with early donor incentives of a special CherCrew limited edition of Me G Records new CD release in the UK to the first 50 donors. They also raffled off Cher collectibles for every donation. Prize donors included Anonymous, Stacy Arrighi, CCA, Cher Crewz / R&R Dream Vacations, Scott Clarke, John Comanse, Sue Dolby-Dawson, James Lonsdale, Janet Novick, Donna Schellack, James Waters, Doug Wemple and Deb Wood.

Last year was a landmark birthday for our spokesperson, and she is touring this year, so we knew many fans would be spending their money on concert tickets. However, these amazing fans dug deep to inspire gifts totaling over $5,000 for our cause, because they truly believe in CCA Kids and want to help! Wow!

Many thanks to all who assisted, donated, and participated by sharing and retweeting posts. We love our fantastic CherCrew!
It’s the event of the year—a car raffle for CCA Kids! Nick Wiese of Mars, PA, and his parents—Mike and Rose—are hosting a nationwide car raffle and CCA needs your help to spread the word! We are selling only 1,000 raffle tickets and the winner will get to drive home in their choice of a Jeep Wrangler, a Dodge Ram, or a Chrysler Pacifica, valued up to $50,000!

The official rules are available online, but here’s the overview: Buy a raffle ticket for $100, or increase your chances by purchasing 3 tickets for $250. The ticket sales will continue until tickets are sold out or through September 30, 2017.

We are so grateful to the Wiese Family for spearheading this fundraiser. Together we can make it a huge success!

About the Wiese Family

Nick, 28 years old, is an active member of CCA’s Adults and Alumni group. He participates on our monthly video calls and has helped arrange several guest speakers for the group, including his brother Arch, who spoke about what it was like growing up from the sibling’s perspective. Nick works at Cinemark Theatre at McCandless Crossing, and has played a role in helping CCA plan for upcoming educational screenings of Wonder that will be hosted this fall.

Nick is a proud “Real Life Auggie,” and volunteers as a part of the speakers’ bureau CCA has set up for schools to request classroom visits. Most recently, he spoke to hundreds of students in the North Allegheny School District, where he shared how the book Wonder has changed his life, giving him a platform to advocate for tolerance, acceptance, and kindness to students who have never met someone with a facial difference.

“I tell the kids my life story, how I was bullied and how it felt. To me, doing that is pure joy, because it lets kids know they’re not alone; that someone has gone through what they might be going through,” he said.

And that is perhaps the most interesting part of the Wiese’s story. Mom Rose has said while growing up, Nick was very well adjusted. They did not seek out the craniofacial community because life was mostly ordinary. Other than surgeries and medical visits and the occasional teasing incident, they did not feel a lack of support in their community and enjoyed a large, close-knit family. However, one day they decided it would be good for Nick to meet other young adults with Apert syndrome and other craniofacial conditions, so they attended their first CCA Retreat in Hershey, PA. Rose said she was stunned at how much it meant to Nick to connect with other CCA young adults. He definitely had support growing up, but this type of friendship was different and really changed Nick’s life.

The whole family found a comfortable fit immediately along with other CCA families and staff. Nick jumped right in as a strong advocate for CCA Kids.

Kate Wieses hope to encourage other families to connect early on so their children grow up with a strong network of friends who understand their unique journey. Rose was so moved by her experiences with CCA that she now serves on the CCA Board of Directors, and she and Mike have successfully garnered two major grants for the CCA Choose Kind Wonder initiative. Their efforts will put Wonder books in the hands of 950 students in the Pittsburgh area and helped other Pennsylvania families attend Retreat! Way to go, Wieses! BUY ONLINE: bit.ly/ccacarraffle or call the CCA office!
get your car raffle ticket today!

