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kacey's story

By Christopher Hamsher

the birth of child, as every parent can testify, is a mixed bag of euphoria and awe, panic and trepidation. When that moment involves twins—and when one of the two is born with a craniofacial difference—those feelings multiply exponentially.

Our twins, **Kacey** and **Colin**, entered our world on July 30, 2004, a blue moon Friday afternoon. Kacey's birth, the first of the two, shocked us: This baby looks different. What happened? She had a cleft lip, an underdeveloped ear that was set lower on her head and several skin tags. As she was whisked away to our hospital's NICU, Kacey's twin, Colin, arrived, healthy but small, ready to meet the world head on.

And while we marveled at their births and the miracle of life, the moment wouldn't permit us to feel joy. The moment seized us. The moment terrified us. The moment was not what we thought it would be.

see **kacey**, page 16



message from the development director

throughout 2014 CCA has been celebrating 25 years of empowering and giving hope to individuals and families affected by facial differences—our silver anniversary. We have seen a small group of affected families become a very large group of families over the quarter century. And, we've watched that group become an extended family to one another. This is a family who cares for each other and has a "reunion" at our annual family retreat each year. But, they're also a family advocating for acceptance and a family who ensures its own sustainability and

see **development director**, page 6

ccakid

meet ben delong



Ben DeLong is a second grader from Pennsylvania who recently turned eight. He and his family celebrated his birthday at a minor league baseball game in Reading, where he got to hear his favorite song, "Take Me Out to the Ballgame."

Ben really enjoys school. He especially likes gym class, but he also likes music, math, reading (and lunch and recess, of course), so there's probably not a moment in the day when he's not having a good time while learning.

When Ben is not at school, he's involved in lots of afternoon activities, including swimming lessons, karate classes and

drum lessons. He's been taking karate for about a year, and started drum lessons this past summer. Or you could catch him watching *Toy Story 3*, his absolute favorite movie, reading *Danny's Day Out*, his go-to bedtime book, or taking care of his fish, appropriately named Fishy-Fish.

At the time of this interview, Ben was getting ready to celebrate Thanksgiving. He and his family plan to drive to Greenville, South Carolina, where they will spend the holiday with his two cousins and their family. And after Thanksgiving comes Christmas, one holiday Ben is looking forward to with great anticipation. Maybe he'll get more sports action figures or maybe even more Disney figures to play with.

Last summer, Ben went to the CCA Retreat in St. Louis. It was his first time flying in a plane, an



experience that was "a little scary, but good." He had a great weekend making new friends, including **Jacob** and **Oliver** from Texas. The best part of the weekend, however, was the dance party.

Ben was born with Muenke syndrome, and has to undergo his

share of surgeries and/or procedures. It's not slowing him down, though, not one bit. You'll still see him kicking it in karate, banging out a rocking beat on his drums and loving every minute of school. And hopefully enjoying some time next summer with the new friends at the CCA Retreat.

meet alexandria mwaura

alex is a 14-year-old who loves to play basketball. In fact, one of her proudest achievements was making the school basketball team for the current school term.

She is in the ninth grade at East Limestone High School in Athens, Alabama.

She was recently chosen to be inducted into the National Senior Beta Club. Alex also is an avid Auburn football fan. She spends her free time surfing the web and chatting via text on social media.

Alex wears a BAH hearing aid. She is followed by the medical staff at Birmingham Children's Hospital. She has undergone several surgeries and is scheduled for chin distraction in summer 2015. She is nervous and anxious about it at the same time, but her faith in God helps her maintain a positive outlook.

She and her family attended CCA's annual retreat for the first time this year. Unfortunately, she became very sick when they arrived in St. Louis. Alex was hospitalized for seven days and ended up going home with a PICC line. After six weeks of IV meds, numerous appointments and an appendectomy, she is now on the road to being healthy and playing basketball again.



Our family is very grateful for the staff of professionals at the hospital, who provided Alex with superb inpatient care and coordinated her after care. We are also appreciative of the compassion and support from CCA throughout this time. (Her brother **Charles** jokes that he had enough fun at the retreat for the both of them.)

Each year, Alex attends Camp Courage in Winder, Georgia. The camp is a week of fun and esteem-building activities for children with craniofacial anomalies. She enjoys catching up with friends, relaxing and sharing stories. The camp assists her to maintain a positive attitude in light of difficult situations.

Alex is very outgoing and never allows others to

make her feel as though she doesn't belong. She pushes forward and never quits. She is also an awesome big sister who loves to care for and spend time with her brother.





meet charles burgess, III

Charles is a second grader and a cool little brother who is very protective of his sister. When others ask questions about his sister **Alex**, his reply is, "Nothing is wrong," and "She is just like you and me."

He often worries about his sister when she is sick or undergoing a medical procedure and prays that God protects her. He feels sad when she cannot participate in activities and spend time with him.

Like his sister, Charles enjoys sports. He plays soccer and basketball and plans to play baseball in

the spring. He spends most of his free time playing video games and with Halo figurines. He is very serious about his shoes and loves to watch basketball.

Charles is excited football season has begun. Unlike his sister, he is an avid Alabama fan. The two often watch the games together and playfully quarrel throughout. Yet even though they don't agree on some things, the two are very close and are always looking out for each other.



ccasupersib

links of love 2014

The 7th Annual Links of Love Golf Tournament took place September 12th at **Bear Creek Golf Club** in Dallas, Texas, **grossing more than \$17,000.**

Registration began with morning coffee and baked goods from **Starbucks** on Inwood Road, and golfers were treated to lunches from **Corner Bakery** as they took practice shots and prepared to hit the links for the afternoon scramble. Featured at each tee box along with sponsor signs were photo signs



of CCA kids and adults representing CCA's cause and the many different craniofacial conditions.

