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## bella's journey, my resolve

By Eve Fuentes

My husband and I were prepared for our daughter to have some type of medical issue, but were not fully prepared for the diagnosis. We knew she had a type of Craniosynostosis through the numerous ultrasounds prior to her arrival, but even the doctors were shocked with the syndactyly of her fingers and toes when she was born. Once we were both discharged from the hospital with laundry lists of her conditions, despite my knowing better, I searched the internet.

My heart sank.

All I felt was that my little girl's future was going to be filled with surgeries and worse, the unknown. To add fuel to the fire, a family relative (a former Special Education Assistant at that!) told me that Bella would be wheelchair-

see **bella**, page 20



## retreat recap

Every year, I hear, "This was the best Retreat yet!" I am not sure how that can be possible, but somehow I feel that way too! The **28th Annual Family Retreat & Educational Symposium** was held in Salt Lake City, UT, June 28th-July 1st, and was by far, our largest retreat to date, with **160 families—representing 168 individuals and 1 dog with facial differences—** from 33 states, plus Australia, Canada, and the United Kingdom. Of the 160 families, 55 families were first-time attendees.

With such a large group, we took over the scenic **Little America Hotel**. The hotel provided us gorgeous accommodations conveniently next to the

see **retreat recap**, page 8



# meet aaron kimberlin



yet Aaron knew it was time to be born. He knew he needed a little help.

Aaron was born at 35 weeks. Araceli and Matthew held their breath until he gave his first breath, as the doctors had warned them his lungs may have not yet been fully developed. Apart from a couple of bruises from the delivery, Aaron looked and seemed like a healthy, and fully developed, baby boy. He followed mom to her hospital recovery room, and posed for a thousand pictures with grandparents, aunts, and cousins.

However, his blood sugar levels skyrocketed all night long. The next day, Aaron was whisked off to the hospital NICU unit where he would spend the next 29 days of his life. The NICU was an emotional roller coaster for everyone involved. Some days, his parents would go home from spending the day at the hospital, and Aaron would be thriving in his blood sugar levels and temperature; they would come back the next day to find out those levels had plummeted throughout the night. Doctors and nurses couldn't quite figure out what was going on with Aaron until day 10.

After several tests, Aaron was diagnosed with a congenital heart defect. He had two holes in his heart, and a valve that needed to be repaired. After about six months of rigorous feeding and medication schedules at home, doctors determined Aaron needed to undergo open-heart surgery. Up until this point, the heart condition seemed like an isolated medical condition. It was right before the first surgery when suggestions pointed out that Aaron may have been born with Crouzon syndrome, just like his mom. Blood tests revealed it to be true.

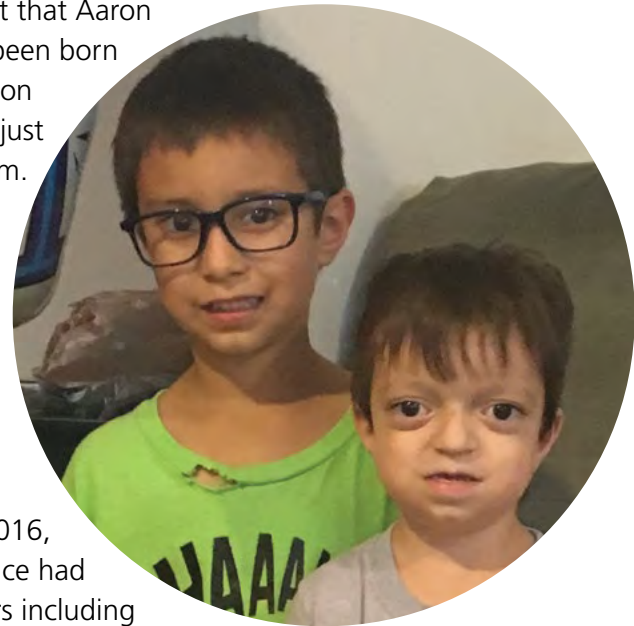
Aaron underwent his first major surgery in February 2016, and has since had three others including a cranial vault, and two to fix hydrocephalus. Every single surgery he has gone through, he has bounced

back like a champ, usually faster than doctors say, and surprising everyone with his resilience and strength. His zest for life is contagious. Aaron's favorite activities include dancing and wrestling with his brother. He has inspired so many with his story already, and will continue to make a difference as he grows older.

**aaron Riley Kimberlin** has always been a bundle of surprises. But his surprises make him one of the most incredible, unique and interesting kids on the planet.

He celebrated his third birthday on June 30 with cake and donuts (he has a tremendous sweet tooth), opening *Incredibles* toys (that's his favorite movie) and blowing bubbles outside. It's amazing to think how far he has come in three short years of life.

In June 2015, his parents, **Araceli** and **Matthew**, along with older brother **Aiden**, were quite surprised when he decided he was ready to meet the world. No hospital bag had been packed, no maternity pictures had been taken,



# ccakid

# ccasupersib

## meet aiden kimberlin

### Super Sib **Aiden** **Matthew Kimberlin**

has a smile that can light up any room. He lives to entertain, whether telling jokes, or being the center of attention. He loves to bring joy to the ones closest to him, and to people he meets.

Aiden is seven years old, and is entering the second grade in August. He excels in every subject in school, and is enrolled in a dual-language program. He has been learning how to speak, read and write in English and Spanish since Kindergarten. Even though he succeeds in all his subjects, his favorite is Math.

He adores his younger brother, **Aaron**. Even though there is a four-year age gap between the two, that hasn't stopped Aiden from opening his heart and making his little brother his best friend. You can often find the two brothers wrestling or holding an impromptu dance party

in the middle of the living room.

Aiden's heart and loyalty toward his brother is unrivaled. Even though Aiden has had to walk through four major surgeries with Aaron so far, he has not let the changes in situations bring him down in any way. He always helps with surgery prep, keeps his mom and dad calm during the surgery and recovery time, visits his brother in the hospital, and makes sure he has everything he needs.

From the time Aaron was born, Aiden has been helping mom with his little brother. When Aaron spent

time in the NICU, Aiden would put stickers on the tops of Aaron's bottles so his mom could take them to the hospital. When Aaron came home from the hospital, Aiden loved to cuddle with his brother, and always exhibited a gentle heart toward the new family member.

This Super Sib joined Boy Scouts about a year ago. He has thrived in his pack earning badges,

camping, learning about safety and survival skills, and helping the community. Recently, he was promoted from Tiger Cub Scout to Wolf Scout.

Some of Aiden's favorite activities include playing video games on the Wii and iPad, and collecting toys, such as bobble heads and McDonald's Happy Meal prizes. After working hard at school all day, Aiden loves to relax by watching his favorite TV shows, like *Duck Tales*, or tuning in with his younger brother to watch anything on Disney Jr.

**Join the Kimberlin family  
August 16 in Dallas for  
Family Night Out!**



# ccaadult

## meet megan brown

### Life Is an Adventure!

From my earliest memories, I have always been on adventures. Whether it was to the hospital to have surgeries, or travel throughout the United States to visit relatives.

I was born with a benign tumor called a hemangioma. When I was a baby, doctors tried different treatments to stop the tumor from growing on my face. Finally, it was an experimental drug, at that time, that saved my life. The tumor faded away due to the drug, but the next step in my craniofacial journey was to have 21 surgeries throughout my childhood.

Despite having that many surgeries, I still had a pretty fun childhood. I am the youngest of four kids. I have two older brothers and a twin sister. My twin sister was not born with a facial difference but has been a built-in friend and protector for me throughout my life. I have always looked up to my three older siblings, and wanted to do the sports and hobbies they did.

Since I was 5 years old, I have played many sports. When I was a kid, soccer was my favorite to play, but now as an adult I love running long distance and shooting hoops. Two years ago, I ran my first half-marathon. The life skills and drive I learned from my siblings and playing sports have carried me in other areas of my life.