Sabrina Robineau and Frederick Seitz, CCA Adults, sold tickets at the Steel Valley Super Nationals in Canfield, OH, in June. Thank you to the entire Seitz family who pitched in to make this opportunity a reality, including super sellers, Stephanie Fray and Jonathan Seitz!

dance for kindness

the fourth grade students at Pope Elementary School in Arlington, Texas, were so moved by the story of Auggie that after reading Wonder they hosted a Kindness Dance! The students worked for a week on decorations and encouraged all of their friends to attend. They charged an entrance fee of $2 and sold pizza and soda at the event. It was a fabulous time celebrating kindness and raising $445.22 for CCA Kids!

Thank you Ms. Deana Peterman and the Pope Panthers for throwing kindness around like confetti!

mrs. friend’s third grade class

today I asked my class what the #1 one thing they learned in third grade was, and they answered, “To be kind!” A lot of our year was based off the reading of the book Wonder by RJ Palacio. Today I gave each students a blue bracelet that says “Choose Kind”—our motto for the year. I told them it was their job to continue to spread kindness as they grow up and move on. We’ve helped our buddies at Oliver Woods, kids at Mott’s Children’s Hospital, raising money for a local fallen hero, and given 300 pounds of used school supplies to kids in Uganda. We’ve also helped each other. Our future looks bright guys, these kids are full of courage and kindness and they are ready to go places!

~ Megan Friend
with lots of fun dining, shopping, and recreation for the entire family.

Social media has reshaped how our families connect over the years, and many of our new families, as well as those who had not attended previous retreats, feel like they already know each other when they arrive to their first Retreat. What it is impossible to convey in words, is that thanks to these online connections, the initial “get-to-know-you” period is replaced by giant, welcoming hugs since everyone feels like forever friends already.

And the very best part is watching our CCA Kids run right up to other kids and squeal with delight! Instant friendships are formed, tiny hands are clasped, and little feet run off to play in sheer joy!

This year, we had expert speakers in the field of craniofacial medicine who generously gave of their time to conduct the 9th Annual Craniofacial Symposium. We would like to thank the following team members and volunteers from Richmond Plastic Surgeons, St. Mary’s Cleft & Craniofacial Team and Children’s National Health Systems:

- Jennifer Humberson, MD
- Albert Oh, MD
- Linda Shait, BSN, RN
- Miriam Weiss, CPNP-PC
- Heather Bender, PhD, LCP

We would also like to thank Pat Jolley, RN, BS and Jennifer Obenchain from the Patient Advocate Foundation; Catherine Navarro (Yoga Instructor); Rebecca Wilkinson from Well Being Workshops; and CCA family members: Dave and Liz Anderson; Lisa Brown, BSW, M.Ed.; Drew Davis; Sandy Davis; Nicole Hilton; Russell and Anna Joyce; Jono Lancaster; Rose Seitz; Steven Weiss and Rebecca White, BSN, RN, MBA for either holding sessions or participating as panel members.

Presenters discussed topics including IEP’s, Dating with a Difference, and Sleep Apnea, just to name a few. This year we had the talented David Roche as our keynote speaker and he was simply amazing! David’s speech had the crowd laughing and crying, and everyone left feeling empowered. He also conducted another session where he allowed other craniofacial kids, teens, and adults to share their stories with everyone!

We also had exhibitor booths this year and would like to thank them for being part of our Educational Symposium: FaceBase, conducting craniofacial imaging, Rare Science, who generously handed out 98 Rare Bears to CCA Kids, and Smile with Simon, whose Patricia Simon, RN shared her story and knowledge of living with a cleft lip and palate through her adorable, loving Simon characters.

And last but not least, a HUGE thanks goes out to all of our amazing families who volunteered their time during the symposium and registration: Joe Brooks, Martha Brown, Catherine Burzio, Christine Clinton, Marty and Lindsey Collins, Abbey Lehman, Jill Laufbaum, Anne Moore, Roseann Opdyke, Sabrina Robineau, Jaci Samhammer, Diana Sweeney, Nick Wiese and Quentin Zaengle.

Friday morning families gathered for Group Meet-Ups, one of our most popular additions to this year’s Retreat. During these small groups, 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.

