

ccanetwork



newsletter of the children's craniofacial association

Cher—national spokesperson

2015: Issue 2

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the guille family

By Darcy Guille

The Red Thread of Destiny is a belief that comes from an old Chinese legend. It means that people who are destined to meet are tied together with an invisible red thread.

An invisible red thread connects those who are destined to meet, regardless of time, place or circumstances. The thread may stretch or tangle but will never break.

Ruby's story begins many years before she was born. After the birth of two biological children, my husband and I both felt God telling us our next child was in China. The invisible red thread first connected our family to a little girl in China. **Brynley** has finger differences and taught us about the world of special needs children. She showed us that "special needs" is simply a label proclaiming these kids are super special and display more fight and determination

see **guille family**, page 16

empowering and giving hope to individuals and families affected by facial differences



message from the program director

Can you believe the retreat is already over? Time sure does fly when you are having fun! The 25th Annual Cher's Family Retreat was held in Newport Beach, CA, June 25 to 28 and was our second largest retreat to date! One hundred seven families attended from 32 states as well as from Australia, Canada, Mexico and Romania. Of the 107 families, 35 families were first-time attendees.

Our home for the weekend was the beautiful **Newport Beach Marriott Hotel & Spa** which overlooked the mighty Pacific Ocean. On a clear

see **program director**, page 8



ccakid

meet chace gatewood

Chace Gatewood is 10 years old and lives in Little Rock, Arkansas. He's in the fourth grade, where he loves math—especially division—and science. Most days after school, he spends time at the library. Chace's favorite books to read are the hilarious "Skippyjon Jones" series of books by Judith Schachner.

He likes listening to rap and hip-hop music and playing games on his Xbox. He loves watching the TV show *The Walking Dead* as well as most anything on the Disney Channel. Chace's favorite movie at the moment is *Annie*. Also, for the last couple of years, he has been collecting coins.

Chace was born with Treacher Collins syndrome and has had multiple surgeries, procedures and treatments over his life.

Nevertheless, he is a strong, intelligent, resilient young man, whose advice to other kids going through similar situations is to "stay calm."

Chace is the oldest of four siblings, brother **Chance** and sisters **Chasity** and **Chelsea**. He really likes his role of big brother. The family also has a pet rabbit, Cherry.

All of the kids were counting the days leading up to the retreat in Newport Beach, California. They enjoyed catching up with old friends and making new ones. This was the family's third retreat; their first retreat was in 2013 in Orlando. Chace really enjoys attending the retreats, taking part in all the fun activities and having the opportunity to meet kids "like me."



Above, Gatewood family

Right, Chace Gatewood



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meet michael richard barrera

Greetings. My name is **Michael Richard Barrera**. I am 13 years old and go to Dirksen Junior High in Joliet, Illinois.

I was born with Treacher Collins syndrome in May 2002. I have had multiple surgeries throughout my life. I have had jaw surgery twice and will be having it again this year. I had a tracheostomy when I was 2, and it was removed when I was 5 years old. When I was 8 I had to have another tracheostomy when my jaw surgery was done. I have had eight ear surgeries and will be getting prosthetic ears—as well as braces—in the near future.

I am now officially a teenager. My favorite thing

to do is play baseball on the Miracle League of Joliet. I love to play video games on PS and Xbox and the computer. My favorite games are Minecraft, Grand Theft Auto, Mortal Combat and Guitar Hero. One of my favorite hobbies is building stuff with Legos.

One of the most difficult things about having Treacher Collins syndrome is when people stare. It makes me mad. I am currently in therapy to control my anger and impulsive behaviors. I am currently learning and using my coping skills, and it helps.

I have a little sister named **Jazmine**. She is 7 years old and can be so annoying, but I love her very much. I

love to spend time with all of my cousins and family.

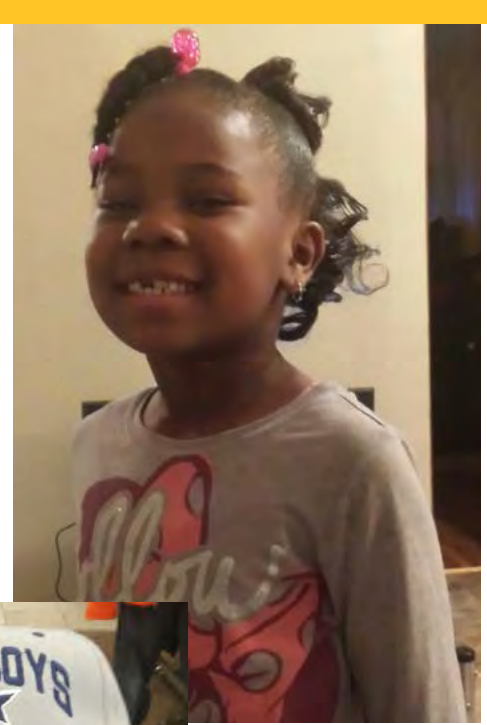
I have two home health nurses that are with me every day. **Sue** mainly works in the evening, and we do a lot of things together. **Gloria** works in the day and goes to school with me and stays with me at home when I am out of school. We also do a lot of things together. My nurses are very sweet and helpful and have become like family to me.

My first retreat was last year in St. Louis. I had so much fun and met so many new friends. I also had the chance to go to the Christmas party in Wisconsin last year. My family and I attended the CCA retreat in Newport Beach, California, this summer and I was very excited. This was my first plane ride ever. I am happy to belong to CCA and to be able to meet other kids.

ccateen



Left: Chance, Chelsea, Chace and Chasity



SuperSibs: Chelsea, above; Chance, left; and Chasity, below



meet chance, chasity and chelsea gatewood

Chace is the oldest of our four kids, and he was born with Treacher Collins syndrome. But to his brother, **Chance**, and sisters, **Chasity** and **Chelsea**, he's the same as them—he just looks different. In fact, they sometimes say they would like to be different, like Chace.