In August 2017, I took a bold step. I offered teachers *via* Facebook, whose classes were reading *Wonder*, that they could Skype me, a real-life Auggie, free of charge.

The response from it has been nothing short of incredible! As of right now, I have shared my story more than 180 times across all 50 United States, plus 12 other countries across five continents.

One thing I have learned from this experience is that when we focus on the similarities, more than the differences, life is more enjoyable and better for everyone. I truly believe God has made me this way for a reason, and through Him I have been able to turn my pain into purpose. Through all the highs and lows in life, the scars on my face are just a roadmap to my past, but they do not define my future and the adventures yet to come.

Megan (right) and her twin sister, Sarah (left)

# Spreading the CHOOSE KIND movement takes teamwork, dirt and sweat! garden tour and tips raises over \$10,000 for cca!

By Virginia Wiese

When my sister-in-law, **Rose Wiese**, decided that she wanted to do a fundraiser for CCA, her first thought was to somehow use her passion for gardening as the starting point. What evolved was a two-evening event this past June in the gardens of the home she shares with my brother, **Mike**, and their son, **Nick**. This little idea blossomed into a fundraiser that netted **over \$10,000** for CCA!

Rose wanted the Garden Tour and Tips event to be not only a fundraiser, but also a chance to educate those attending about CCA. She says, "Garden Tour and Tips was a special opportunity to talk with folks about CCA and what the organization has meant not only to our family, but to countless other families

that are faced with the challenges of craniofacial differences. Every single day, CCA is working to spread kindness. And, if you support an organization whose message is spreading kindness, it's a powerful message for the whole world."

To help with the success of the event, Rose counted on a group of friends and family who helped her with everything from invitation development, and spreadsheets for tracking RSVPs, to the design for the T-shirt, and hands-on work in the garden. One friend, who is also an avid gardener, even made beautiful cement cast leaves that were a huge fundraising hit.

The week before the event, **Bill**, a close family friend, tragically passed



away. That same week, Rose's oldest brother, **Pat**, also died unexpectedly. With the Garden Tour and Tips less than a week away, Rose questioned whether she could still host a successful event and contemplated cancelling. But during this time, she also realized the powerful "ripple effect of kindness."

"So many people came out to share stories of how Bill's and Pat's kindness touched their lives. And they, in turn, shared of themselves, and showed amazing support and kindness to us during that sad time. It was truly humbling... and also inspiring. I wanted to honor the ripple of kindness we

received by continuing the kindness, and the Garden Tour and Tips was a perfect opportunity. Thanks to the support and love of family and friends, the event was a big success!"

**Thank you, Wieses,** for opening your hearts and home to help all of our CCA family.

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*Rose is passionate about God and her family. She and **Mike** have been married for 34 years and are blessed with four great kids and a wonderful daughter-in-law: **Arch**, and his wife, **Stephanie**, **Nick**, **Elizabeth** and **Dan**. Rose is also passionate about CCA, where she serves on the Board of Directors.*



# 7th annual morgan meck invitational benefiting cca



**O**n April 18th and April 19th, the **Mecklenburg family** hosted the seventh annual Morgan Meck Invitational benefiting Children's Craniofacial Association. There were 40 golfers from across the country, and approximately 70 people who attended dinners and participated in a significant way. The guests also included four amazing CCA "Kid" attendees: **P.J. Reynafarje, Keegan Strogatz, Michael Brown,** and **Jono Lancaster**. This gave our participants the opportunity to appreciate the lifecycle of CCA Kids from newborns, to active and engaging toddler, to a highly accomplished activist in the Treacher Collins community whose speech will forever be

imbedded in the minds of all participants.

We also had the opportunity to honor **Chris Jones**, who has partnered with CCA to educate 10,000 students in the **Capistrano Unified School District** about the importance of acceptance and inclusion. Her work included making *Wonder* part of the district-wide 6th grade curriculum and inviting **Peter Dankelson** to bring Auggie to life in the eyes of these students through a dozen "Real Life Auggie" presentations per year.

We are so grateful for our committed friends and neighbors who join us for this two-day event that continues to raise the bar each year. **Morgan Mecklenburg** welcomed all participants and thanked

them for continuing to support Children's Craniofacial Association and for helping all her friends from CCA; she then encouraged them to "spend more money for her friends at CCA!" **Erica Mossholder** and **Jono Lancaster** truly moved the group with their personal accounts attesting to the amazing work CCA does for CCA Kids and families.

First time participants **Bryant Michels** and **Joe Ploytycia** won the overall championship, and **Maria Amelio** extended her undefeated record as Ladies' Champion; however, the true champions of the tournament were our CCA Kids who inspired this small group of friends, corporate sponsors, and auction participants to contribute over **\$120,000** to benefit Children's Craniofacial Association. A special thank you goes out to our **Platinum Level Sponsors: Crum & Forster Insurance, Bobby and Kristen Baillargeon, EverGuard Insurance, SES Insurance, Blair and Shelley Schrum, Maria Amelio, Greg and Donna Bonnell, Robert and Karen Reader, and Kevin and Jennifer Trapani.** A

special thank you is also deserved for **Christine Condino-Mecklenburg, Shawn Craig** and **Holly Jaenichen** for providing incredible golf and hotel experiences for the auction, along with **TaylorMade Golf** for allowing CCA to benefit from its Charity Purchase Program.

**Coto de Caza Golf and Racquet Club** was the host venue, and all out-of-town participants stayed at the **Laguna Cliffs Marriott Resort & Spa** in Dana Point, California. Private dinners were held at **Hanna's Restaurant and Bar** in Rancho Santa Margarita and at the **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 auction item donors who have made this a memorable and meaningful event.



**retreat recap**, from pg 1 downtown area with fun dining, shopping, and the newly “dropped” rentable scooters and bikes for the entire family. The majestic mountain views were an added bonus, as was the slightly cooler-than-Dallas weather!

Each year we strive to improve upon the years prior, and this year we introduced some new efforts, including texted communication reminders, and also a morning Zumba party. The biggest laugh, however, came one month before Retreat, when everyone received a text encouraging them to Rise and Shine and Zumba with CCA Dad **Jerry!** Even though it was a little premature, when Saturday morning finally rolled around, and we actually got to work out together, it was a blast.

Another addition that completely wowed us



was the “Camp Care” room, lovingly envisioned, created, and staffed by **Bethany Johnson**, with Thursday assistance from **Christine Holding**. We felt there’s long been a need for some extra support while our families experience the highs of Retreat, but also anticipate the lows of returning home ... a place not nearly as amazing as “Planet CCA,” a term coined by **Teresa Joy Dyson**. Bethany stepped up and created a true sanctuary—a place of respite and warmth—in the hotel. With soft lighting, encouraging posters, and candlelight, Bethany welcomed individuals into the room to talk about things they were feeling and experiencing. “The Feelings Lady,” as she calls herself, helped many kids and adults get in touch with parts of themselves that

needed to be explored, and we are immensely grateful for her work over the entire Retreat to make this calming, loving environment for our families.

We also had some amazing sponsors this year, who graciously helped us plan and host our 10th Annual Craniofacial Symposium. We would like to thank the following experts and professionals from **Primary Children’s Hospital, Lone Peak Hospital**, and the **Craniofacial Foundation of Utah**.

- **Rodney Schmelzer, MD**
- **Barbu Gociman, MD**
- **Faizi Siddiqi, MD**
- **Jonathan Skirko, MD, MHPA, MPH**
- **Laura Rodriguez, CPC, CPMA, CMC, CMIS**
- **Juliana Powell, LCSW, CCLS**
- **Alina Schmelzer, LCSW, CCLS**
- **Alvin Stosich, MD, DDS**

We would also like to thank our incredible keynote speaker, **Ben Kjar**, who positively charged, inspired, and rallied our families to proclaim themselves “Victors, not Victims!” He and his wife, **LaCol** joined us all weekend, meeting our families and connecting with the kids. **Jono Lancaster** from **Love Me Love My Face Foundation** and **David Roche**, from **Love at Second Sight**, also held



rich and important sessions that encouraged the audience to own, claim, love, and tell their stories. CCA family members **Rose Seitz, Stephanie Cooper, Deena Dyson, Nancy Merrill, Harlena Morton, Shaun Vysocky, Dede & Peter Dankelson** and **Rasheera Dopson** also participated as panel members, rounding out an informative and empowering Symposium.