Thank you to the following volunteers for helping during the meetings: Lisa Bock, Jennifer Kilmer, Janis Macut, Denise Rast, Dorina Watkins, Emily Paulson, Meg Storie, Paula Guzzo, Harlena Morton, Sabrina Robineau, Kris Dale, Alison Morrissey, Dave and Liz Anderson, Ed and Amy Kern, Rachel Lance, Melissa Jurek, Tosha Walker, Theresa Hospodka, and Carrie Ingram.

Families headed to the Watermine Family Swimmin’ Hole and cooled off in a lazy river and for the more adventurous types, the awesome waterslides. Everyone had a splashing good time! For those who stayed back at the hotel, they were able to meet a Police K9, thanks to our Retreat Volunteer of the Year, Barbara Muller and have their photo taken with Lentil! Thank you Lindsay Condefer, Lentil and Sprout for all you do for CCA!

Once again, families from across the United States and beyond brought baskets of goodies from...
their areas for CCA to raffle! These baskets held everything from sports souvenirs and memorabilia to local food specialties and everything in between. The generosity of our families never ceases to amaze us.

Friday night’s Teen Night wouldn’t be possible without the help of our chaperones each year. Thank you Reed and Heather Wills, Harlena Morton and Shannon Donahue for all of your help!

Saturday, the families gathered for breakfast and then we jammed everyone in the hotel lobby for a giant group photo. Seeing everyone together in one area in matching shirts was an awe-inspiring sight!

After lunch, we held a Talent show and let’s just say…CCA’s Got Talent and lots of it! Not only was the dancing, hula hooping, karate moves, singing, gymnastics, instrument playing excellent … it was incredible to see the hearts and souls of our families displayed on stage, and there was not a dry eye in the house. The audience beamed as all ages performed well-rehearsed, moving, and exciting acts. By popular demand, we will be doing another Talent Show next year, so put on your thinking caps and start planning your performance for next year!

Saturday evening, after a special tribute to our CCA Sibs, read by Jessica Eakright, CCA Mom, CCA Adult Bianca Moon and a group of our CCA Kids, CCA Teens, CCA Siblings and CCA Adults performed Bianca’s original song, “Wonder.” We would like to send out a special thank you to Edward Edwards for helping us coordinate this touching performance. After everyone joined together in singing an encore of the song, the dancing began, and continued long into the night!

Sunday morning is always bittersweet. There were lots of hugs, promises of staying in touch and, as always, a few tears. We really enjoyed meeting all of the new families and catching up with old friends. There is no magic quite like Retreat to warm the heart and soothe the soul. It is the booster shot of joy we all need. We hope everyone had the TIME OF THEIR LIVES!

We were so fortunate to have four amazing photographers and return videographers to capture moments at our events. One of the best ways to combat the post-Retreat blues is looking through the awesome photos and watching the Retreat video. This gift of time and talent to CCA Families is truly appreciated. We extend our deepest gratitude to Michelle Zingraf (michellegracephotos.com), Lisa Kammerman (kammerman.com), Eva Nicholas (evanicholasphotography.com), and Dillon Donalds (dillondonolds.com) for capturing gorgeous candids for us and to Trip and Faith Owens of Threefold Films (threefold-films.com) for filming during Retreat. Stay tuned on social media for more photos and videos, and enjoy some of their work in the photos here.

You too can get in on the fun next year! Don’t delay, registration is officially open for the 2018 Salt Lake City, UT, retreat, June 28th-July 1st and we hope to see you all there!

Be sure to read about a first-time retreat attendee, Melissa McGowan (page 10), and her family’s experience.

Annie Reeves
CCA’s Program Director
friends. Even though they were having fun like any group of young kids would, I had a different feeling watching them play. I knew that these girls could understand her like no one else could, and having friends like that will be invaluable in the years to come. It was also inspiring to meet affected adults (for us, especially those with Abby’s condition) who were thriving and passionate about their life purpose. I’m so thankful that Abby will grow up having them as role models.