The kids all love to play Xbox, watch TV and go

to the library. They have attended three CCA retreats, one in Florida, one in St. Louis, and California, and had a wonderful time at all three. They look forward to attending the retreat each year.

ccasupersib

all the way for cca

The **Texas Moms** held their third annual All the Way for CCA Golf Tournament April 24, 2015, at Battleground Golf Course in Deer Park, Texas, hosted by **Empowering Motivated Women**.

The weather predictions were quite scary, but we had a beautiful, albeit humid, day. **Alisa's** daughter, **Monica**, said a heartfelt prayer before the golfers were on their way to the course. We had 26 teams of four golfers this year. Our event included breakfast, games on the course with a **Harley-Davidson** hole-in-one prize hole, sausage and pork chop barbeque sponsored by **Primoris**, silent auction, raffle and lunch with awards ceremony. The lovely **Texans Cheerleaders** joined us again this year for photo ops and autographs.

More than \$35,000 was raised for CCA, but we couldn't have done it without the help from our amazing friends and supporters **Alisa Shelton** and **Lynna McGuyer**—they once again went way above and beyond. Thank

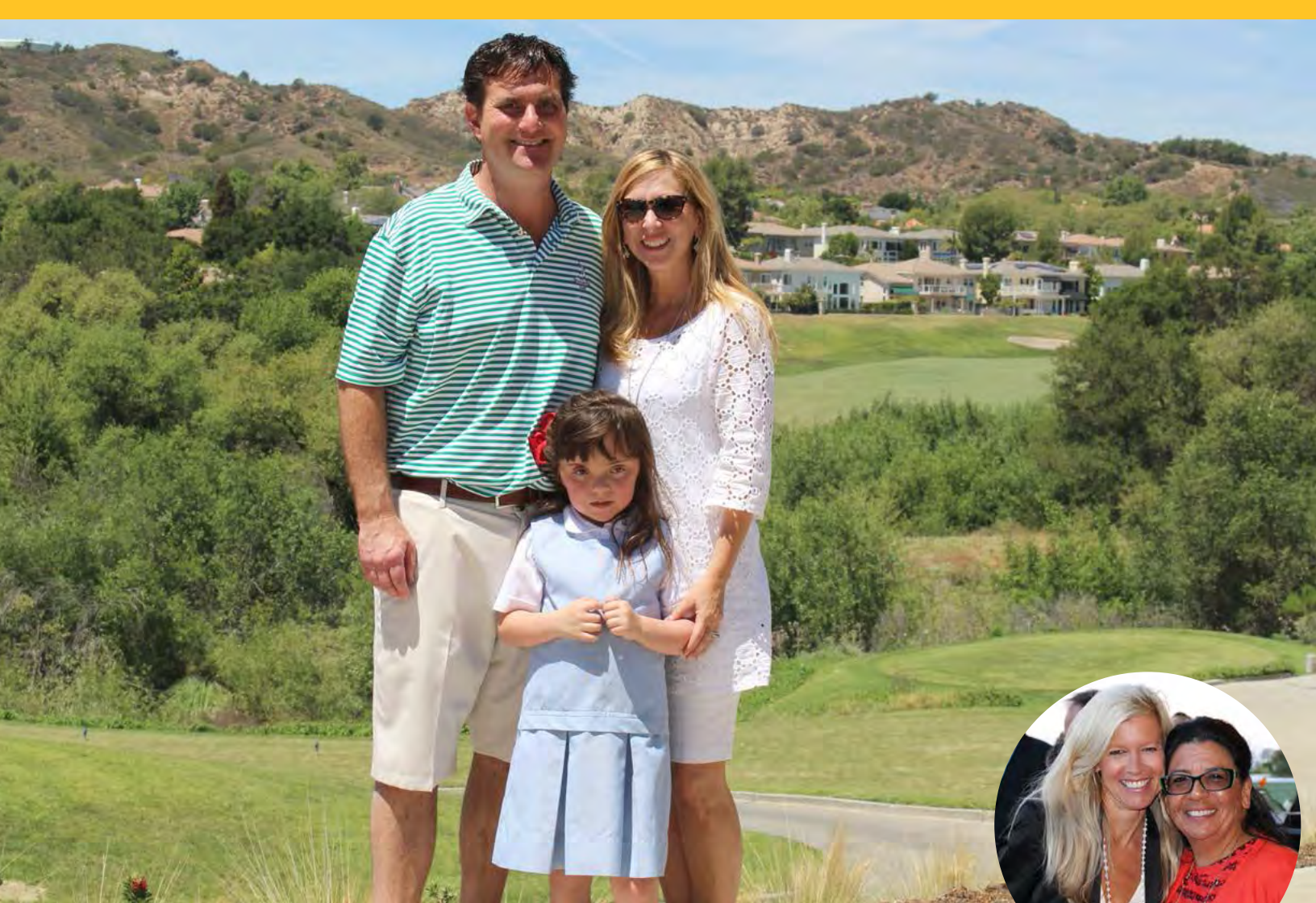
you so much for your continued outpouring of love and generosity!

We also want to thank our photographer, **Carla Pike**, from **Carla McClure Photography**, for donating her time and talent to our cause. We had so many sponsors this year, including our top sponsors: **USA Environment, Shelton Services, F.I.R.S.T., Empowering Motivated Women, CRB, Max Con, Interior Creations by Lynna, ISB Capitol, TCG Digital Concepts** and **Divicom**.

CCA kids **Ashley Bock, Jakob Happ, Mason Leibham** and **Wade White** joined our event and created quite a buzz with their visits to the players while on the course. The kids were happy talking to the players, taking photos with everyone and helping with the raffle and auction. Thank you to CCA dad **Stefan Happ** for giving a heartfelt speech about all that our kids endure.

Everyone had a great time!





2015 morgan meck's match play

On April 29 and 30, the Mecklenburg family hosted the fourth annual Morgan Meck's Match Play Invitational, benefitting Children's Craniofacial Association. We were blessed to have another full field, ranging from local friends and neighbors to friends from all over the country, to join us for this two-day event.

Morgan welcomed all participants and thanked them for continuing to support CCA and for helping all her CCA friends. Then she encouraged them

to "spend more money for her friends at CCA!"