Graciously, our exhibitors assisted in completing our Symposium efforts. We are so grateful for their time, information, and fun activities they provided. Thank you, **Primary Children's Hospital, Lone Peak Hospital, KLS Martin, Craniofacial Foundation of Utah, American Cleft Palate Craniofacial Association (ACPA), Craniofacial Foundation of America, CCD Smiles, CranioRehab** and **ConnectMed**.

And last but not least, a HUGE thanks goes out to all of our amazing families who volunteered their time during the symposium, registration, and retreat: **Sharon Allbright, Dave & Liz Anderson, CJ & Bette Barbalaci, Lisa Bowers, Jerry & Virginia Carchi, Christine Clinton, Stephanie Cooper, Bernice Crimaldi, Kristine Dale, Josey Daley, Dede Dankelson, Nancy Dau, Rasheera Dopson, Whitney Dunn, Deena Dyson, Bob &**

**Paula Guzzo, Melissa Jurek, Ed & Amy Kern, Jennifer Kilmer, Sarah Klinger, Jill Laufbaum, Eric & Jen Lucas, Doug & Janis Macut, Melissa McGowan, Johnny & Jessica McMahan, Bill & Christine Mecklenburg, Nancy Merrill, Harlena Morton, Bobbie Quiroz, Kevin & Erin Richmond, Kristen Roberts, Jaci Samhammer, Mark & Laurel Sanborn, Rose Seitz, Patricia Simon, Kathie Steinagel, Haley Streff, Heather Sutton, Shaun & Courtney Vysocky, Tanner Walker, Tosha Walker, Dorina Watkins, Andy &**

**Melanie Yarbrough**, all of our raffle ticket sellers, and everyone who brought raffle baskets.

We kicked the retreat off Thursday evening with a Taco Night and a gorgeous mini-concert by the **One Voice Children's Choir**. One of our amazing CCA Teens, **Hannah Steinagel**, is a member of the choir. The choir performed several of their most popular songs, and roused us all with hits from "The Greatest Showman," especially "This is Me," which turned out to be the anthem for this year's Retreat. Following the choir's performance,



they took pictures with our families and mingled with the crowd. While connections were being made, we had a magician set up and give a fun show to our younger attendees.

Friday morning started bright and early with breakfast, and then the families gathered for Group Meet-Ups, one of our most popular additions to the Retreat. During these groups, families were able to meet others with like or similar syndromes/craniofacial conditions, as well as others around



their same age. It was so wonderful to watch the families gather, and while we hope to make next year a more intimate experience, the groups' enthusiasm this time was hard to contain. There were lots of games and get-to-know-you's, and next year we are already planning to deepen this experience, which so many people believe to be crucial to the Retreat weekend. Thank you, once again, see **retreat recap**, pg 10



**retreat recap**, from pg 9

to the volunteers who helped during the meetings and for all the attendees' patience and participation as we accommodated everyone!

Following the Group Meet-Up's, the families went off on their own for lunch and gathered back together for our Talent Show, or as I like to call it, "CCA's Got Talent!" This year there was dancing, hula



hooping, singing, comedy, gymnastics, piano solos, and more! To see our kids open up and share their talents—and cheer each other on—is why we do this event. We love the saying, "Let's root for each other, and watch each other grow." That's the CCA way!

During Family Night the basket raffle race was on! Families from across the United States and beyond brought baskets of goodies from their regions and hometowns for CCA to raffle! These baskets held everything from sports souvenirs and memorabilia, to local food specialties, and some boozy goodies, too. The generosity of our families never ceases to amaze us and once again, we already have ideas how to keep this popular activity for next year, but improve upon the execution! Thank you for your generous baskets and your feedback.

While parents were buying raffle tickets, and stuffing them in the raffle bags, the teens were swimming together in the main pool and making new friends. Teen night wouldn't be possible without the help of our chaperones each year. Thank you **Erin Sutton**, **Janna Emfield** and **Dennise LeBaron** for making this year's teen night such a success!

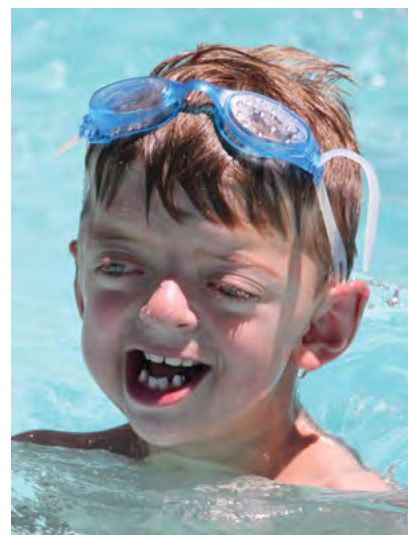
After dinner, the CCA Adults headed to Casino Night where they learned

how to play several casino games, but more importantly, they had their own special night where they could mingle with others their own age and support one another. This year we featured some pretty sweet prizes, too! We appreciate all the help that went into this special event.

As I previously mentioned, Saturday morning we gathered for an energetic Zumba session held by **Jerry Carchi**. I attended this session and let's just say, he got our heart rates up! Everyone had such a wonderful time, and Jerry has graciously volunteered to do Zumba again for us next year! After Zumba, everyone gathered in the ballroom for a group photo! It's quite a task gathering **nearly 600 people** for a group photo, but with the help of our amazing photographer, **Brady Dunn**, the direction of **Andy Yarbrough**, and the orderly lining up of our families, we got it done, and it's such a powerful photo! THANK YOU to everyone who participated.

This is a time-honored tradition and we appreciate you sharing your smiles for it.

Saturday evening, after an afternoon of some fun in the sun at the pool, everyone came together for our dinner/dance. Before kicking off the dancing, we showed a crash edit video of the weekend that **Brady Dunn** put together. It was a fun moment to reflect and see snippets of all the fun we'd just had. Special guests at dinner included our local surgeons and their wives, including **Dr. Rodney** and **Alina Schmelzer**, **Dr. Larry** and **Brenda Sargent**, and members of the cast of **Wonder** who joined us during the entire weekend, were recognized. **Bill Mecklenburg** called





up **Jason, Christina, Jacob, Emma and Erica Tremblay; Megan and Millie Davis;** and **Greg, Donna and Elle McKinnon** on stage, and officially adopted them into the CCA FAMILY! Their presence all weekend was truly magical, as everyone



felt incredibly honored to have them in attendance, and loved meeting these kind, genuine, authentic souls in person. We hope to see them every single year from now on! We then insisted on an encore presentation from our Talent Show. Our very own **Peter Dankelson** and **Bianca Moon** joined together to perform

Green Day's "Time of Your Life" song. Once the performance concluded, the dancing began and our DJ brought the house down with a great mix of current hits, classics, and our special Retreat hit favorites!

Sunday morning is always bittersweet. There were lots of hugs, promises of staying in touch and, as always, a few tears. We always relish meeting 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 and our shared

community helps us envision a world where we are all accepted for who we are, not how we look. We hope everyone had the TIME OF THEIR LIVES!

You too can get in on the fun next year! Don't delay, registration is officially open for the 2019 Scottsdale, AZ, Retreat, June 27th-30th, and we hope to see you all there!

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

**Annie Reeves**  
Program Director







# first-time retreat attendees

**W**e are the **West family**. Our son **Jayson** has spent nearly 5 of his 6 years of life living with an undiagnosed craniofacial syndrome. Through the generosity of a lab, we were finally able to obtain Whole Exome Sequencing which discovered a mutation on the gene MN1. We later learned this was a newly discovered craniofacial gene and there were a few other MN1 patients like Jayson! We finally were on the verge of a diagnosis!!