We also featured new pin flags this year with a photo to match the tee box signs of the CCA kids and adults including the Links of Love event logo,

which helped create even more awareness. Pin flag sponsors included **Vance & Judy Kemler, Michelle Helton** and **Lanham Stark** with **Keller Williams Realty.**

Our volunteer crew were **Rich Thomas, Debbie & Mike Miller, Genny DeLong, Judi Freeman, Margaret Lavender** and **Robin Williamson**, who helped with tasks from auction setup and registration to on-the-course contests, dinner festivities and clean up!

Hungry golfers finished the day with another great **Spring Creek Barbeque** dinner, door-prize raffles, awards and auctions. We had a couple of young golfers this year. CCA kid **John Gorman** teamed up with his uncle and two grandfathers, and **Madden Sinnes** golfed with his grandfather, **Dan Kaiser.** John's mom, **April Gorman**, gave a heartfelt testimonial for CCA, leaving all participants feeling good about their efforts that day on behalf of CCA.

Thank you to our volunteers, participants and especially to this year's sponsors:



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(\$1,000 or more in Monetary/Goods/Services Sponsorship)

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Ben E. Keith / Real Ale Brewing Company
Corner Bakery
Spring Creek Barbeque

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A big thank you to all who helped make the 2014 Links of Love event a success!



development director, from page 1

financial independence. These are the things that make Children's Craniofacial Association a unique organization.

CCA families support each other on many levels. Throughout the year, our families network with each other, online using social media or our Yahoo listserv, by emailing, calling and even meeting in person. Through these opportunities, CCA families share information, opinions and helpful hints, which enhance resources that CCA provides.

CCA families take a hands-on approach to advocating for themselves and others in our large family. Hundreds of families have joined the "Choose Kind" project launched by CCA. They've taken the *Wonder* book and CCA "teaching resource packets" to schools, libraries and other outlets across the country.

CCA families don't wait for an organization to do it for them. They roll up their sleeves and take responsibility for making sure this remarkable message—"When given the choice, choose kind"—is in the hands and on the minds of students and communities across the country,

and they're taking a stand against bullying of any kind of differences.

One of the most unique traits of our extended family is their passion for making sure CCA has the funds necessary to continue offering programs and services that they themselves need and consider so important. Even kids who grew up in the "family" are now joining the fundraising effort. Funds are raised through golf tournaments, walks and just about any event or effort one might think of. Because of these important

"family and friends funders," CCA has been able to sustain programs and services when many organizations have had to drastically scale back.

And, just as important as the dollars raised from those we serve are the funds contributed without condition by those who believe in what we're doing. Our hearts are full for our donors, many of whom generously give to CCA because they know one of our CCA kids. Again, "family" seems to be a recurring theme.

The DJ always plays Sister Sledge's "We Are Family" during our annual

retreat dinner dance, and the whole group joins one another on the dance floor. Because we truly are one big CCA family!

As we go into the holiday season, CCA staff and board of directors thank all of our families, our donors and our volunteers for making this past year's silver anniversary celebration a memorable one and for embracing this cause to keep it going strong for another quarter century! Merry Christmas and "kind" wishes to you and whomever you call "family" in the New Year—and always!

Jill Patterson

CCA Development Director

WE ARE FAMILY





seth's stride

Seth's Stride for CCA was held September 13th. This is our 6th year of continuing our mission to raise awareness and acceptance in our community. It was so wonderful to have some of our CCA families join us again this year and to see the changes in the kids. Thank you all for coming! It is hard to believe **Seth Swihart** was only 5 years old when Seth's Stride for CCA was "born." Time sure does fly and he thoroughly enjoys it each year, referring to it as "my party." We had another successful year and a great time was had by all!



Click on
DONATE
at ccakids.org



2014 miles for cca kids poker run

the 2014 Miles for Kids Poker Run took place Sunday, July 12th, raising awareness and **almost \$5,000** for CCA. Event coordinators **Reverend Lewis Boykin** and his wife **Pastor Carla Boykin** enlisted the help and expertise of **Gen White** and also secured "Leaders of the Pack" sponsors, **Connect Insurance** and **The Law Offices of Stephen Blaine Smith**.

We would also like to thank "Road Captain Sponsors": **2nd Sunday Biker Church, Adkerson, Hauder & Bezney, The Allen Wickers Sports Pub & Grill, Big Slicks, Westminster, Quaker Steak & Lube, Plano, Rock 101 Little Elm, Big Tony's Grill, McKinney, Harley-Davidson of Dallas, Allen, Complete Appraisal Services, Mattress Cleaners,**

Prestige Auto Brokers, and Ekvall & Byrne, LLP.

Also we'd like to extend a special thank you to members of **2nd Sunday Biker Church** and **DWMC**, who volunteered at registration and each of the stops. Their hard work and dedication were critical to the day. Many area businesses contributed raffle prizes, and we thank everyone for their generous support and dedication to this worthy cause.

Join us next year on July 11, 2015, for the Annual Miles for CCA Kids Benefit Ride!





FLORIDA

2014 craniofacial acceptance month

This year marked the tenth year CCA observed September as Craniofacial Acceptance Month across the nation. CCA families, friends, volunteers and related support groups widened the circle of acceptance for individuals with facial differences. The goal is to create awareness that beyond the face is a heart.

Many of our CCA families were able to get their local newspapers to

feature them and some were even featured on their local news or radio stations. We mailed out over 200 Craniofacial Acceptance Month packets to 35 states and Australia! And, for the seventh year, CCA held National Picnic Day in September as part of Craniofacial Acceptance Month. CCA families across the nation held picnics in Arkansas, two in California, Delaware, Florida, Georgia,

Illinois, two in Michigan, Minnesota, Nebraska, New Jersey, two in Ohio, Pennsylvania, Texas and Virginia. This is the best turnout we've ever had! A special thanks goes out to **Larry Whitler** of **WOCA The Source Radio** in Ocala, FL. Not only did he have the Florida picnic host, **Casey Deakins**, on his radio show but he also attended the picnic and

put together this amazing video:

www.youtube.com/watch?v=f8tkPqkv-oY&feature=youtu.be&list=UWuufDf4Na9cBX9waCa0Ffg

CCA thanks everyone for all of their hard work in making Craniofacial Acceptance Month another great success!