Erica Mossholder, along with CCA dads **Tate Gorman** and **Russel Newman**, truly moved the group with their tributes to the miracle work CCA does for CCA kids and their families. Erica emphasized the platform CCA has become for choosing kindness and building acceptance for all individuals with any "difference" in life through CCA's *Wonder Project* coupled with the platform for CCA kids of all ages to

build self-confidence and self-esteem.

The championship was ultimately decided with a three-hole, match-play contest, with **Brad Walsh** and **Ben Briscoe** finishing with two birdies to claim victory over the first runners-up **Bill Blake** and **Bill Mecklenburg**. **Maria Amelio** won the women's championship for the fourth consecutive year, and **Steven King** and **Lou "The General" Murray** captured the senior championship.

The true champions were our CCA kids, who inspired this small group of friends, corporate sponsors and CharityBuzz Auction participants to contribute **more than \$90,000** to benefit CCA. A special thank you goes out to **Crum & Forster Insurance**, **EverGuard Insurance** and **SES Insurance**, whose companies and employees collectively donated at least \$10,000 each as Platinum Level Sponsors. A special thank you is also deserved for **Christine Condino-**



donors from morgan meck's match play

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Participants

Brad Walsh
Ben Briscoe
Russel Newman
Mike McDermott
Rick Cullen
Doug Goode
Bill Blake
Bill Mecklenburg
John Peppard
Dan Larkin
Maria Amelio
Michael Bluzer
Jim Trueman
Todd Ricker
Joe Davies
Chris Campbell
Ian Leisegang
Eric Miller
Steven King
Lou Murray
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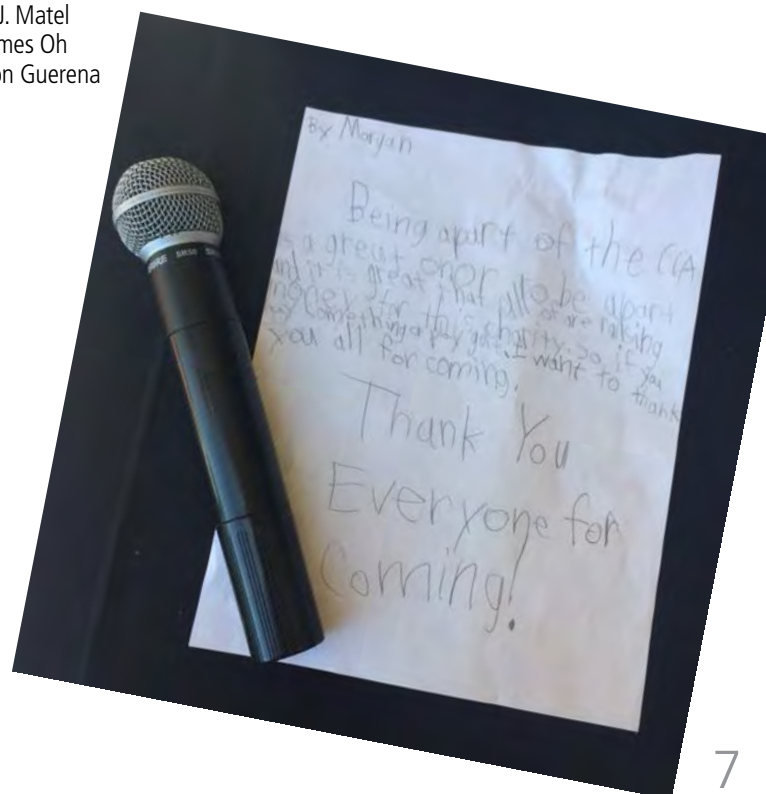
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Los Angeles Country Club
Los Angeles Angels
Miami Heat
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Ping Golf

Mecklenburg, Shawn Craig and Trina Conti for providing incredible golf and hotel experiences for the CharityBuzz 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.

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.





program director, from page 1

day you could even see Catalina Island. The views were truly breathtaking.

Thanks to modern technology, many of our new families and those who had not attended previous retreats became friends on Facebook and through CCA's Yahoo Group during the past year. That meant the initial "getting-to-know-you" period was taken care of before we even arrived at the retreat. Family members were glad to finally meet in person and immediately made connections.

This year, we had some amazing speakers who generously gave of their time and expertise to conduct the **7th Annual Craniofacial Symposium**. We would like to thank **Lori Takeuchi, MPA** and **CCLS**, and **Carolynne Garrison Howard, PhD**, from **Dignity Health/ St. Joseph's Hospital and Medical Center** in

Phoenix, AZ; **Madison "Peach" Steiner-Akins**, Founder/President of **Peach's Neet Feet**; **Steven R. Cohen, MD**, from **Rady Children's Hospital** in San Diego, CA; youth and motivational speaker **Rohan Murphy**; **Latreia Wyche**, Professional Certified Life Coach from **Discovering Your Abilities**; and **Carrie Brooks**, who is a CCA sibling of CCA adult **Joe Brooks** and Mary Kay Consultant. We would also like to thank CCA family members, **Jessica Bock**, **Destiny Carlisle**, **George Dale**, **Doug Macut**, **Janis Macut**, **Keaton**



Macut, Jonathan Seitz, Rose Seitz and **Becky White** for being panel members for the Sibling and Parent Discussions. Presenters discussed topics

kids instantly gathered around her and started developing friendships while the parents were also getting to know one another.



including esteem building, overcoming emotional barriers, personal journey of being a craniofacial surgeon, relationships and more. Thanks to all for a very informative, productive day.

After meeting for a beautiful outdoor breakfast Friday morning, **A Tu'u Mai I Te Here** performed a Polynesian show with live Tahitian drumming and music for our families. Everyone was in awe and towards the end of the show, they asked for audience participation. We had a stage full of kids, siblings, teens and even

We kicked off the retreat on Thursday evening with an ice cream social. Families were entertained by a stilt walker and juggler. The



some adults. Everyone learned the Polynesian dance and had a great time. After lunch, the families attended a **Peach Party** where they were able to decorate Vans shoes, cookies, color pillowcases, have their face painted, make necklaces with beads from Beads of Courage, paint pictures and much more, all while listening to some amazing music. Each kid went home with a bag full of goodies! CCA would like to thank **Madison "Peach" Steiner-Akins, Annie Smith, Annalise Smith, Corey Smith** and all of the volunteers for putting

together an incredible party for our families. They had a blast and we look forward to having you join us next year!