There are many frustrations and heartache that come with living a life undiagnosed. Without a diagnosis, we didn't have a "family." We lacked a support network with shared diagnoses, procedures, surgeries and struggles. We felt alone. Other families with medically

complex children often have the opportunity to attend conferences and bond with those with common experiences. We desperately wanted this type of support. It was something we always dreamed of.

When we learned of the Children's Craniofacial Association and the family retreat, we knew we had to attend! What a crazy coincidence—it was in our area this year, Salt Lake City. Unfortunately, the registration date had passed. I reached out to **Annie** and got placed on the waitlist. I had no idea that her email inviting us to attend the retreat would literally change our lives.

We woke up the first morning of the retreat with feelings of excitement as we were about to embark on a new experience. We were thrilled, but nervous as we wondered how

much we might have in common with people with various craniofacial diagnoses. Certainly we would be the only MN1 patients; how much would we have in common



with the other craniofacial families?

We were welcomed with open arms and started having great conversations with families the second we arrived. One family told us about a research study being done by Face Base in a nearby room and encouraged us to participate. We walked in to see a doctor and his assistant with cameras and equipment; they would be used to take pictures and measurements of facial structures to store in a database and help diagnose children with craniofacial syndromes. What an amazing opportunity to be a part of this study! Surely, we would be the first MN1 family in the database!

The doctor asked us what Jayson's diagnosis was.

**Me:** "It's an ultra-rare craniofacial syndrome without a name. He's only one of 11 in the world, so I doubt you've heard of

it. It's a mutation on gene MN1."

**Doctor:** "MN1? Actually, I am familiar with it."

**Me:** "Really???" It's so rare, I really didn't think anyone would know what it was. It is currently being researched and we were told a paper should be published any day identifying a new craniofacial syndrome."

He looked both confused and intrigued.

As we filled out some paperwork, his voice softly said...

**Doctor:** "So I think it was actually my paper that discovered MN1 in 2011."

**Me:** "What???"

He had my full and complete attention.

**Doctor:** "Yes, I authored the paper on my patient. She had tumors and NF2 but I knew there was more going on with a craniofacial syndrome so I..."

**Me:** "What is your name??"

**Doctor:** "**Pedro Sanchez.**"



**Me:** "Hold on."

I grabbed my phone and opened up my bookmarks. I had the only paper ever written about MN1 saved on my phone. I pulled it up and zoomed in.

Oh. My. Gosh.

Sure enough, it said Pedro Sanchez.

I lost my ability to talk. I got dizzy and light headed as a warm feeling came over me telling me we were here for THIS REASON.

I grabbed my mouth as I let out a quiet sob. I took a deep breath and looked this amazing doctor in the eyes. Tears streamed down my face as I spoke a mile a minute. I could not contain my emotion.

**Me:** "Do you know how much you mean to us??? You have changed our lives. My son has a diagnosis because of you. He was undiagnosed for five years. Our geneticist didn't think the MN1 mutation was clinically significant, but we showed him your paper! Your

paper in 2011 suggested MN1 was craniofacial gene and a geneticist in Boston decided to build on your research by studying Jayson and five other children in the world with



this mutation. We got a diagnosis because of the work you did. Do you know your work means everything to us? Without you, we wouldn't be here! Do you even know that?"

Tears just kept coming. I couldn't control them. I was living a dream I never

dared to fantasize about. I unexpectedly met the man who DISCOVERED Jayson's craniofacial condition.

I saw the doctor's eyes welling up as he searched for words.

**Dr. Sanchez:** "I have never met another MN1 family. Ever. I didn't know about the current research paper in progress. I didn't know if I would ever meet another MN1 patient."

I started crying again. Not only was it a complete dream come



true to meet the man who changed our lives, but we learned that this moment completely changed his life too.

**Dr. Sanchez:** You are the reason I came today. There is a higher power behind this. I was meant to meet your family today.

No doubt about it, doc. No doubt.

We experienced a true miracle, and I'm certain many lives will never be the same because of this connection. Next year I don't think we will be the only MN1 family in attendance. The doc and I will make sure of it! The retreat connected us not only with life-long friends and a new craniofacial family, but also with this doctor who has vowed to be a part of our lives forever. We will never forget the CCA retreat of 2018, the event that changed our lives. Thank you to all who made this possible.

If you know another MN1 family, please have them contact us by email at [tristinwest.littlejsjourney@gmail.com](mailto:tristinwest.littlejsjourney@gmail.com)





## pep recap

Thanks to the **Cronin family** of Saratoga Springs, New York and the **Patient Experience Project (PEP)**, CCA benefited from one of our favorite types of events, one that raised awareness and funds at the same time. On February 28th, PEP and the Cronins celebrated the third annual **Rare Disease Day at the Movies**, which raised **over \$7,000** for CCA.

Each year, Rare Disease Day helps raise awareness for patients who suffer from conditions that affect fewer than 200,000 people in the United States. PEP strives to bring patients and professionals from the medical and pharmaceutical fields together to help find treatments and cures for these individuals.

One way they bring patients and the

community together to raise awareness is through the Rare Disease Day at the Movies. **Angela Cronin** attended the first two movie nights in 2016 and 2017. Angela was interested in the work that PEP was doing because the events were “well supported, quickly becoming an annual must-attend for many people in the area.” Her daughter, **Megan Cronin** is an amazing twelve-year-old girl, who happens to have been born with a facial difference, gene mutation, and brain abnormality. Megan loves soccer, school, and spending time with friends. Her zeal for life earned her the **New York State Attorney General’s 2017 Triple “C” Award**, recognizing the Courage, Character, and Commitment she displays each day.

Soon after attending the 2017 screening, Angela

heard about *Wonder* being released in theaters. She felt Megan’s story and the message of kindness were a perfect fit for 2018’s Rare Disease Day at the Movies. She decided to ask PEP’s event planning committee if they would be willing to plan a screening of the movie. She also hoped they would share Megan’s inspirational story. She requested that funds from the ticket sales be donated to CCA. The planning committee took the movie’s message of kindness a step further, transforming it into a movement of kindness in which the entire Saratoga Springs community could support and participate.

In the months leading up to the screening, hundreds of students from five schools in New York’s Capital Region were asked to submit entries to a poster contest that expressed their personal understanding of empathy

and acceptance. PEP and the Cronins spread the word about the event to the legislators, government officials, and general public. On the day of the screening, the winners of the poster contest were revealed during a reception and exhibition before the screening. Presentations were made by **U.S. Congressman Paul Tonko** and **Saratoga Springs Mayor, Meg Kelly**, honoring the students’ messages of kindness. A special video message from **Jacob Tremblay** was played for those in attendance at the theater. He told the sold-out crowd to “be a little kinder” and remember “that kindness costs you nothing, but pays off beyond measure.”

The community of students, teachers, and community leaders made this particular Rare Disease Day at the Movies event very special. The children



shared their beautiful words and images with the people of Saratoga Springs. The artwork and messages in the posters were inspiring. Angela says none of this would have been possible without the “teachers who served on the planning committee, **Julie Vanderhoff, Maureen Niesz, Barbara Wersten and Kristen Bobear.**”

**PEP President and Founder, Dan Bobear,** commented, “In a world too often marked by conflict and indifference, these students remind us all how powerful it is to demonstrate empathy. We’re proud to have a sold-out event and hope the funds raised will make a difference in the lives of

families affected by facial differences.”

CCA is very grateful for this large donation of **\$7,000+**, because it will help our community of children and adults born with facial differences travel to receive the medical treatment they need, and connect with other patients on a similar journey. One community helping another is a fine demonstration of empathy in action.