TEXAS



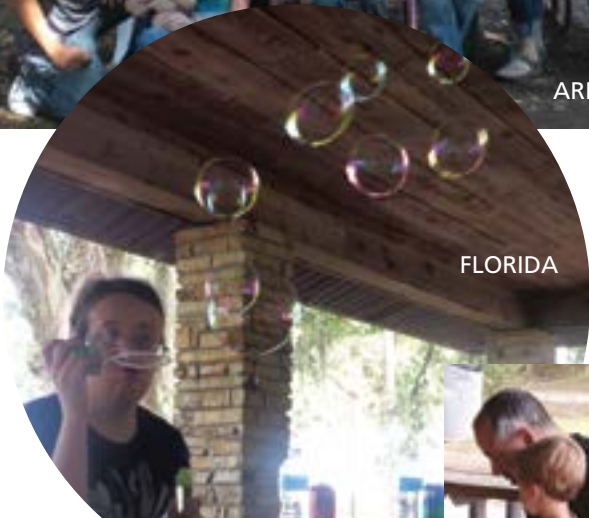
NEBRASKA



ARKANSAS



VIRGINIA



FLORIDA



VIRGINIA



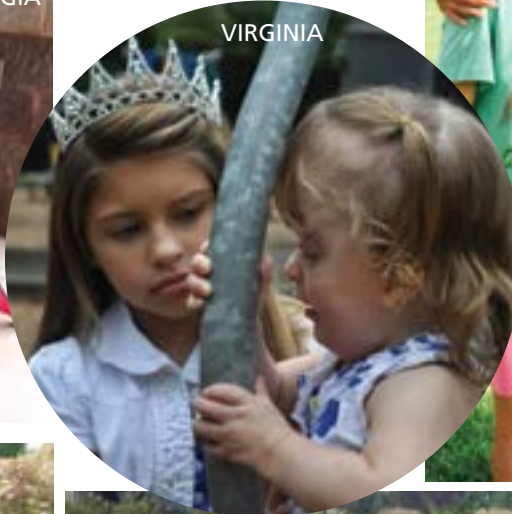
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NEW JERSEY



ILLINOIS



NEW JERSEY

raegan's rally 2014

by Ashley Daugherty

This year marked the 5th year for Raegan's Rally at Deerassic Park in Cambridge, Ohio—hard to believe! Each year the event seems to grow in number as well as success and this year did not disappoint.

Raegan Daugherty started kindergarten this year, and it was really fun to see some of the staff and her friends from school in attendance. She even had a classmate run, complete and place in the 5k!



The 5K kicked off the event through scenic Deerassic Park. The deer at the park created a very eye-catching experience throughout the course this year. The top three male adults, top three female adults, and top three kids were awarded for their speedy finishes in the challenging 5K course.

After the race, everyone gathered inside the lodge for the silent auction and raffle. Guests also enjoyed homemade

goodies from the concession stand made by Raegan's grandmothers, **Nancy Athurs, Peachy,** and **Joy Hannahs** as well as locally made **Conn's Potato Chips.**

Some of the highlights of the silent auction included: an American Girl Doll, Necklaces from Kay Jewelers, Mosser Glass (donated by **Mindy Mosser**) and a handmade rocking horse. The raffle was packed with exciting gifts, including: Target gift cards (donated by Raegan's Aunt, **Kaci Cree**), hair product baskets,

a giant present made out of candy (donated by Raegan's Aunt **Christi Smith**), Thirty-One, OSU memorabilia, car



washes, pet grooming gift certificates (donated by **Dirty Dog**), kids baskets (donated by Raegan's grandmothers), massages (donated by **Brenda Richards**), oil changes (donated by **Classic Ford**), car detailing, Columbus Zoo and Wilds tickets (donated by **Arin Harper**), Mary Kay (donated by **Allana Decker**), and more.

Tickets were also sold in advance for the opportunity to win the choice of the following: Ultimate Fan Package for Charlotte Motor Speedway (which included two luxury suite tickets, VIP parking, garage tour and driver intro

passes) or a Spa Day from Allure Spa; these prizes were donated by Raegan's Uncle, **Matt Long** and family friend **Elizabeth Camp** respectively.

The day was wonderful! We would like to thank all of our friends and family that help make this event a success year after year. Big thanks goes to **Mark Meeker** and **Staff** at **Deerassic Park** for all their help and continued support. And we extend our gratitude to **Mike Meeker** for capturing the day for us!

Raegan's Rally 2014 netted **over \$6,000** for CCA Kids!



acceptance in the park: A Fundraiser in Support of CCA

by Deena Dyson

CA Family **Darryl, Deena,** and **Teresa Joy Dyson** held "Acceptance In The Park: A Fundraiser/Picnic in Support of CCA" on September 28th, at Vasona Park in Los Gatos, California.

Over 70 people bought tickets to enjoy the fun which included outdoor games, *Wonder*-related activities, a rousing raffle, delicious lunch and kid's yoga in the shade. It was a beautiful day with family and friends. **Over \$2,000** was raised for CCA, as well as a priceless amount of awareness about our kids!

Many thanks to Teresa Joy's **Brownie Troop #60427** and **Troop Leader Cassie LeBaron** for supporting the raffle, to **Rebecca Sunda of Printer Chicks** for donating the printed tickets, to **Sergio Coyote Barbecue** for the discounted catering fee, to **Joy and Rod Strickland** for doing so much on the big day, to **Ann Marie Wood** for all your help to bring family and to everyone who attended and donated! What a blast!





thank you for choosing kind!