Friday evening, we held the traditional family night and teen party. This year, we added a very special event. For the first time ever, we held a **Wonder Reader's Theater**. To read more about this, please see page 12.

As usual, 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. While parents were buying raffle tickets and stuffing them in the raffle bags, the teens were lounging by the pool, watching a movie while eating popcorn and doing the things teens do best!

Saturday the families gathered for a beach party! California has been in a drought for quite some time and guess what happened the day of our beach party? It rained! But the rain didn't stop our



group from having a great time. We made the best of it and bundled with towels, made sand shelters and a brave group actually played in the ocean. Nothing can stop our families from having a great time!

Saturday evening's dinner/dance is a family favorite, and this year was no different. But before the festivities began, the families were all shown a video from Cher. She was out of the country and took the time to record a special message for our families. Afterwards, we all did a standing ovation for Cher and sent her the video to thank her. After everyone thanked Cher,

see **program director,**

page 10





the dancing began and continued late into the night! We were thrilled to have **Matt Figueroa** from Arizona as our DJ again this year. He was our DJ for the 2012 retreat in Arizona, and he has been a crowd favorite ever since.

Sunday morning is always the hardest. There were lots of hugs, promises of staying in touch and, as always, a few tears. We really enjoyed meeting all the new families and catching up with old friends. We hope everyone had the TIME OF THEIR LIFE!



Registration is officially open for the **2016 Fort Lauderdale, FL**, retreat, and we hope to see you all there!

Now please enjoy reading about a first-time retreat attendee, **Stacey Hofman**, and her family's experience.

Annie Reeves
CCA Program Director



Above: Retreat first-timers Ryan, Halle and Francisca Hofman

retreat first-timers

By Stacey Hofman

I have to admit another year almost passed by without the **Hofman family** experiencing the Annual CCA Cher's Family Retreat. As we have each year for at least the past five years, we tossed around the idea of traveling to Newport Beach for the retreat we were reading about in the CCA newsletters. Although we have always been tempted to attend the retreat, we never understood the

impact it could possibly have on our family.

Initially, I think most of us parents feel that the retreat is for our child or children with a craniofacial difference. At least this is how I felt when we made the decision to attend. "It will be good for **Halle**," I thought. It turns out it was great for not only Halle, but for the entire family.

My daughter Halle was born with Pfeiffer syndrome 15 years ago and





Above: Retreat first-timers Halle and her dad, Cory Hofman

has received the majority of her care at Chicago



Children's Hospital, now called Lurie's Children's Hospital. Despite the many hours we have spent at doctor appointments and hospital stays, we had never met another person with Pfeiffer syndrome until the retreat in Newport Beach. I believe there is power in human connection, and I witnessed it first-hand as I watched my daughter get to know others who have traveled a similar path. At the retreat she found mentors and role models that I am confident will impact her life in positive ways for years to come.



Even more surprising to me was that I realized the need I had to connect with other mothers who have journeyed the same roads. I found my emotions to be close to the surface as I met others and heard

about their experiences I felt were so similar to mine. There was so much that didn't need to be said because we just knew.

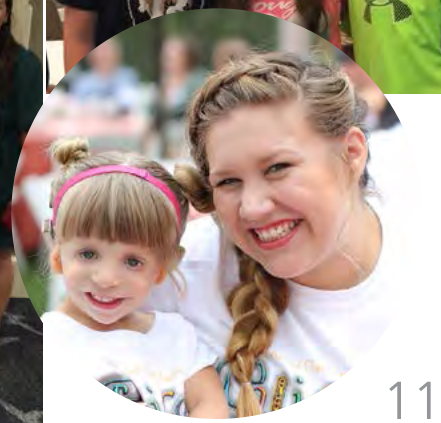
My experience at the retreat helped me gain a real appreciation for CCA and the valuable resource it is to our families. Days after

returning from the retreat, a friend called me to ask for advice for a friend of hers that had just had a baby with craniofacial anomalies. I recommended that she become familiar with CCA and felt confident that it will serve as a great resource for her as she learns about her child's condition, and hopefully it will help her to find strength in others' stories and know that she is not alone.

Thank you, CCA, for the time and energy you all have given to make the 2015 Newport Beach Cher's Family Retreat happen. Halle, her siblings and my husband and I had



a wonderful time and look forward to many more CCA retreats in the future!





wonderful reader's theater performance at the 2015 retreat

families attending this year's retreat in Newport Beach were treated to a staged reading of excerpts from the book *Wonder* by R.J. Palacio. The performance was adapted and directed by **Mr. Edward Edwards** who became involved with CCA two years ago after he directed a similar performance for the Santa Monica Public Library. Mr. Edwards was joined by

several other professional actors and local talent who volunteered their time to make the performance successful.

A special thank you to **Ed O'Neill, Sophia O'Neill, Paul Schackman, Paul Linke, Jaimi Paige, Aidan Blain,** and **Alden Cressy** for participating in the production. Several CCA siblings read parts as well including **Aaron Guzzo, Destiny Carlisle, Robbie Seitz, Amelia Sanborn,**

Jacob Dankelson, Cody Dale, Lauryn Johnson, Dillon Lucas, Liam Parson, Taryn MacLennan, and **Dylan Eakright.***

CCA's own **Peter Dankelson** starred in the lead as Auggie Pullman, inspiring all of our families to see that there really are no limits to success for CCA kids. *Wonder* is helping widen the circle of acceptance for CCA kids in ways that were



inconceivable prior to its publication in 2012. Bring the *Wonder* Reader's Theater to your child's school by contacting Annie Reeves in the CCA office.