# ely potter: good news

How many of us can say we are award-winning writers? Well, CCA Kid, **Ely Potter** can now call himself one after writing an essay about *The Future of Peace* for the **International Essay Contest** organized by the **Lions Club**. Potter won \$5,000 and a trip to New York City where he was honored at the United Nations. Truly incredible!

His mother **Jamie** wrote to CCA to tell us that Ely said he wanted to send his gratitude to the organization. Ely says, "I want to thank CCA, all those people always made me feel like a normal person." Ely says, "I especially want the kids like me to know they can really achieve anything they set their minds to. And just because other people call you different, different is sometimes a very good thing to be!"

First the Potters found out that Ely had won the district level contest, which pushed his essay further along to the state level in Delaware. Guess what, he won that too! Days later the family was informed via email that he won the Lions International Essay Contest.

Here is the text of Ely Potter's essay on peace and

his impassioned plea for nonviolence.

Ely, we hope to see more work written by you. From one writer to another, keep up the good work!

—Kara Jackman

*There are many fabulous things that the human eye can see and our hearts can feel. Many of those things can be the darkness of pain and depression. Most of those feelings come from chaos and destruction. But know this now, the eternal feeling we know as peace can be stronger than those negative feelings. When there is peace no darkness or evil will corrupt our world. Earth might seem chaotic and deadly with all the murders and natural disasters going on across our planet. People are fearful; people are drained out; but how do we overcome these obstacles? I'll tell you... with peace that many of us have stored somewhere in our DNA. Many brave men and women have reached out to the troubled ones and pulled them out of the deadly waters and into the peaceful light. Many people helped those who were in great danger by giving them fresh food, games, friendship and helped them back onto their feet again.*



*Does this tell you peace can be in anyone?*

*It is time to let peace guide us not only in catastrophic times but on a day to day basis. Many people think peace is like what we see in superhero movies. A superhero isn't just a man with laser vision but are ones that bring peace and sweep away the danger that surround our world.*

*Martin Luther King, Jr. is one of the most flawless examples of a peaceful figure. He says "I have a dream..." more times than anyone. Well, I have a dream to persuade the readers who are listening to my words that peace can never be passed by. Peace is the strongest weapon. It may not fire bullets but it can change the most powerful substance in a villain or a normal average Joe; their hearts. Peace can also spread out of the blue, thus it can be created. In fact, you are creating peace right now. Do you see? Peace isn't something you*

*can physically create. It is created within your heart, brain and actions. Peace can be quietness, calm, and breathtaking.*

*Everyone who is reading this drop your blood boiling fists. If we all can have clean hands in this world, everything that came out of Pandora's box would be sucked back up except for hope which all of us hold inside our hearts. With weapons gone and hearts brighter than heaven itself, we will all enter a new world; a world with not only peace but nonviolence. I might not be in that new world but I can see it through my crooked eyes and my foggy glasses, and most of all I can feel it in my heavenly heart because as I said, "Peace isn't an object that you can touch; it's something you can feel." This is how I see peace in the future as a nonviolent world. Even though I can't see well through my two eyes I can see it clearly in my heart.*

# wonderkid speaker training

**W**e, at CCA, are so humbled to have an overwhelming interest from schools and organizations requesting our CCA Kids and Adults to go and speak to their students. Teachers and students are eager to learn about our CCA family's personal craniofacial stories and how your experiences have shaped you all into the amazing and inspiring people you are today. Due to the high demand to share, we decided to create the CCA Speaker's Bureau. The Speaker's Bureau's goal is to unify the message and content presented to schools when representing CCA. All speakers within the Bureau receive free public speaking training and formal education from professionals. This qualifies our speakers to be equipped with the tools and confidence needed to speak in front of an audience.



SINCE 2018

## **SPEAKER'S BUREAU** CHILDREN'S CRANIOFACIAL ASSOCIATION

This will be the first year for The Speaker's Bureau to be implemented, and I am very excited by the interest I have received thus far! If you are interested in sharing your own experiences, I would love to help guide you through the process, and be your go-to person for any concerns or questions that may arise along the way. We value all our CCA speakers' efforts in helping us spread the message of #ChoosingKind across the world. It is not too late to save your spot for the upcoming virtual trainings we will be hosting. There are no restrictions based on locality, age, or any other factors. However, if you are a child under the age of 14 years, we require a "family certification." This means an adult will need to accompany the child to all the events, and therefore undergo the same training process. If you have any questions or concerns, feel free to email me at [khadija.ccakids@gmail.com](mailto:khadija.ccakids@gmail.com). I will be glad to help!

**-Khadija Moten**, Outreach Director



# miles for cca kids poker run

**W**e are so grateful for another great year of the **Miles for CCA Kids Poker Run**, organized by **Lewis Boykin** and the **DWMC** riders! Once again they showed up on a sunny day, May 19, 2018, to ride motorcycles and share in the love for our craniofacial families. The guest of honor, **Rob Gorecki**, accompanied the ride with **Greg and Jill Patterson**. We are so excited that the fundraiser netted nearly **\$3,000** for CCA! Thank you to the Pattersons, Lewis, Rob, and the generous sponsors: **Adkerson, Hauder & Bezney, P.C., 1st Call Recovery LLC, Acacia Insurance Managers, LLC, and Praise Hymn Fashions.**



**bella**, from page 1



relate to the “knowing” of what surgeries were necessary, but also “dreading” the day of handing your little child to a gowned stranger. It still puts a lump in my throat even thinking about those moments. Bella had 10 doctors right from the start, and diagnoses included Apert syndrome, Atrial Septal Defect (ASD) (aka: hole in the heart), vision issues, bladder reflux, etc.—too many to remember! I was so overwhelmed with appointments that I was seriously on the verge of a nervous breakdown. “How am I going to do this?” or “Why me?” were questions I asked myself. I would beat myself up and wallow in self-pity all day. I wanted to hide from the world, even leave this planet.



But then I remembered the voice of that lady and my resolve. My paradigm shifted from anger to courage. Wow, maybe that lady had a purpose in my

life after all—to light a fire under me to do things for Bella’s future.

Then, glimmers of hope started showing up. When we went to the pediatric cardiologist to check on her ASD, he said, “Well, all her valves are strong and guess what? The hole has healed on its own!” Then, the pediatric neurologist told us, despite her toes being fused, she could be a prima ballerina if she wanted to! When she had her front and back craniofacial surgery at 8 and 10 months respectively, she healed well and got through her thumb release like a champ! She had gotten through her first year of life healthy and whole. She couldn’t speak yet, but through these accomplishments, it was like she was showing me that she was going to be okay. Her smiles and happy demeanor told me she was a victor, not a victim. What an inspiration!

With the help of Nevada Early Intervention Services (NEIS), Bella was assigned a case manager/social worker at 1 month old. We have to thank the NICU nurses at my husband’s hospital for telling us about this program. NEIS would follow Bella’s learning progress from 0 to 3 years old and then the Clark County School District (CCSD) would have her transition into Child Find, a program offered

by the county to place her into pre-school and kindergarten.

Despite the challenges she had to face, I told myself to be strong for her no matter what. She attended “special pre-k” classes when she turned 3, and then on to “special k” for kindergarten. Despite her orthopedic issues, she was progressing and they started to mainstream her. The plan was to place her in a regular classroom for the second half of the year.

As she approached first grade, I heard of an Arts Integrated Elementary School that was opening up close by. It was in Las Vegas, so the only way to get in was to enter the school’s lottery with thousands of other parents, and pray like mad. I received 3 emails once the lottery closed: The first said she didn’t make it, then the next two said she did. I jumped on getting her IEP paperwork faxed to the





new school that night. We were so glad she got in and haven't regretted it since.

Little Miss "Smiley" Bella has gotten through her nine surgeries like the little soldier she is—four for her skull, three for her fingers, one for her bladder, and the recent one last year, to smooth her temples and forehead. She still has a few more planned as she goes through puberty.