The rest of the weekend was a whirl of activity and emotions. The kick-off dinner started with lively conversations, and then we enjoyed Roche’s short film, *Love at Second Sight*. After the film, the kids watched a magic show, and the adults got to chat, purchase CCA shirts (check out my new one in the pictures!), and scope out the raffle baskets. We were all exhausted when we got back to our room, but we were also already looking forward to the next day.

Friday began with group meetings, first grouped by syndromes and then by age groups. Our moderators prepared fun ice breakers that got the whole family involved and helped us get to know one another better. Connecting with families who understood exactly what we have gone through and what we’re facing was powerful. After the group meetings, we had time to get ready for the big off-site trip to The Watermine Family Swimmin’ Hole. We picked up our boxed lunches and had a picnic in the park while waiting on the shuttles. We couldn’t have asked for better weather, and it’s safe to say that everyone had a blast swimming, sliding, cannonballing, bucket dumping, and floating on the lazy river (although I found out the hard way that one shouldn’t get too lazy…closed eyes could lead to going under a waterfall). Being out and about as a group also gave me the opportunity to share about CCA with others. True, we practically took over the place, but there were some people, who were there outside of our group, and now they’re in on the awesomeness that is CCA along with the “normalness” of our kids—they just want to have fun in the water like everyone else!

After post-water park naps, we attended the family night dinner and basket raffle (I would like to point out here that although we entered many tickets in the drawings, we decided to let our friends win everything this year. You’re welcome.). I think it’s great that the CCA teens and adults also had special events that were geared toward them that evening. I wanted to peek in to see what was going on, but I managed to restrain myself. Between this and not running up to my “celebrities,” I’d say I practiced some excellent self-control. There was, however, an outside-of-CCA celebrity there who I couldn’t hide my excitement to meet. Jacob Tremblay, the star of the upcoming movie *Wonder*, also attended the retreat. He was very polite and happily took a picture (or four) with anyone who asked.

On Saturday morning, we turned the Hyatt Regency into a sea of gray for our retreat group photo. I can’t wait to see how the photographer’s pictures turned out! After this, we had some free time which we used to explore the area a bit and go out to lunch with a few other families. What happened after lunch was, for me, the highest point of the whole retreat: the talent show. I didn’t know it at the time, but I later learned that this was the first year in several years that the talent show was held. I honestly can’t imagine the retreat without it! Every person who got up on stage was incredibly inspiring. From singing and dancing to...
playing instruments and hula hooping, we had it all. The performances were so heartfelt that my husband whispered after the first few acts that he was worried he might be dehydrated after this because it was all making him cry. It was just so wonderful to have people share their passions in this way.

Unfortunately, the fun had to come to an end, and that end began with Sunday’s farewell breakfast. I’m not sure why, but it seemed like everyone (including me) waited until then to take a lot of the group pictures they wanted. Let’s rethink this next year, folks; too many of us were crying (or laughing from Cheerios photo bombing groups shots)! Despite the tears, it was nice to spend a little more time with everyone before heading home.

Abby was sure that if she didn’t say goodbye that we wouldn’t have to leave. It was hard to convince her otherwise, but she eventually gave goodbye hugs to all her new friends.

I really can’t say enough about how wonderful the CCA retreat was. There were over 500 people there, and I now consider them all part of our extended family. I need to take this opportunity to give our sincerest thanks to everyone who had a hand in planning this event. Please know how deeply appreciated your work is.

We may have been first-timers this year, but the McGowans will now be regular retreat attendees, which is funny considering this last bit I’d like to share.

On Tuesday night before the retreat as Tom and I were finishing packing, he said, “Melissa, I just want to make sure we’re on the same page here. This will not be an annual thing for us. I’m sure it’ll be nice to go and meet people this year, but we’ll only go, maybe, every five years or so.” I felt like I couldn’t really argue over something I’d never attended, so I didn’t really say much back. Fast forward to Thursday, after the first day of the retreat. As I’m getting ready for bed, Tom came up to me and started talking excitedly, “So next year in Salt Lake City…”

We hope to see you there!
For the next 5 years that bond became stronger and stronger, and her love for me grew and grew; I even called her “Mum.”