** A portion of this performance was made possible by grant funds from the **Tony Stewart Foundation.***





chance raffle

The Chance Raffle, a fun event held during the CCA Annual Family Retreat, raised **\$2,515** this year. Wonderful gift baskets, goodies and other parcels from hometowns, states and even other countries were provided by retreat attendees. Each family received their first ticket free at registration. After that, tickets were purchased in strips of 20 for \$5 and dropped into the drawing for whichever prize one wished to win. The winners were drawn immediately following Friday's Family Night festivities, and winners spent the rest of the weekend figuring out how to haul home their stuff!



disneyland raffle

Thanks to a generous donor, CCA raffled a set of four tickets to Disneyland in Anaheim, California in May and June. A fabulous \$400-value, each raffle ticket was just \$20 apiece. The raffle raised **\$780!** The lucky winners were the **Vysocky Family**. Congrats!

happy birthday, cher!

The **Cher Crew** (Cher fans) held another CCA fundraiser in honor of **Cher's birthday** this past May to celebrate our honorary chair, Cher, turning 69 years young! The tally for CCA Kids got up to a tremendous **\$4,600!**

Thanks to everyone who shared our posts and retweeted the funder news, and to our own pretty lady for personally tweeting her message of thanks to everyone!



madelyn myre's wonder funder

by Maddie Myre

Hi! I am **Maddie Myre**. I received the book, *Wonder* for Christmas and I couldn't put it down. After reading how hard Auggie's life was in school, I felt inspired to make a difference. So, that is why for my birthday, I decided to ask my friends and family to make donations to your cause instead of presents. For my 11th birthday in February, I received **\$250** in donations. Please accept this birthday donation from me. I just hope it can help make a child's life a little bit better.



Maddie, we are deeply touched and inspired by your Wonder-ful kindness! Thank you from everyone at Children's Craniofacial Association and all CCA Kids!

good news

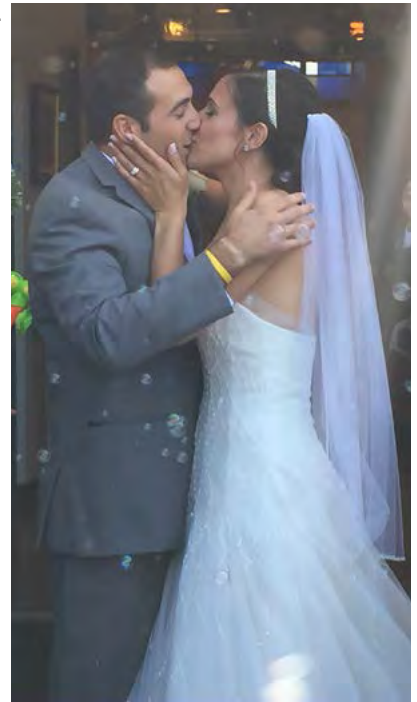
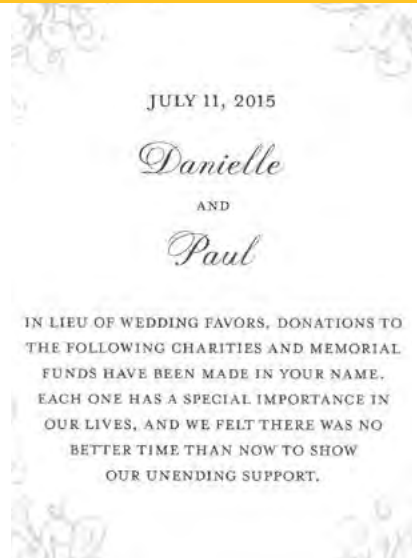


Our office was visited recently by **Mr. Gregg Darnall** of **Dallas Children's Charities** to present us with a check for grant funds of **\$3,000**, raised by the **Dallas Margarita Society**. Thank you!

wedding donation

Paul and **Danielle Bordonaro** made a **\$500** donation to CCA in lieu of wedding favors (and made donations to four other charities as well) to honor their guests.




This organization has provided tremendous support and countless memories for my family... Thank you for everything (CCA) has done for my family and I know this money will go toward creating lasting memories for other CCA families.
Very sincerely, Paul (and Danielle) Bordonaro



BUY A CRANIOFACIAL ACCEPTANCE MONTH T-SHIRT!
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Buy and/or sell "Beyond the Face is a Heart" wristbands for Craniofacial Acceptance Month



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PICNIC

September is craniofacial acceptance month

This year marks the eleventh year CCA will observe September as Craniofacial Acceptance Month 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 and to get people to see that "beyond the face is a heart."

As part of the 11th Annual Craniofacial Acceptance Month, CCA will hold its **8th Annual National Picnic Day** on **September 12th** (or other date in September of your choice). CCA families across the nation will hold picnics giving them a chance to get together with other families in their areas, while promoting awareness in their communities.

If you would like to hold a picnic, contact CCA Program Director Annie Reeves. CCA will invite all of the families in your area and help you organize your picnic.

In addition to raising awareness and acceptance, CCA is raising funds to support programs and services available to all individuals with facial differences and their families. Contact CCA Development Director, **Jill Patterson** for materials about this year's fundraising efforts.

We hope you will join this important effort! Please call 800.535.3643.



Don't forget to **TURN FACEBOOK YELLOW** during the month of September by using a CCA Craniofacial Acceptance Month avatar, downloadable from our website at ccakids.org/acceptance-month.html



guille family, from page 1 than we could ever hope to achieve. Thanks to our love for our special needs child and newly lit passion for adoption, we followed the red thread to Ruby.

Ruby was born in Ukraine. Her birth occurred in a hospital, but because of her craniofacial differences she was deemed worthless. She was quickly moved to a baby orphanage, hidden away and raised inside four walls for the next five years. We first learned about Ruby from another adoption advocate who met her when Ruby was just a baby in a bouncer seat. This advocate told Ruby's story as best she could, with pictures she had collected from a therapy team who had recently visited the orphanage. The team talked of her cheerfulness,

friendliness and how special she was.

Time was of the essence because Ruby's fifth birthday was fast approaching. Upon turning age five, Ruby would have been taken from the only place she had ever known, put in a car and driven far into the countryside to live her remaining days in an adult mental institution.

The adoption process in Ukraine is a drawn-out, tedious exercise requiring adopting parents to be in country for an extended period of time. My husband Kevin spent three weeks in Ukraine. I (Darcy) spent six weeks there wading through the seemingly unending bureaucracy. But we were finally able to bring Ruby home with us. We arrived back home stateside in October 2012, grateful for our adventure but so happy to be home.