August (Auggie) Pullman was born with a facial difference that prevented him from going to a mainstream school—until now. He's about to enter 5th grade at Beecher Prep, and if you've ever been the new kid, then you know how hard that can be. The thing is Auggie's just an ordinary kid, with an extraordinary face. But can he convince his new classmates that he's just like them, despite appearances?

CCA is on a mission to spread the word about acceptance of facial differences and the book, *Wonder*, by R.J. Palacio has given us a perfect platform. The book promotes the message to "Choose Kind" and takes a stand against bullying.

CCA would like to see the "Choose Kind" campaign endorsed by schools across the country, and we are promoting a grass roots effort to make that happen. **If you have children between the ages of 9 to 13 we need your help.** First, please read the book, then share the book and supporting materials with your children's school(s).

Educators are excited about *Wonder*, because not only does it have an anti-bullying message, but it also meets National Common Core Standards for K-12 Literature. In particular, the book meets the Character Component benchmark for 5th grade literature.

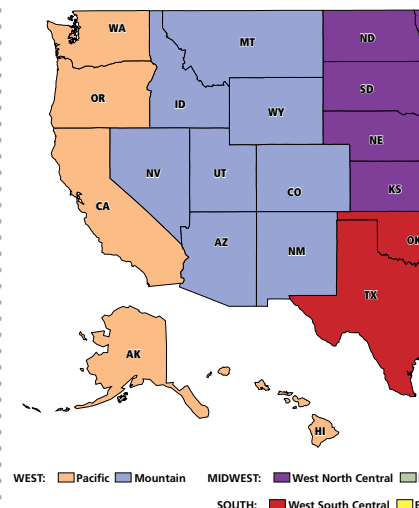
For more information on how you can help, contact AReeves@ccakids.com.

In addition to the book *Wonder*, "Choose Kind" Bookmarks, Buttons and Wristbands are available for purchase for personal use or to use as fundraisers. Order from CCA's Webstore or contact JPatterson@ccakids.com.



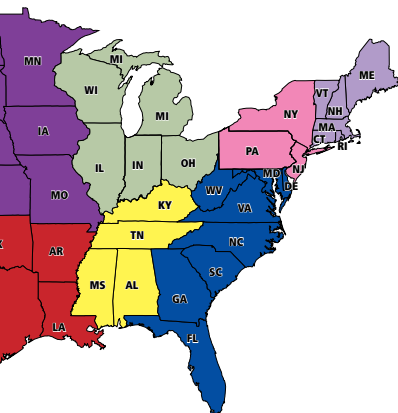
Wonder is available at ccakids.org/wonder.html for \$12

would you like a cca volunteer?



Public awareness about craniofacial conditions is important on several levels. It's important families find quality medical care, that healthcare professionals are aware of the special medical and emotional needs of children and adults with facial differences, the public understands and accepts facial differences and that individuals with facial differences are accepted.

...e to become
...er?



East North Central Middle Atlantic New England
East South Central South Atlantic

CCA is looking for volunteers who will distribute educational materials throughout their communities. If you would like to help educate your community and take part in this National Awareness Effort, call or email CCA Program Director, Annie Reeves at 800-535-3643 or areeves@ccakids.com.

tobyn's gift to cca kids



Pictured left to right, back: Tobyn, Gerry (Mom), Paul (Dad), Paulette
Left to right, bottom: Steve, Tonya

In September we received a letter from **Tonya Fischer**, along with checks for more than **\$1,500!** It seems the **Brill Family** lost Tonya's twin brother, **Tobyn**, last spring. When her daughter-in-law told them about CCA, they decided our organization was the perfect place to contribute "Tob's" memorial donations. Here are a few things they wanted us to know about **Tobyn Paul Brill**.

Tob was born April 3, 1961 in Salt Lake City, Utah, to a Christian family. Both of his parents worked in the Lutheran church. He had three siblings, elders Paulette and Steve, and twin sister, Tonya.

He was diagnosed with Treacher Collins syndrome and had his first surgery at 6 weeks. The family moved to Minnesota, where Dr. Tague Chisholm treated him at Abbott Hospital. He had 15 surgeries to reconstruct facial features and help him function.

Tob went on to graduate high school in 1979, college in 1984, started his career with AT&T in 1985 and continued with Lucent & Alcatel-Lucent in management as a financial accountant until his death in March 2014.

He went in for a routine hip replacement and post-operative complications afterwards due to breathing issues caused his heart to stop and attendants were unable to resuscitate him or intubate him in time.

On behalf of *all* CCA kids and their families, Children's Craniofacial Association sends our condolences to all of Tobyn's loved ones and is extremely grateful to the **Brill Family—Paulette Schroeder, Steven Brill, Tonya Fischer and Gerry Brill**—for this kindness and support in Tobyn's name!

imagine desert west dress down day for cca



Besides learning about Apert, the students were also shown a slideshow of pictures from the 2014 CCA Retreat.

Many of the students were moved by Jill's story and wanted to donate more than \$1. In the end, Imagine Desert West donated **\$1,000** for CCA!

Jill was deeply moved by the number of staff and students who took part. Now the school plans to make this fundraiser an annual event.

Thanks to everyone who participated and helped spread awareness, education and understanding that fosters acceptance, which is what Craniofacial Acceptance Month is all about.

Thanks so much to Jill Laufbaum and Imagine Desert West faculty and students from CCA kids!

Imagine Elementary School at Desert West

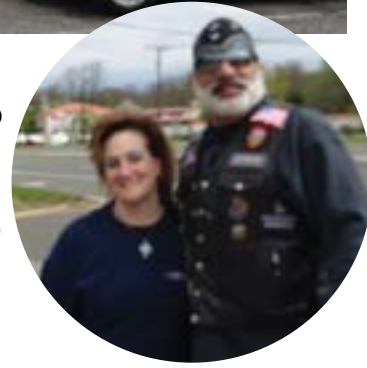
in Phoenix, Arizona, held their first fundraiser for Children's Craniofacial Association. This fundraiser was to help celebrate Craniofacial Acceptance Month. The staff and students paid \$1 to be able to dress down for the school day.