But despite that bond, she tried to reconnect me with my birth parents in case, maybe, they just needed more time. All the attempts were declined.

So on May 18, when I was 5 years old, Jean adopted me and officially became my Mum… but she always had been!

Jean was a single mom in her 40s with no job and living in a rented accommodation, but she had so much love and fight that none of that mattered and she gave me a start—a family I so nearly missed out on. I hate to think where I'd be without her.

I didn't think I looked any different when I was younger, I used to tell the kids in my class that I could do math on my hearing aid and that my Mum went to the hospital and out of all the babies there she chose me! I thought I was cool, I loved being different! I loved standing out.

Life was good, we even celebrated my Adoption Day as a second birthday and as a kid that meant more presents—yes, I was spoiled!

As I grew older, I did start to notice the stares but I didn't quite process it at first. I just thought people were looking.

But as I became more aware, I noticed the stares along with the name calling and kids pulling their eyes down and laughing at me. “Run away from him in case you catch it!”

Needless to say this broke my heart; I was embarrassed to talk to my friends, and scared to talk to the teachers, so I spoke to my Mum about it.

She cried.

I felt so guilty that I had made my Mum cry, my very own super hero. I felt like I was hurting her.

As I grew older I became better equipped at dealing with it all, and I didn't tell my Mum, the teachers or my friends. I kind of developed this attitude: it was me against the world, which is at times a strength and a weakness.

By the time I reached high school, the older kids were mean but I was popular amongst my peers, and I excelled at sports and in the class room. Life was good.

My most difficult time was when I hit 15 and onwards: my friends started getting into relationships and that just didn't happen for me. I always seemed to be everyone's best friend... the one they went to when they wanted relationship advice.

I started to wonder if anyone would ever find me attractive looking like this. I'd think, if my birth parents couldn't love me, who could?

I began to hate them and the world we live in; it seemed like everything was based around looks and image and that there wasn't a place for me in it looking different.

My world became full of negative thoughts!

I'd often look in the mirror and push my eyes up to try and imagine what I would look like if I was “normal.”

As I did, I thought, “Looking like this, will I ever find work? Will I ever have a family of my own? Why me? How can I go on?”

I got through school and headed to college with life seeming to get harder and harder. Friends started getting small jobs and going on holidays together. They always asked me to go, but I always said no; I began to hide away!

And when I did go out, I spent more time hiding away in toilets and getting from A to B as quickly as possible, looking at the floor and thinking that every laughter I heard was about my face.

I left college with no goals, and seemingly no direction in my life. I was jealous of my friends and wanted to do everything they were doing, but I couldn't. The world was stopping me.

When I turned 19, my friend Ben came to me with a bit of tough love. “Quit feeling sorry for yourself, I've got you a job in a bar alongside me, it's a right laugh,” he said, “We get drunk and the chicks are hot!”

I thought he was having a laugh, but he was being serious and gave me my uniform, and I was starting in a couple of weeks.
I freaked out, all of the times that I spent in bars and clubs, I had found them so humiliating.

But somehow, I managed to get myself to the bar. It was student night. Mum was crazy excited and as I turned up, I was pumped! Nervous and dripping with sweat, but I was pumped!

As the bar started to fill up, I was fine serving pints, but as the night wore on, it became harder and harder.

I started to see all those stares and all those people staring at me and making fun of me... I wanted to disappear!

My first break came, and I called it quits, and got a taxi home. Mum must have been waiting for me at the bottom of the stairs because I opened the door and she sprung up, “How was it, how’s it gone?” I wanted to cry. I wanted to tell her everything but all I could say was that it was ok, but the money, the hours weren’t for me.

I went to my room consumed with the thoughts of “Why me?” and “Why did I have to look like this?”

A week passed and I headed back to give it another try, with a little more hope and determination this time ’round. But nothing had changed, it was still horrible and everyone in the world was horrible!