I think the hardest procedure for her was when she had distractors in with hardware sticking out of her temples and back of her head. My husband had to turn the two screws at the back of her head 1 ml at a time, a task I just could not do. I know there are many other children/adults out there that have dealt with so much more, and my heart truly goes out to them and their families.

Her journey in life (so far) has humbled me many times and taught me patience, unconditional love, courage and true, "dig-deep" strength. Look at her now, still smiling, singing, dancing, using computers and smartphones, doing schoolwork, being complimented many times for her handwriting, and enjoying our family sport, archery. Wow, she has come a long way, and will only get better! What did that lady say again?

So now my response to parents who have asked me the question, "How do you deal with all of it?" My answer is always the same, "You just do." My mother, my spiritual mentor, is an avid reader of all types of books. I swear she's a part-time magician because it seems no matter what I'm going through, she has a



book for me to read. Her unconditional love for the three of us has always been my rock. Even as I approach 50, my mother remains the nurturer that I aspire to be for my Bella. She dug in her personal library, which I often call "the abyss," one day and came out with a book that talked to me, *The Gifts of Imperfection: Let Go of Who You Think You're Supposed to Be, and Embrace Who You Are*, by Brené Brown. If you haven't read this book about **Wholehearted Living**, I invite you to do so.

Personally, it was an "aha" moment, for sure. Call it a spiritual awakening, or

just the proverbial "slap in the face" that I so needed. Either way, it taught me to accept and love who I am, a proud mother of a **Super Special Child**, not a "special-needs child," who has helped me to grow up, be more spiritual and grateful every single day.

Think about it. Through our children's journeys, we have touched, seen and felt the true things that matter in life: unconditional love, laughter, the miracle of healing, and patience. So who's the real child in my situation? I am. As parents, we think we are the masters, or the bosses, but in our collective situations, our children are actually the masters. They "do" because that's the only way they know how, and we parents get to learn the true meaning, the true essence of life. What a beautiful thing!





## delaneys fishing trip

In March, Central Florida native, **Delaney Cunha**, and her Mom and CCA Board Member, **Kelly**, enjoyed a day on the high seas learning how to fish with **Chasten Whitfield**. Chasten, (AKA “Chaz”) has always loved fishing and philanthropy. She has been able to combine her two passions through her **Chastention** ([www.chastenwhitfield.com](http://www.chastenwhitfield.com)), where she introduces children that face medical challenges to the sport of fishing.

Chasten’s charitable life began at the tender age of five, raising money for St. Jude’s Children’s Research Hospital. Each year from kindergarten to fifth grade she held a garage sale; in those six years she raised \$6,000 for St. Jude’s.

In a cruel twist of fate, she says, her brother was diagnosed with “a rare tumor in his hand, so it was my first lesson in things coming full circle.” As she was managing life with her sick brother, she entered junior high where she was bullied for “being the only girl who fished.”

Chasten says, “All my friends were doing all-star cheer and I wasn’t the best cheerleader, so my mom talked me into a fishing tournament.” She won first

place in that competition and the rest is history.

The money she won fishing went right back to kids in need, this time to a camp for kids that suffered severe burns. Chasten also began speaking out at schools about bullying and sharing the importance of choosing kindness towards others.

In 2016, her two worlds of doing good and fishing collided again. Chasten recounts the encounter that started the work that she is currently doing, “I did a fish camp off a pier during the summer of 2016 and met a little boy in a wheelchair who had never been on a boat or fished. I was determined to help him catch a fish and when he did, he did donuts in his wheelchair screaming, “I caught a fish!!!” That feeling of joy, and the self-esteem that little boy just gained, was unbelievable.”

At that moment, Chasten knew she had found her calling. The boy and Chasten became friends. She took him on her boat to go fishing. He was the first in over 47 kids she would introduce to the sport of fishing. Chasten sells t-shirts on her website to fund these trips on the water for kids with medical challenges. **Yellowfin**



to fight what they normally fight, they just have to fight for a fish... that's it."

And fight for a fish was exactly what Delaney, born with Pfeiffer's syndrome, did on a bright, beautiful day in the middle of March. Delaney and a camera crew went out on the Yellowfin boat to catch some fish.

Chasten met Delaney after contacting her when Delaney won the Tampa-area parenting magazine cover contest—through the help of our dedicated CCA friends voting on social media. We love this story because it highlights the work that Kelly and Chasten are doing to promote acceptance in the world, but even more importantly to bring joy to the lives of kids.

boats helped build a boat hearty enough to hold a wheelchair and other medical devices. There

are other small businesses that sponsor her work or volunteer their time,

making these fishing expeditions possible.

Chasten wants the experience with the kids to be "a day for them to forget all their troubles. A day where they don't have



# madison peck then and now



**M**y name is **Madison Peck** and I was born in 1995, seven weeks early with a cleft lip. My parents were fortunate enough to have known about my difference early on in my mom's pregnancy, and we were also fortunate enough to live near an amazing hospital that specializes in craniofacial differences. I was born in Dallas at **Medical City Hospital** and had amazing care there. **Dr. Jeffrey Fearon** and **Dr. Ian Monroe** have helped me so much, as well as my oral surgeon and orthodontists **Dr. Jeffrey Genecov** and **Dr. Richard McFarland**. Over the course of my twenty-two years of life, I have had nine corrective surgeries on my cleft lip. For me, this was all normal. Surgery was very normal, to the point where I wasn't scared of them. Medical City always did a great job of making my hospital stays enjoyable.

I have been a **Girl Scout** for over twelve years. When I was in high school, I decided to earn my **Girl**

**Scout Gold Award**. This is a very difficult and time-consuming project.

When brainstorming about what I wanted to do, and how I wanted to give back to my community, I decided what I wanted to accomplish. I feel very passionate about helping others like me and I feel that it is my duty to give back. Learning that your child might have a difference can be a very intimidating and scary time. I love meeting families and talking to them and showing people that children who have craniofacial differences can grow up to have happy and fulfilling lives.

Living with a craniofacial difference, I have grown up having to educate people, and inform them about what a cleft lip is. People just do not have the knowledge and this is why I feel so passionate about spreading awareness to people about craniofacial differences. The more people understand, the more kindness can be felt,

and the more people can help.

With my Gold Award, I wanted to do just that. I found Children's Craniofacial Association; they were the perfect organization to help me with my project! I created care packages for children going through craniofacial surgeries that included pillows and blankets. I also created information pamphlets for their parents and provided them with information and contacts to help them. CCA was so helpful to me then, and years later when I was close to graduating college, I decided to contact them again.

I am graduating in August from **Stephen F. Austin State University**, with a degree in Health Science. With my degree,

I would love to be able to work with nonprofit organizations, just like CCA. I think giving back to others is the **best** way to live. Kindness is most important, and through education, kindness can be spread.

CCA has helped me so much, and I am so excited to be able to help and give back to them through a college internship. They were gracious enough to take me on, and I've been having a wonderful time interning for them! To get to see their impact and the effort they put in to helping others is a wonderful and amazing thing. It inspires me to work hard so that I can do work like this and help other people in the future.

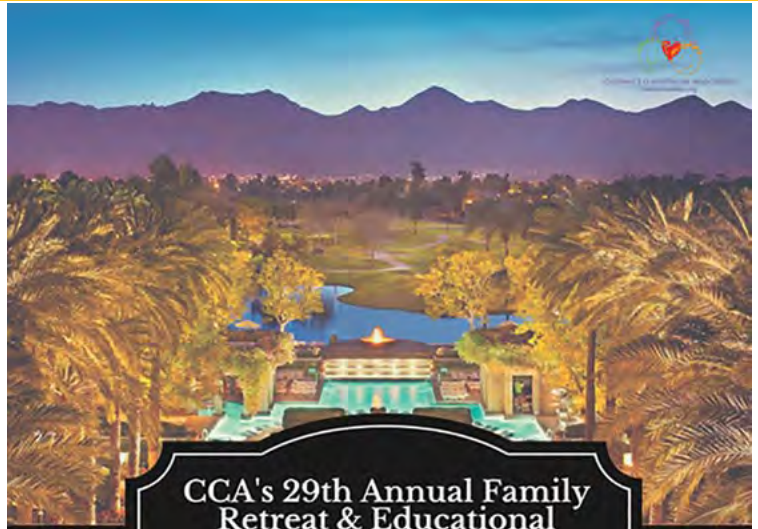




# choose kind



CCA Staffers Christine Andler, Khadija Moten & Erica Mossholder have been happy to have Madison (second from left) help on special projects this summer.