Before taking part in the Dress Down Day, the students learned about CCA from **Jill Laufbaum**. Jill is a teacher at the school, and was born with a craniofacial condition known as Apert syndrome.

more fundraising news



The dedicated folks of the **Freehold Kruiser's Car Club** in Freehold, New Jersey, led by **Pete Zaklukiewiz**, held a car show last May to benefit **Trevor Larys'** fundraising efforts and sent a check for **\$700** in his name to CCA! Thank you!



As always, we wish to send out a big thank you to everyone holding a Birthday Wish campaign on Facebook to raise funds for CCA! We're especially excited about the birthday of our own **Annie Reeves** who beat her "wish" total from last year and garnered **OVER \$1,500** for our CCA Kids! Thanks to Annie and her friends!

3 cheers

for volunteers!



CCA is fortunate to have so many wonderful families, and one of them is **Genny DeLong** and her family! Genny's craniofacial team is located in Dallas, TX, so they had to relocate here for a few months. While in town, they came to the CCA office on numerous occasions and assembled volunteer packets and WONDER packets for schools, stuffed goodie bags for our Links of Love golf tournament and even volunteered the day of our tournament. We are very grateful and can't thank them enough! Three cheers **Genny, Debbie and Mike!**

OP4G (Opinions for Good)

help Children's Craniofacial Association by becoming a member of Op4G (Opinions for Good) and taking online surveys in your spare time. Op4G is a different type of market research firm. They're based on a private membership community of nonprofit supporters who anonymously participate in market research activities. They pay in cash, and a minimum of 25% (with the ability to be up to 100%) of your earnings goes to the nonprofit of your choice. Op4G has 340 nonprofit partners, and in 2012 gave over \$210,000 to their panel members, like you, for their insights. In return, their members have donated over \$79,000 of those funds to their Non-Profit Partners, like CCA. Give your opinions and help out Children's Craniofacial Association! Go to www.op4g.com to sign up and get started today!

a living legacy

We wish we could thank those who thought ahead, arranging planned giving according to their wishes—many times without even telling us—all those who made the decision to champion CCA by leaving our charity in their will.



For this reason, we initiated the CCA Legacy Society, for those who wish to name Children's Craniofacial Association as a beneficiary. Through this effort, we will chronicle information about those who care for our future and the future wellbeing of our CCA kids.

If you wish to fill out a declaration form and become a legacy member, please contact us. If you have already set up a bequest in CCA's name, please allow us to include your intentions in our records, describing your gift of security for the future of Children's Craniofacial Association.

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.**

Donate a Car, Boat or Motorhome to

children's
craniofacial
association



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kacey, from page 1

One child was not with us. At the first moment we could call ourselves a family, it already felt fractured and incomplete. After several hours, hours that felt like days, nurses summoned us to visit Kacey in the NICU. Looking down at her tiny, delicate five-pound body, a body draped in a diaper that mostly enveloped her, we saw not a baby who looked different but beheld our new daughter, a daughter with her mother's beautiful skin and long fingers. A daughter who was alive and strong.

Two days later doctors informed us that Kacey had Goldenhar syndrome, a term totally foreign to us, and at the same time told us that Colin, her twin brother, was stable enough to go home. Although Kacey was safe and stable, her hearing ability was yet to be determined, and she could not efficiently eat due to her cleft lip. Trying to balance our daunting parental responsibilities over the next week proved emotionally and physically exhausting: Both babies needed our love and attention, but we were spread thin, driving back and forth from the hospital multiple times a day. The care of the NICU nurses, for both Kacey and for us, buoyed our spirits and comforted our worries. Within the week, doctors

also diagnosed Kacey with hypothyroidism, which contributed to her lethargy and feeding difficulty.

After eight days, our doctor recommended that Kacey be transferred to Children's Hospital of Philadelphia for the expert help of specialists who could begin to piece together Kacey's overall health, assess her hearing ability, and offer assistance with the feeding issues we were encountering. On a late Sunday evening, CHOP's transport team packed Kacey in a pod-like structure, similar to something out of a science fiction story.

We held one another tightly, and while the team assured us that Kacey would be safe on her journey, comforting words could not allay the enormous fear we felt watching our baby leave us. Even though CHOP was only a 45-minute drive away, it felt as if they were taking her to the moon.

Over the next two weeks, several specialists examined and tested Kacey, including **Dr. Scott Bartlett** and the craniofacial team. Audiology tried to accurately determine her hearing ability. Endocrinology monitored her hypothyroidism. Occupational therapy evaluated her muscle tone. Genetics tested her chromosomes and other genetic factors. A feeding specialist worked with us to try to find effective feeding methods for a child who didn't seem to have much of an appetite.

We tried to keep the growing mountain of medical information straight. Those two weeks were an utter blur; however, we did receive joyous news when the audiologist determined that she had full hearing in her right ear, and we did take solace in the few quiet moments that we could hold and bond with her.

After 23 days in two different neonatal care units, enduring mostly sleepless nights and transporting hope and love to and from the Children's Hospital, doctors permitted us to take Kacey home, and when we walked through the door, the moment we had anticipated on the day of their births finally arrived. Although no fanfare awaited us and no enormous banner hung outside our home to announce their first homecoming, we appreciated the quiet and the calm. We thanked our parents for providing such love, attention, and support; their vigilance was unwavering. Then, we carefully carried Kacey upstairs to reunite her with her brother. We laid down the twins side-by-side in one of the cribs, and to our amazement, they recognized each other as "womb" mates: Their eyes widened with delight, and each squirmed with excitement.