I was looking for that opportunity to sneak off, maybe my first break, but before that the bar just got crazy busy, and I was stuck! I got into a routine of looking at people's mouths to get their order, then I’d look into the pint glass, rather than everything around me. Even so, I couldn’t help but notice this huge guy leaning right over the bar staring at me. I thought “Oh crap, I hope someone serves him before I get to him. He’s gonna make this night a living nightmare.”

Nobody did, so it was down to me. I asked him what he wanted to drink.

“Hold up mate, what’s wrong with your face?” he asked. “Was you dropped when you was a baby?”

“No I was born like this.”

“Is that a hearing aid?”

“Yes...” I’m thinking what an arsehole!

“Yes, it’s a hearing aid.” (I was just waiting for the insult! The joke.)

“Can you hear anything without it?”

(Here it comes, I braced.)

I replied “No, I can’t hear very well without it.”

“Mate, ya lucky,” he boomed, “I’ve got a wife at home and I’d do anything to not hear all the whining and nagging that she does!”

I actually laughed, and replied, “I turned my aid off when my Mum nagged at me!” He bought me a drink, shook my hand, asked my name, and off he went.

I finished my shift and couldn’t help but think and realize that I’d gotten him so wrong... and if I got him wrong, who else and what else was I getting wrong?

The laughing, the stares, were they actually about me? Had I just created it in my imagination, fearing and thinking the worst of every situation?

I continued to work in the bar and my confidence began to grow; I started interacting more and staying behind for drinks.

I met a girl called Beth. Beth did ballet and loved the Foo Fighters! I thought she was the coolest person I’d ever met and I fancied her so much.

But she would never be interested in me, I thought.

One night she came over and as we spoke she became shy and a little awkward. She asked me if I wanted to go for a drink?

“Yeah we’re all going,” I said.

“No I mean just me and you?”

see jono, page 20
I’m thinking, “Really, why would you wanna do that?!”
So I had to ask, “Really?”
“Yeah, I think you’re pretty cool,” she said.
I kid you not: in that moment I went from thinking I was ugly to thinking I was a rockstar!

The power of words!
I didn’t play it cool at all. I couldn’t hide my excitement and was like “Hell yes, I’d love to! when do wanna go?”

We went out the next day. We walked around our local lake. We were both so cold but didn’t have any contact; I was crazy nervous. Conversation was flowing though, so okay so far!
She invited me back to her student digs and we ate homemade vegetarian curry in candlelight, whilst sitting on her bedroom floor, drinking red wine. She had no furniture and we talked about everything and anything.

Upon conversation, she told me that she found herself staring at me all the time. I got uncomfortable, but she then said it was because she loved looking at my face. She came close and kissed me!

My first date, my first kiss and with the coolest person I’d ever met!
I spent the night and as we were sunbathing, I was flicking through a magazine and every article was still about looks and image: celebrities photographed and called out for having wrinkles, or still having baby bumps, despite their newborns being born last week.

And the stories of individuals getting surgery to change their appearances, just because they can. It seemed never ending.

It angered me, and I wanted to challenge that outlook.

I shared my story with a writer who published the journey that I had been on, from hating my appearance to loving all that I am.

The BBC saw my story, loved the message that I had, and together we produced a documentary called Love Me, Love My Face. This was a huge success with opening viewing figures of 9 million! The BBC loved me and decided to offer me presenting work, because they loved me on screen! I was able to present and do programs on subjects that were close to my heart.

These went global, and I had people from all over the world getting in touch with me, but that came with both positive and negative comments.

For me, the best thing to come out of it was families that were living with Treacher Collins were reaching out to me. They loved my confidence and asked me to meet their son or daughter; it was something that I craved when I was younger, so I made it happen, travelling all over the UK.

Schools got in touch, wanting me to work with students low on confidence. This then developed into anti-bullying workshops, and
talks on how your attitude toward yourself and others will play a huge part in all of our lives.

Families and schools started to reach out from all over the world, so again I made it happen, covering areas such as Australia, New Zealand, Ukraine, Mexico, Canada, and all over the States.

This year, along with my friends I’ve started the **Love Me Love My Face Foundation** supporting families and individuals living with TCS and other craniofacial conditions, in hope we can do more, on a larger scale.