**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](mailto:areeves@ccakids.com)



Get your own Love More Judge Less tee in the CCA webstore!  
 .....  
[bit.ly/ccashop](http://bit.ly/ccashop)



## craniofacial acceptance month

This year marks the 14th year CCA will observe September as Craniofacial Acceptance Month (CAM) across the nation. Each year, CCA families, friends, volunteers and related support groups band together to widen the circle of acceptance for individuals with facial differences. The goal is to create awareness of craniofacial differences. If you would like to receive CAM info, please contact **Annie Reeves**. The info is perfect to share with local businesses, schools, libraries, hospitals and more!

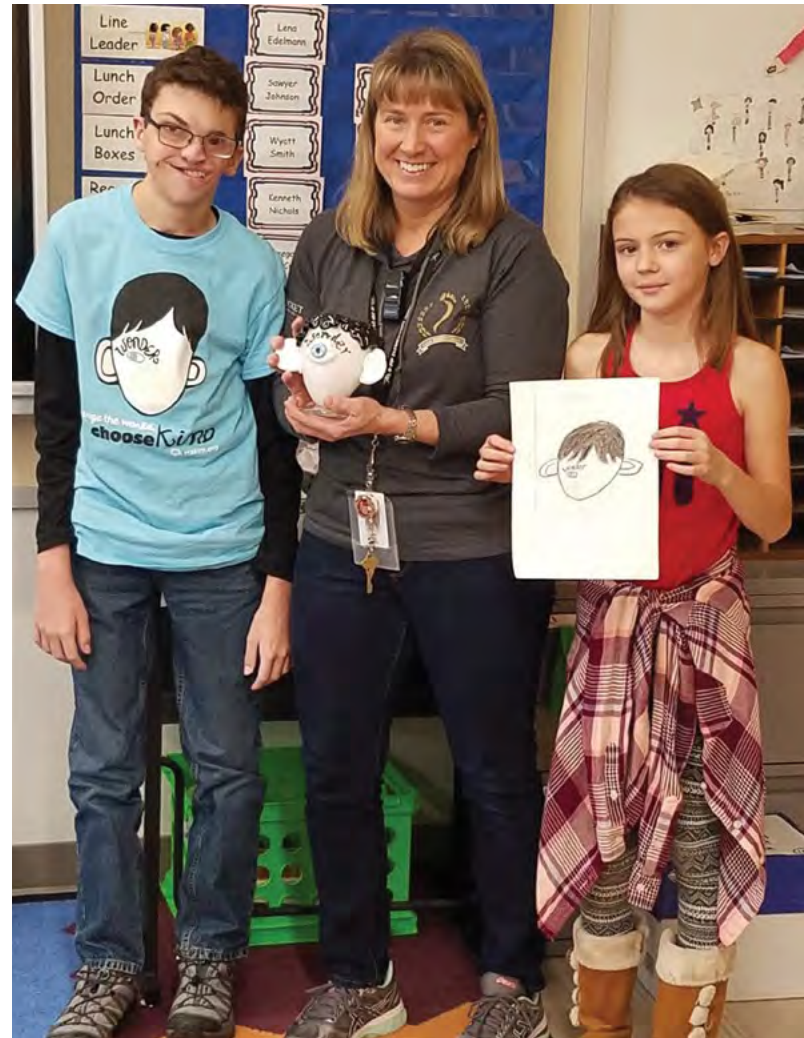
Also, it's never too early to start planning a picnic! CCA will hold its 11th Annual National Picnic Day on September the 8th in Dallas. CCA families across the nation will hold events which will give them a chance to get together with other families in their areas, while promoting awareness in their communities. If you would like to hold an event, please contact Annie Reeves, and she can give you all of the details. [areeves@ccakids.com](mailto:areeves@ccakids.com)

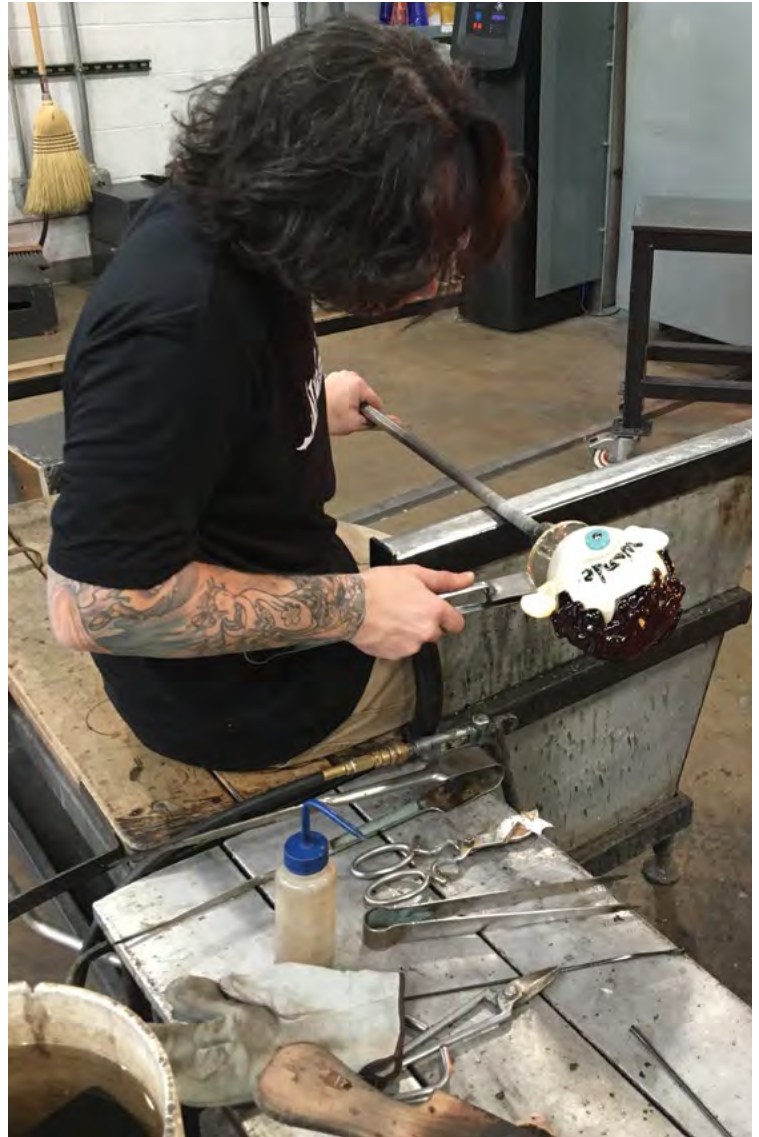


## dale family is a wonder

**b**ack in January, **Jeremy Dale** visited **Hugh Gregg Elementary** school in Corning, NY to talk to 3rd, 4th and 5th graders about *Wonder*. Each year the third graders in this school work with the **Corning Museum of Glass** to make a custom piece of glass that one of the students designs. This year the design that was made was a very special *Wonder* piece drawn by **Mercedes Ortiz**. The glass piece was unveiled during Jeremy's visit and will be on display at this school for all students to enjoy.

After the school visit, Jeremy was extremely fortunate to visit the Corning Museum of Glass and work with two glass blowing artists to make an additional *Wonder* piece. The artists put Jeremy to work by gathering the hot glass from the furnace, rolling the hot gob into the colored pieces and assisting in making the facial features of the piece. The final product turned out great! A special thank you to the Corning Museum of Glass and the two artists, **Erin Nelson** and **James Geekie**, for their time and donation of the *Wonder* piece for the CCA retreat!