Ruby flourished in her new family setting, supported by her brother and two sisters. Our first need upon arriving was to get Ruby's body strengthened. She sat around for five years in an orphanage and the inactivity had taken a toll. Her muscles were practically nonexistent.

She could barely walk, much less run, jump or skip. We found an amazing

therapy team who worked with Ruby to assist in getting her stronger and mobile. In time, her balance improved and her self-esteem blossomed. She even performed as a cancan cutie in the local melodrama the summer after arriving home!

Ruby has craniosynostosis which, had she been born in the US, would have been addressed at the age of 3 months. We will eventually tackle her head shape when she is around 9 years old. She also has hypertelorism, creating balance and visual challenges. Her eyes will be moved closer to midline once her head has been reshaped. Until then Ruby's other medical needs have kept us busy.

There is a belief in Ukraine that rotten teeth create strong adult teeth, and Ruby's teeth were rotten. Ruby's first surgery was to cap and/or pull all the infected teeth. Ruby was also diagnosed with severe sleep apnea, resulting in the removal of her tonsils and adenoids.

The doctors discovered she also had a chiari malformation which creates symptoms of severe sleep apnea, balance and various other physical difficulties. We monitored and alleviated her sleep apnea



with a bipap machine until this past December, when the doctors decided it was time to operate on her brain. She had a chiari decompression in early December and did very well immediately following the surgery.

Unfortunately, at home, Ruby was experiencing dizziness with vomiting. Most alarming was her personality change. Our spunky girl had disappeared. We learned her personality change indicated hydrocephalus had reared its ugly head. It was time for a shunt.

Ruby had shunt surgery this past January. She again did great immediately following surgery. However, when we got her home, the pressure change was so dramatic within her

brain that Ruby forgot how to walk. We spent an unexpected week in Colorado Children's Hospital monitoring the shunt and waiting for her to stabilize and walk without assistance.

Ruby left the hospital wearing a neck brace and utilizing a walker. After one month of using the walker and reeducating her neck on proper placement, we are happy to report that she is brace- and walker-free! The chiari surgery helped alleviate some of her sleep apnea, but it persists. We continue to explore this challenge and are confident we will find answers for our sweet and funny girl.

William Jennings Bryan said, "Destiny is not a matter of chance, but of

choice. Not something to wish for, but to attain." When sharing our story with people, most either proclaim we are crazy or saints for choosing to adopt Ruby. We feel we are neither. We prefer to call ourselves blessed.

When we first met Ruby, she could not even walk a straight line. Fear gripped our hearts. I asked God to let me know for sure we were doing the right thing. After all, we had other children at home to consider. The very next day we were taken to Ruby's baby doctor in the orphanage who expressed her thanks we were there to adopt Ruby.

You see, the day prior, this very doctor had started

see **guille family**,
page 18

testimonial



My son, Quinn Johnson, was born on October 6, 2011, with a wide unilateral cleft lip and palate. We live in a rural area where there is no one who specializes in this condition, so we need to travel.

When I was pregnant, my perinatologist recommended the Children's Hospital of Philadelphia (CHOP). CHOP is three and a half hours away not including stops we have to make traveling with kids. We started going to CHOP when my son was four weeks old.

We then traveled there on a weekly, then monthly basis as Quinn was fitted for a retainer that helped naturally pull his lip together. The retainer needed tightening on a regular basis up until he had his lip repaired at the age of four and a half months.

This got to be very expensive. There were follow-up appointments after that, and he had his palate repaired at ten months old. He continues to have surgeries to place tubes in his ears due to his cleft and has follow-up appointments, and he sees his cleft palate team yearly.

There are a lot of organizations out there that offer resources for your child's condition but none that I have found that will help you with the financial burden of having to travel long distances to get your child the best care possible. That's the last thing you want to think about when you're faced with what to do and where to go, because this is your child and you want the best for them.

I then found Children's Craniofacial Association (CCA), and Annie is

absolutely wonderful. She is always so pleasant to talk to and willing to help you out in any way she can. CCA has helped us with hotels, food and gas, and it is such a relief to have financial help so you can focus on your child and not how you are going to get him to his surgeries and appointments.

I am very thankful for CCA and appreciate everything they have done for us—without them I do not know what we would have done. I hope one day I will be able to repay them plus more for all the help they have provided to our family, so they can help another family that is in the same situation as we are.

Thank you to CCA and everyone who donates to them and for all your continued support!

Colleen, Lance, Kailee, Quinn, Avie – Athens, PA



guille family,
from page 17

paperwork to send Ruby to the adult mental institution where children usually live a short time before dying from neglect and starvation.

At that moment, God whispered to me, "You are right where you need to be." I pleaded, "Lord I can't do this without you, show me the way." I knew as God whispered that we would take Ruby home and she would be a treasure.

And she is. She is a bright, funny, witty child we are blessed to call daughter. Ruby is tenacious and she inspires. She shows others the light and love of God like no one else can. Every step, God has been there guiding and placing the right people in our path. It is amazing to see the transformation Ruby has gone through in her short time here with us, but the most amazing blessing is to see the people transformed after meeting this strong and courageous little girl.