One obstacle that aggravated our already frayed nerves was the feeding tube that protruded out of Kacey's nose. Despite the feeding specialist's best attempts to find an efficient way to feed her, she did come home with a nasogastric tube, but her emerging stubborn nature caused her to pull it out four



days later, at which point her feedings began to improve.

At four months, Early Intervention services commenced and focused on improving her low muscle tone. Blood was drawn regularly to monitor thyroid



function. At six months of age, she was finally deemed big enough to undergo surgery to repair her cleft lip and remove her skin tags.

When she was four, doctors performed a partial adenoidectomy to alleviate loud breathing and snoring issues. Physical and occupational therapy worked with her on some general developmental delays with walking, speech, and fine-motor coordination. When she was six, endocrinology determined that her growth rate was below the normal curve and prescribed growth hormone. At age eight, Dr. Bartlett grafted part of her rib to her mandible to address its deficiency and also injected fat from her thigh into her cheek to compensate for the asymmetry in the soft

tissue. What's next? Well, fortunately, that will be determined based upon her growth and personal preference.

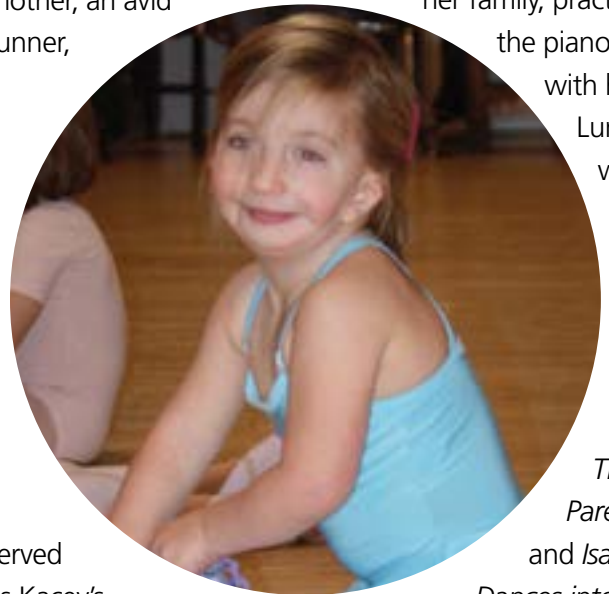
When Kacey started kindergarten at her school, we made two specific

decisions in regard to her special needs. First, we preferred that the school not place Kacey in the same classroom as her twin brother, since we wanted her to develop her own

identity and peer group. Second, since Kacey had normal hearing in her right ear, we elected to not use an FM system for her in the classroom, and we impressed upon her the importance of self-advocacy and positioning herself in close proximity to the teacher. As Early Intervention had worked with Kacey prior to starting kindergarten, we developed an IEP in the first part of her kindergarten year, and because we had the great fortune of having a supportive, proactive hearing-support teacher, Kacey's classroom teachers accommodated her needs accordingly.

At Copper Beech Elementary School, she excels in social studies and plays viola in the school orchestra. She cites music,

gym and recess as the favorite parts of her school days. Last year, Kacey participated in Girls on the Run, an organization that uses running to inspire self-esteem, healthy habits and positive interaction among girls. As a culminating activity, Kacey and her peers ran a 5K alongside their running buddies. Her mother, an avid runner,



served as Kacey's running buddy; they set small goals, endured the pain, and eventually crossed the finish line! Accomplishing the race together was something especially meaningful to their mother-daughter relationship: It allowed Kacey to experience one of her mom's passions.

At home, Kacey often curls up with a book; she loves getting lost in stories and imagining how a story will develop. She also delves into nonfiction books, particularly those about

history. She reads the "Who Was?" series over and over.

Kacey loves playing with her Barbie and American Girl dolls with **Haley**, her "funny, sweet and diva-like" 8-year-old sister, as well as whiffle ball and Minecraft with her twin, Colin, who Kacey describes as "loyal, protective and kind." She also enjoys relaxing with

her family, practicing the piano, playing with her dog, Luna, and watching movies such as *The Goonies*, *Tangled*, *The Parent Trap*, and *Isabelle Dances into the*

Spotlight. Fortunately Kacey's best friend, **Caitlin**, lives in our neighborhood, and having such a caring, nonjudgmental friendship just around the corner is awesome.

In the summer time, Kacey swims for the Penbryn Piranhas and enjoys going on excursions with her dad and siblings. Luckily for the whole family, Kacey's Grammie and Pop have a beach home in Wildwood, New Jersey, a

see **kacey**, page 18

kacey, from page 17

place where she turns into a boogie-boarding, body-surfing, wave-loving fool who has to be dragged out of the water! She also cherishes her family trips to Kennebunkport, Maine, to visit her cousins and to devour her Aunt Megan's blueberry pie.

Kacey has played soccer, softball and done gymnastics in the past, and she plans to play field hockey in the future, but it's her obsession with dance that fuels her dreams. The combination of movement and music provides her with a sense of freedom and joy, and the challenge of learning complicated steps and improving her agility motivates her to focus and compete. Ballet, jazz and tap, as well as hip-hop and theatre dance keep her moving all day long. This past year, Kacey danced with Cassidy Dance Studio's competition squad, which afforded her the opportunity to attend regional competitions in Lancaster, Pennsylvania, and Sewell, New Jersey. If she works hard, dances every day, and continues to improve, she hopes to receive a dance scholarship to the New York City American Ballet Theatre.

Now in fifth grade, Kacey still loves going to school, but as adolescence

approaches and kids grow more judgmental, we can't help but worry that Kacey might become the target for petty comments. Kacey, however, doesn't seem fazed when someone stares at her—a stare that doesn't convey dislike but rather curiosity: How's this girl's face different? What's unusual about her ear? After all, aren't our brains hard-wired to notice differences? To alert us that something is different about our surroundings?