**J**eremy Dale also visited the **Brentwood School District** in Long Island and talked to students in grades 3rd through 6th. After his visit, the school wanted to do something to continue to promote the Choose Kind

message. They created special T-shirts, and sold them throughout the school. The proceeds from the T-shirt sales were donated to CCA. Thank you Brentwood for your generous donation of **\$1,120** to help more CCA Kids!



# hailey's fan club



Here in Salt Lake City, we were so thrilled to hear that the CCA Retreat was coming to Utah in 2018! For our family, this would be the first time to attend with our 8-year-old daughter, **Hailey**, who has Apert syndrome. For those who haven't heard, Utah was given the award for "Most Charitable State in 2017," which is probably why our fundraiser was such a quick and easy success. We more than doubled our initial fundraising goal and collected **over \$5,000**. This was enough to cover all the audiovisual needs for the retreat!

From the day Hailey was born, she has had a way of bringing people

together. Family, friends, and neighbors are always interested in her because, despite the obstacles in her way, Hailey is outgoing and friendly. Hailey reaches out to people all day every day on the phone, on FaceTime and Facebook, through texting, and in person. I think this is the reason that, as a collective community, people were excited to donate money to CCA on behalf of "Hailey's Fan Club."

Some of our biggest donors were **Charles and Laurel Barlow, Michael and Nicole VanBibber, Dick and Marilyn Mower, and Sinclair Oil Corporation.**

As a community of Utahans, we've welcomed all of you with open arms. We hope you found our state to be as beautiful and generous as we do. We were so excited to share the weekend with our favorite group of people, in our favorite place, sponsored in part by our most supportive group of fans. With love, from the **Sutton Family.**





## 2018 retreat raffle

Each year, our CCA Families haul a little piece of their home states to the Retreat for the Family Night Basket Raffle. Baskets overflowed with coveted items like touristy T-shirts, local brews, flavorful regional snacks, signature hats, bumper stickers, magnets, and also beautiful handmade items

like quilts and blankets. We had 82 baskets this year for families to bid on, and together, we raised **\$3,725!** That's a lot of tickets... and truly, a lot of love! Thank you everyone for representing your towns, states, hobbies, and talents, and raising funds for CCA in the process.



# testimonial



**K**aleb was born March 13, 2010. I had just turned 19 a couple months earlier. He was born with bilateral microtia and atresia. Being so young, I had no idea what that meant, or how to handle it. Eight years later, we have found a way to finally get him started with his reconstruction surgery. It has not been easy. We have gone to many doctor appointments and have weighed out all our options.

Kaleb now has insurance, and we are thankful his doctor is in network, as these surgeries are extremely expensive. Although Kaleb has insurance and I have a job, the expenses are still a lot.

I had the great pleasure to get introduced to CCA. The process was so easy and quick. They have helped us with multiple expenses. They helped us find a place to stay, put food in our bellies, and have gas to get around while Kaleb had surgery. There are no words to express how thankful and blessed we are to have gotten this help. The surgery was approved with such short notice, and CCA was able to help us get there.

Thank you so much to everyone at CCA. Kaleb and his family really appreciate it!

– Elisa Flores

## calendar of events

date event contact

### 2018

Aug 16 5-8 PM	<b>Family Night Out</b> West Village Dallas Kendra Scott and Village Burger Bar 3699 McKinney Ave suite 105-b Dallas, TX 75204 Shopping, Family Networking, and Free Appetizers	<a href="mailto:Candler@ccakids.com">Candler@ccakids.com</a>
September	<b>14th Annual Craniofacial Acceptance Month (CAM)</b> Nationwide	<a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a> 214.570.9099 800.535.3643
Sep 8 11 AM-1 PM	<b>Dallas Area CAM Picnic with BBQ Lunch</b> Sandy Lake Park Carrollton, TX Food at 11:30 AM, Free Park Entry, Entertainment, Free Ride Tickets	<a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a> 214.570.9099 800.535.3643
Sep 15 1-4 PM	<b>Michigan CAM Picnic</b> Ben Celani Pavilion at Bicentennial Park 35400 Seven Mile Rd. Livonia, MI 48152	<a href="mailto:kdowd22@gmail.com">kdowd22@gmail.com</a>
Sep 15 2-6 PM	<b>PGH's 2nd Annual CAM Picnic</b> 465 Scott Ridge Rd. Harmony, PA 16037	<a href="mailto:bowerszoe@zoominternet.net">bowerszoe@zoominternet.net</a>
Sep 21-23	<b>12th Annual Children &amp; Youth Conference by the American Legion</b> Sheraton Indianapolis City Centre Hotel Indianapolis, IN 46204 Peter & Dede Dankelson are featured speakers	<a href="mailto:Emossholder@ccakids.com">Emossholder@ccakids.com</a>
Sep 22	<b>Alexa's Craniofacial Awareness Dinner &amp; Comedy Show</b> <i>benefitting CCA</i> Antigua Event Center Riverbank, CA	<a href="mailto:alexasaceforcca@gmail.com">alexasaceforcca@gmail.com</a>
Sep 28	<b>11th Annual Links of Love Golf Classic</b> Firewheel Golf Park 600 W Campbell Rd Garland, TX 75044 11:30 AM Registration; 1 PM Shotgun Start <i>Sponsors and Teams Needed</i>	<a href="mailto:Candler@ccakids.com">Candler@ccakids.com</a>
Nov 2-3	<b>Coto for the CURE ProAm Tennis Tournament</b> <b>Coto de Caza Golf &amp; Racquet Club</b> 25291 Vista Del Verde Coto De Caza, CA 92679 <i>Sponsors and Participants Needed</i>	<a href="mailto:BMecklenburg@ses-ins.com">BMecklenburg@ses-ins.com</a>
Nov 7-9	<b>NAES Biennial Conference 2018</b> Atlanta, GA Peter & Dede Dankelson are featured speakers	<a href="mailto:Emossholder@ccakids.com">Emossholder@ccakids.com</a>
Dec 4 5-8 PM	<b>9th Annual NorthPark Center Gingertown Build</b> NorthPark Center 8687 N. Central Expressway Dallas, TX 75225 Watch as talented local architects build a Gingerbread town into life, and hear Jono Lancaster speak!	<a href="mailto:Emossholder@ccakids.com">Emossholder@ccakids.com</a>
Jun 28-Jul 1	<b>29th Annual Family Retreat</b> Hyatt Gainey Ranch Scottsdale, AZ	<a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a> 214.570.9099 800.535.3643

# Thank you!

CCA WISHES TO EXPRESS OUR APPRECIATION TO OUR 2018 FAMILY RETREAT SPONSORS AND VOLUNTEERS

## SPONSORS:

Thank you to our sponsors who donated funds or in-kind goods and services to make the 2018 Family Retreat & Educational Symposium, presented by Primary Children's Hospital, truly, "The time of our lives!"



## Intermountain Primary Children's Hospital

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CHARITIES**

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**KLS MARTIN**

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BOSTON CHILDREN'S HOSPITAL  
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# children's craniofacial association

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# 3 cheers

for volunteers!

We are happy to recognize **Kathleen Philippi** of Coto de Caza, CA, and give her a huge HIP HIP HOORAY for being a dedicated volunteer each year for the **Morgan Meck Match Play Invitational**.

Kathleen lends her time and talent to this event annually, prepping items for the silent auction, stuffing and sorting gift bags, and most importantly, photographing the two-day event. We are fortunate to have her encouraging smiles, and capturing moments on the course! She's pictured here with another champion for CCA, **Chris Jones**, also of Coto. These two ladies have more than great style in common: their love for CCA Kids! Thank you both for all your kindness and generosity.



Kathleen and Chris at the Morgan Meck Match Play