The red thread had wound its way from our family to an unwanted orphan in China and then tightened as we walked a tightrope to this very special gem in Ukraine.

calendar of events

date event contact

2015

Aug 30	Seth's Stride Canton, OH	Stacy Horne stacy@hostetlerskbr.com
September	11th Annual Craniofacial Acceptance Month Nationwide	ARees@ccakids.com 214.570.9099 800.535.3643
Sep 12 11A-1P	8th Annual National Picnic Day Sandy Lake Amusement Park Carrollton, TX	ARees@ccakids.com 214.570.9099 800.535.3643
September 12	Raegan's Rally/Walk for CCA Deerasic Park Cambridge, OH	Ashley Daugherty ashleyddaugherty@gmail.com
Sep 19 10:30A-2:30P	California Picnic Rotary Park 1200 Safford St. Oroville, CA 95965	Jennifer Foxen jenjonf@gmail.com
Sep 19 Noon-3P	Florida Picnic Moss Park Pavilion 1 12901 Moss Park Rd. Orlando, FL 32832	Alyssa Johnson Casey Deakins www.facebook.com/craniofcf
Sep 19 1-4P	Michigan Picnic Bi-Centennial/Ben Celani Park Pavilion 35400 Seven Mile Road (East of Wayne) Livonia, MI	Kellie Dowd kdowd22@gmail.com
Sep 20 11A	California Picnic La Jolla Shores Beach 8200 Camino del Oro La Jolla, CA 92037	Courtney Vysocky www.facebook.com/events/612029085567405/
Sep 20 Noon-3P	U of M-Mott Children's Hospital Picnic Montibeller Park 4305 Ellsworth Rd. Pittsfield Charter Township, MI	Coreen Abston cabston@med.umich.edu
Sep 25	8th Annual Links of Love Golf Tournament Bear Creek Golf Club at DFW Airport Dallas, TX	JPatterson@ccakids.com 214.570.9099 800.535.3643
Dec 5 11:30A-2:30P	CCA Holiday Party-Midwest Brat Stop/Parkway Chateau Kenosha, WI	JPatterson@ccakids.com 214.570.9099 800.535.3643
Dec 12 10A-Noon	CCA Holiday Party-Dallas Southfork Ranch Parker, TX	ARees@ccakids.com 214.570.9099 800.535.3643

sponsors needed for cher's family retreat!

In surveys CCA families have expressed to us that our retreat is the most important program we offer. Did you know it costs Children's Craniofacial Association approximately **\$100,000** to hold our Annual Family Retreat each June?!

From time-to-time we've had T-shirt sponsors. But, we are in need of more sponsors. If you know of anyone who might be interested in supporting this worthwhile program, please have them contact our office. Email contact@ccakids.com or call 800.535.3643.

registration is now open for 2016 annual cher's family retreat June 23-June 26 in Fort Lauderdale, Florida

Please join us for an educational symposium, beach party, ice cream social, dinner/dance and much more!

For more information,
please contact Annie Reeves,

ARees@ccakids.com

We hope to see you there!

Registration ends May 13, 2016. Register by May 1st to get the early bird price of \$100. Registration will increase to \$125 starting May 2nd.

responding to people in your community

Lori Takeuchi, MPA, CCLS and Carolynne Garrison Howard, PhD

When your child is born, you might feel tempted to isolate yourself to shield yourself from questions from strangers. You cannot avoid the community, nor should you.

People who do not know you may have questions and comments about your child or they may even stare. Some people are honest and inquisitive, and others are rude. As a parent, you will need to decide how you will address the questions and stares. There will be days you might feel like explaining the diagnosis, while other days you do not feel like explaining anything. You can do both.

It is important to face your fears and the situation — and to take your time. Try different outings and events to find your comfort level around strangers.

Once you can work through each step of interacting with the community and make a choice as to how you are going to handle it, you are more in control. You are able to move in and out of situations with more comfort.

Understand your own emotions. As a parent, you can recognize, understand and take control of your feelings and responses. You may have a variety of feelings when someone comments in a negative way towards your child.

- You may feel angry, frustrated or sad.
- You may wonder: “Why is she saying this to my child?” “Why does he have to say this to me?” “Why are they treating my child like this?”
- You may act on your emotions and thoughts of anger.
- You may feel like withdrawing.

Your reaction, your way. When you begin to understand your typical reactions, you can choose the way you would like to respond. You want to react in a way that makes you feel more in control in the situation. When you have the feelings of anger or frustration, you can make a decision to calm yourself.

- Walk away, take deep breaths or visualize a calming thought.
- Think different thoughts: “They are ignorant.” “They will never know how amazing my child is.”

- Physically control yourself: Take slow, deep breaths. Take a 15-second timeout. Squeeze a fist. Stretch your neck.

What do I say? You can judge the comment or question. Listen to the question. If it is well intentioned, you can provide a variety of information that will help them get answers and educate them. Listen and then respond. They might have never seen a child with your child’s specific craniofacial condition and want to know more. Make sure you use a name for the craniofacial condition.

What to say to an adult. Try to have a response that is not emotional.

- *In a comfortable situation*, you may respond with a specific answer each time: “She was born with microtia. She did not have an outer ear. She is a healthy child. That is all I would like to say right now.”
- You might want to protect your time with your child, yet want to respond: “I am happy to answer a few questions, but this is our play time.”

You can provide as much information as you are comfortable. Some days you might be in the mood to elaborate and other days you may not. You may want to ask them what their experience is with people who have craniofacial differences.

End the conversation by saying “Thank you for asking, I hope my answers have helped. I am going to play with my daughter now. Have a nice day.”

- *In an uncomfortable situation*: Use a flat and even tone:
 - “Why are you asking that question?”
 - “That is an inappropriate comment”
 - “I would prefer not to talk about it”
- If they continue to ask you the same question or not show respect, repeat yourself:
 - You: “I would prefer not to talk about it”
 - Them: But I just want to know why her ear looks like that.”
 - You: “I would prefer not to talk about it”
 - Them: “But...”
 - You: “I would prefer not to talk about it”

What to say to a child. Children are not subtle. They will stare. They will ask what is wrong. They will ask why a body part is different. This is your time to reassure the child inquiring as well as your child that everything is all right.

Make it clear, brief and simple. Then go about your business. "Mary was born this way. It is called_____. Thank you for asking."

Pay attention to your body language. Hold your head up high. Use direct eye contact, good posture and relaxed arms. Portray confidence, even when you might not feel it.

They are gone. Now what should you do? The interaction is over, and you need to briefly reflect and assess how you are feeling. Are you able to go back to the activity? Do you need a moment to relax yourself physically and emotionally?

- Take deep breaths and shrug your shoulders.
- Be aware of how you feel. Mad? Sad? Calm?
- Choose what you will do to let it go and enjoy your day.

Model constructive responses for your child. Your child hears your responses. You want them to know that you are proud of them. You are modeling behavior for them. You continually work on building your child's self-esteem. The more open and proud of your child you are, the more it will translate to their personal view of self-esteem.