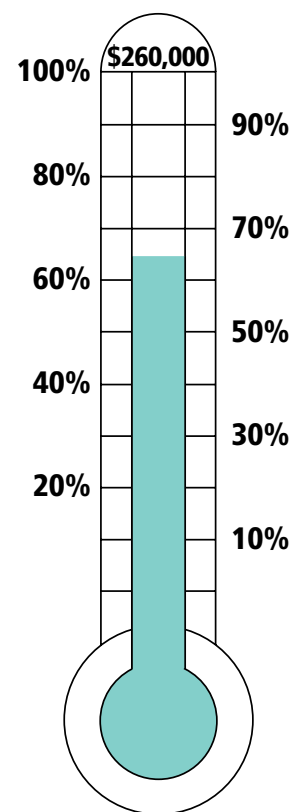
Don't we notice and give an extra glance when we see "strange" hair or "odd" tattoos or "weird" piercings? As parents, we have always tried to ensure that we did not react when we saw someone staring because if we felt uncomfortable or upset or defensive, wouldn't that reaction imprint upon her? And so, Kacey is comfortable with who she is and how she looks, which helps us worry less.

Looking back on her medical history, Kacey has endured far more poking and prodding than all of her family members combined; we marvel at her fortitude and the acceptance she displays about her differences. Essentially, she's just a normal kid, just like all the kids that our family met at our first CCA retreat in St.



Louis this summer. Just like Auggie in *Wonder*. Kacey's toughness helps us deal with our own insecurities and fears, and this ongoing experience will continue to help us grow as caring, compassionate humans who appreciate the beautiful diversity of life.

2014 FAMILY FUNDRAISER GOAL THERMOMETER



To see CCA's list of donors as of September 30, 2014, see page 21 or visit our website. The list can be found at

[www.ccakids.org/
donor-list.html](http://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



testimonial

We are very grateful for all of the support CCA has provided our family. They have helped us cover gas, food and hotel expenses. Without CCA's support, we wouldn't be able to make these trips to Dallas happen. Thank you for the help! **Alberto** and our family really appreciate your continued support.

Paula Uribe

FREE SHIPPING

cozy shirts available in the **cca** web store



Long Sleeve Black T-shirts
(Youth Sizes S-L \$20)
(Adult Ladies/Men S-XL \$25 2XL \$28)

calendar of events

date event contact

2014

Dec 6 **CCA Holiday Party—Midwest** JPatterson@ccakids.com
11:30A-2:30P Brat Stop/Parkway Chateau 214.570.9099
Kenosha, WI 800.535.3643

Dec 13 **CCA Holiday Party—Dallas** ARees@ccakids.com
10A-Noon Southfork Ranch 214.570.9099
Parker, TX 800.535.3643

2015

April TBA **4th Annual Morgan Meck's Match Play Invitational**
Coto de Caza Country Club
Coto de Caza, CA BMecklenburg@redwoodsgroup.com

Apr 24 **3rd Annual Texas Moms' All the Way for CCA Golf Tournament** Becky White
Battleground Golf Course ledestiny@gmail.com
Baytown, TX (Houston area)

Jun 25-28 **25th Annual Cher's Family Retreat** ARees@ccakids.com
Newport Beach Marriott 214.570.9099
Newport Beach, California 800.535.3643

Jul 11 **3rd Annual "Miles for CCA Kids" Benefit Rids** lewis.boykin@aggressiveusa.com

September **11th Annual Craniofacial Acceptance Month** ARees@ccakids.com
Nationwide 214.570.9099
800.535.3643

CCA Wristbands!

Order your wristbands today
in Adult 8" or Youth 7" – \$1 each



how to raise funds for cca

CCA depends on funds donated by individuals, proceeds from family and friends' fundraising efforts, corporate giving and foundation grants. As the number of families CCA serves grows, so does the need for additional funds. So, any help our readers contribute is most appreciated. Here are some ways to help.

- **www.goodsearch.com** (Powered by Yahoo) Enter Children's Craniofacial Association as your beneficiary charity. (You only have to do this the first time. You may add others if you wish.) CCA will receive up to a penny each time someone uses the GoodSearch search engine.
- **GoodShop.com and iGive.com** Go to GoodShop.com or iGive.com, online shopping sites, both featuring hundreds of great stores including Best Buy, Macy's, Apple, and more. It's easy! Just shop as you normally would! You get the same prices, but a percentage comes to CCA!
- **Cash for Trash!** Save your discarded cell phones, empty laser / ink cartridges, GPS devices, digital cameras, MP3 players and old laptops. Call CCA for more information.

- **Matching Gifts**

Many companies offer a matching gift program that could double—or even triple—your gift to CCA! Contact your human resources office to find out if your company has such a program.

One family donated \$2,500 and had it matched in order to get their free retreat hotel stay!

- **Planned Giving**

Tax preparation time is also a good time to consider long-term tax savings. When you consult an attorney or investment professional regarding your wishes for distribution of your assets in your will, consider a provision for CCA. Your planned gift in the form of an endowment will live on after you.

- **CCA Web Store**

You can shop at www.promotes.me/cca for your T-shirts, mugs, caps and more. So shop now and shop often!

- **Clubs / Hobbies**

Have your club organize a benefit for CCA. Use your hobby or something you love to do to raise funds.

- **Denim Days**

Raise funds at work for CCA. Establish a special day or days for employees to make a designated donation (cash or check) to CCA in return for wearing

blue jeans. The donation is usually \$1 to \$5, depending on how often the event takes place (for example \$1 for a weekly donation, \$5 for a monthly donation). Any higher amount would be at the discretion of the donor.

- **Civic Organizations**

Public awareness leads to contributions. Contact and solicit opportunities to speak to your local civic organizations such as Rotary Clubs, Kiwanis Clubs, even HOG organizations (CCA has many 'biker' supporters). Distribute brochures and/or newsletters or other CCA-sanctioned materials for awareness and information. Ask for contributions.