I often think what would I have achieved if I had found that acceptance earlier, and that’s what motivates me to do what I do.

My face was never ever gonna stop me from finding work or love. All the hate in the world wasn’t ever going to stop me! Sure it made it a little more challenging, but every single one of us has our own fears and insecurities; we’re all gonna receive hate or get told we won’t achieve our dreams!

**I’ve learned over the years the only thing that was stopping me was myself.** I had chosen to hide away… I filled my own head up with negative thoughts. And I also took control and stopped it by choice.

**Today, my face hasn’t changed, yet my world has.** Along with my friends, family and even the strangers that I’ve met along the way (that any of us can meet at any point in our lives), I have created this amazing world that I live in… my world, my very own adventure.
In October 2016, we received the unfortunate news that our son Matthew needed to undergo a second cranial vault remodeling operation. We made the decision to travel to Dallas, TX to have the surgery, in hope that Matthew would never have to go through this again.

Our insurance refused to pay for any of the medical expenses, placing the entire financial burden on us. Having to raise the entire cost of the surgery, plus all of our travel expenses was absolutely overwhelming. I heard about CCA through an online support group and decided to fill out an application.

Over the next couple months, the staff were extremely kind and compassionate. They would quickly answer any of my questions. They accepted our application for assistance. They paid for and even booked our hotel at the Residence Inn, where we had an extremely positive experience. They also paid for a large portion of our airfare.

I don’t know how we could have done this without CCA. They made an extremely stressful situation just a little bit easier to deal with. I loved working with the staff, and I only wish we had the opportunity to meet them in person while we were in Dallas. I can’t say enough about our wonderful experience with them.

Chesney Price
registration is now open for 2018 cca’s annual family retreat
June 28-July 1 in Salt Lake City, Utah

Please join us for an educational symposium, talent show, dinner/dance and much more! For more information, please contact Annie Reeves, AReeves@ccakids.com.

We hope to see you there! We are accepting applications for scholarships for this Retreat until December 31, 2017. Register by May 1, 2018 to get the early bird price of $100. Registration will increase to $125 starting May 2nd.

Hello, my name is Amelia Gerard. I am eleven years old and live in Jupiter, Florida. I am the luckiest girl on earth to have a brother as wonderful as Caden. He was born with hemifacial microsomia. His ear is not fully made and, he is deaf in his right ear. Also he has a crooked mouth so he needs help with that too. He is the center of my family. So, I learned a little more about his disorder, and then I decided to raise money for CCA by having a lemonade stand!

On the day we had our lemonade sale, we started telling friends and family to spread the news. The price for lemonade wasn’t much, but more money was given than needed. We sold freshly made cookies, as well. We handed out flyers and bracelets that came from CCA. My brother helped and so did my sister. We had fun and were happy because we knew we were doing something great! As we ended, we started counting money and we raised $83!

But as time went on, more people donated money, and then our grand total was $123! We are happy we supported CCA, and hope to do it again.
At an early age, Macey desired to do a lemonade stand. Mom procrastinated every year, but constantly imagined what it would look like. Well, 2 years ago I decided I would make it happen.

Macey loves CCA’s Annual Retreat, so she decided that she would use the money to help pay for the Retreat. So after 2 successful lemonade stands in 2015 and 2016, she and her sister raised enough money to attend the Retreat last year.

This year we decided as a family we would donate the proceeds to our charity of choice which is CCA. We have never forgotten how CCA was there for our family when we needed them, and how they help families every day. The girls worked extended hours preparing posters and delicious treats. We packaged well over 100 treats! They got up the next morning and helped me make the lemonade without any complaints.

The community showed an outpouring of support for the girls, and the donations came in far beyond the treats and lemonade we had to sell. It is our prayer that the funds will help another family get the medical treatment they need or the therapeutic fun of a CCA retreat.

Loving everything you do at CCA! Love Macey and Allyson’s Lemonade Stand and Stacey Atkins, #CCAMom

“Through God all things are possible.”