When your child is old enough to understand, ask them what they would like you to say to strangers or other parents from school when questions arise. Agree on an answer and use it when you are in the community with your child.

It is an ongoing process. You might feel proud about your responses in hindsight and other times wish you had said something differently. You will continue to work on your responses. Try to remain consistent in your reactions to be a model for your child, your other children and family members.

Always remember that your child is more than a medical condition. Your child is more than a physical body. You know their gifts—cherish and celebrate them. No stranger can take that feeling away.

GO PAPERLESS and

view the newsletter

online in FULL COLOR!

Email AReeves@ccakids.com

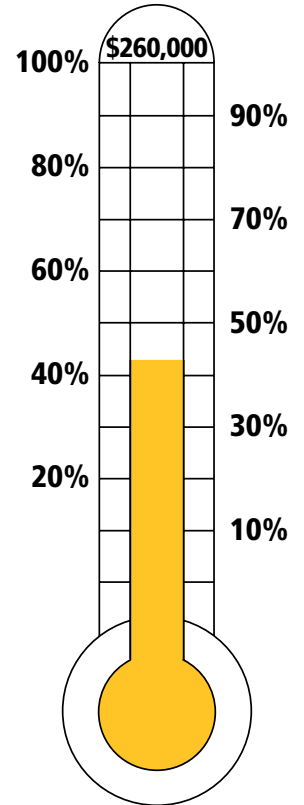
and let her know

you want to **save the**

environment and

save money for CCA.

2015 FAMILY FUNDRAISER GOAL THERMOMETER



To see CCA's list of donors as of June 30, 2015, please go to our website. The list can be found at

www.ccakids.org/donor-list.html

state assistance:

did you know that many states offer funding/small grants to individuals with disabilities and their family members to attend advocacy, learning events and conferences? The **CCA Retreat qualifies** because of our educational symposium. If you would like more information regarding your state assistance program, please visit ccakids.org/state-funding.html



megan cronin's birthday

When the **Cronin Family** visited our CCA office, they brought a "birthday gift" of **more than \$1,200** collected in lieu of gifts for Megan's 10th birthday! How kind and

generous of Megan to give instead to all CCA families in honor of her own birthday! That's how our CCA Kids roll! Thank you, Cronin Family, and to all of your friends and family who think so much of our Megan! XO



community gathering for cca kids

dr. **Melissa L. Brown's Orthodontics** office held a gathering of the local dental community and their staff, serving food for dinner, boasting live entertainment, several raffle baskets, a few big prizes like free braces and a TV donated by **Corning Incorporated** and other great items to win on raffle tickets purchased by patients' family and friends throughout springtime. The event was a smashing success, raising **\$3,315** for Children's Craniofacial Association! Also in attendance was CCA Kid and special guest, **Jeremy Dale** and his mom, **Kristine**. Thanks ALL!

wonder funder

by Rachel Haug

the 4th graders at **Lincoln Elementary** read the book *Wonder* as a class interactive, read-aloud activity. They fell in love with Auggie, the main character. While browsing Facebook one night I came across a video of a boy named **Austin**, who has a craniofacial anomaly. I showed the 4th graders the video, and they were so excited to help him raise money for his upcoming surgery, his 54th. In the middle of planning our fundraiser, Austin's gofundme account was no longer taking donations. Still wanting to help, we did some searching and decided that all our money raised would be donated to CCA to help kids just like Austin.

The 4th graders planned special-themed days, where students paid 25 cents to dress up or participate. Themes included pajama day, crazy hair day, hat day, stuffed animal day, and the most popular, bring your own electronics day. The kids made posters and collection envelopes and made announcements at morning assemblies. They helped count money each day and were blown away when they found out they raised **\$400!** The book and fundraiser go to show that we can learn so much from people's differences.

NOW SELLING YEAR 'ROUND



"I read Wonder!" T-Shirt

Stock sizes: Youth M-XL \$15, Adult S-XL Ladies S-XL \$20

FREE SHIPPING ON T-SHIRTS!

Special Quantities / Sizes / Prices available upon request



sangre ridge elementary school honors their cca kid

We received the following from teacher, **Joleen M. Royer**:

“Enclosed is a donation from my third grade students. We have a classmate that will have another facial surgery this month, so we painted flowers and sold the paintings to family members, to raise money in his honor. Please use our donation of **\$453** to help other children.” Classmate, **Bennett Dzailowski**, was born with Nager syndrome.

What a fabulous way to raise funds! Thank you to Ms. Royer’s class at **Sangre Ridge Elementary** in Stillwater, Oklahoma for this contribution in honor of Bennett!

matching gifts

Children’s Craniofacial Association (CCA) provides support for patients and their families affected by facial differences resulting at birth, later in development, or from accident or disease. Support is provided through our programs and services at no charge so we rely heavily on your gifts to do this. We encourage you to consider maximizing the impact of your donations through your company’s Matching Gifts program. Please contact your

Human Resources department to see if your company will match your donations to double your contributions for CCA!



Wonder Gift Sets

now available all the time!



Go to ccakids.org/wonder-gear to order yours!

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

frederick's firstgiving fundraiser

Not his first go-round at this, **Frederick Seitz** (he's been fundraising for CCA since he was little Freddie) started yet another fundraising campaign, this time with a lofty goal of raising \$10,000 by year's end. Our CCA board chair, **Bill Mecklenburg**, told him if he could get at least a quarter of it—\$2,500—by the time of our Annual Cher's Family Retreat, he'd add another \$1,000! Well, challenge accepted! At our CCA Annual Family Retreat in June, Frederick's total was **over \$2,600**.

Bill presented a check to him during the retreat festivities, and surprised the crowd with an announcement of challenge funds to match new donations of up to **\$25,000** offered by CCA's long-time donors **Kevin and Jennifer Trapani**. Families quickly responded and we had Frederick's \$10,000 goal met by the end of the evening.

We are accepting new gifts now toward the challenge grant!



What a great feeling to know your gifts will be doubled! We're so very grateful to the Trapanis for this opportunity and to everyone who's joining this effort to meet this challenge!