- **Friends / Family**

Letter Appeal Draft a letter to family, friends and acquaintances—anyone who has met or encountered your child. Contact CCA for a sample letter.

- **Kitchen Shut Down**

Raise funds by raffling off chances to win meals for every day of the week, so the winner can "shut down" their kitchen. Local restaurants can donate meals or coupons. This idea could also be used for a week of entertainment, such as movie rentals or theater

tickets. Call CCA for more information.

- **Collection Cans** Ask local businesses to place a can or box (provided by CCA) to collect donations.
- **Get On Board!** Read our newsletter and learn about and participate in the events, raffles and funding efforts of CCA and our supporters. And, when you are finished with your copy of our newsletter, spread the news! Pass it along or leave it in a waiting room. (Remember to remove your address label.)
- **FirstGiving** There is a free customized CCA "firstgiving" site for anyone who wants help raising funds for CCA. Log onto firstgiving.com/ccakids and tell your personal story or post an event you're having. You can even set a goal and track success! When you tell your own story about your CCA Kid or why you are involved with CCA, folks will respond because they know YOU!

donors, january 1 – september 30, 2014 *

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Anonymous, in honor of Daniel
Anonymous, in honor of Sadie Bono
Anonymous, in honor of Courtney Broome
Anonymous, in honor of Ashley Compton and Tony Miglini
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Anonymous, in honor of Hope Evans
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Anonymous, in honor of Tate Gorman
Anonymous, in memory of John Haycraft
Anonymous, in honor of Amanda Hoika
Anonymous, in memory of Dolores Winters
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Geraldine Brill, in memory of Tobyn (check for combined gifts in memory)
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Joe Brooks, in honor of Jill Patterson's birthday
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* Listed are all **Monetary Donations**. We are extremely grateful for these and all other fees, purchases, fundraisers, cash and in-kind gifts, which may not be individually recorded here. (Note: For space consideration, donations under \$100 will only be published year-end. However, all dedications for those gifts are published here.)

We do our best to accurately recognize donors. If you notice an error, please let us know.

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 who was born with a cleft lip and palate on 2/25/96
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 Charles Schwab, Park Cities
 Chemung Canal Trust Company
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 Chevron Phillips Chem Co LP
 Children's Surgical Associates
 Community Bank
 Complete Security Systems, Inc.
 Corning Credit Union
 Corning Dental Associates RLLP
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 Reed Wilcox Insurance
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Up to \$1,000

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 American Legion Collection / Jaci Samhammer
 Be Brody's Angel / Lucas Family
 Beit Rabban Day School ~ Wonder
 Cher Fan Fundy / Josiah Torres w/ CherCrew fans
 Ann Dolsen Elementary Wonder Funder
 Nehansey Middle School Wonder Funder
 "On The Border" Restaurant funder / Kellie Dowd
 Sales of John Moulton's CDs / Mary Zimmerman
 St. Patrick School Casual Day
 Seaford Elementary Wonder Funder
 Stevenson Elementary ~ Wonder
 Thirty-One Funder / Liz Anderson & Michelle Buchanan
 Trinity Catholic Elementary School Wonder Wristband Sales
 UCF: Lead Scholars Fundraiser / Anne Moore & Friends

\$1,000-\$5,000

Acceptance In The Park Picnic--Raffle / Dyson Family
 Chance Raffle / Retreat Attendee Families
 Chase's Quest Zumbathon / Carrie Ingram & Volunteer Zumba Instructors
 CherCrew Birthday Surprise for Cher to benefit CCA Kids / Jill Emerson
 Dress Down Day @ Imagine Elementary at Desert West / Jill Laufbaum
 Kitchen Shut-Down Raffle / Laura Beeler & Alicia Yost
 Lawton C Johnson Summit Middle School Wonder Funder
 Medford Schools Wonder Funders for CCA's Retreat Scholarship Fund
 Miles for CCA Kids Poker Run / Lewis & Carly Boykin
 to Send a family to the 2014 Annual Retreat / thru Razzo Foundation
 Quilt Raffle / CCA Families & Friends
 Annie Reeves' Birthday Wish Collection
 Rick's Raffle / CCA by Burgin/Dornier Families
 Round Rock ISD / Libraries Wonder Funders
 Sadie's Night at the Ballpark / Bono Family, Gorman Family
 Seth's Stride
 Trevor's Trip To Triumph / Kim & Erik Larys

\$5,000 or more

Quilter's Guild of Dallas Miniature Quilt Auction / 2014 Beneficiary: CCA
 Paula Guzzo's 60th Birthday Celebration Funder / Bob Guzzo
 Raegan's Rally

\$10,000 or more

Team Lentil Effort toward Retreat Scholarships / Lindsay Condefer & Lentil

\$15,000 or more

7th Annual Links of Love for CCA

\$30,000 or more

All The Way For CCA / Becky & Wade White, Lisa Bock, Jennifer Kilmer
 10th Annual Friends of Jeremy Golf Tournament / George & Kris Dale

\$50,000 or more

3rd Annual Morgan Meck's Match Play Golf Invitational / Mecklenburg Family

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 2015 annual cher's family retreat

June 25-June 28
in Newport Beach, California

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 22, 2015.

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!

financial assistance

do you travel to receive quality medical care? If you do, and need financial help, CCA has a financial assistance program that will help with food, travel and/or lodging. Call CCA for an application at **800.535.3643**. All we ask is that you **apply at least four to six weeks prior** to your next appointment.

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FRIDGE ART

We're so proud of you and your art!

calling all picassos!

CCA has added a new section to our website called "Fridge Art" and we would love to feature your masterpieces! If you are a CCA

Adult, CCA Teen, CCA Kid or CCA Sibling please send us one of your creations. We

will be accepting the following types of files: .jpg, .tif,

.pdf, .ai, .eps, .psd Please email your art to Annie Reeves along with

the artist's name, age and state to areeves@ccakids.com.

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