

ccanetwork



newsletter of the children's craniofacial association

Cher—honorary chairperson

2012: Issue 2

inside

- cca kid
- issiah eakright. 2
- cca teen
- jonathan johnson 3
- cca supersibs
- dylan & audrinna eakright 4
- morgan meck's
- match play 5
- retreat photos. 6-9
- cca mugshot. 9
- first-time retreat 10
- how to raise funds 11
- robbie's haircut 15
- good news 16
- calendar of events. . . . 16
- testimonial 17
- craniofacial acceptance
- month 17
- family dynamics 18
- rick's/chance raffles. . . . 19
- donor in the spotlight. . 19
- fundraising news . . 20-21
- cca kids blog. 22
- donor list 23
- 3 cheers 24



lane's story

By Daphne Sellers

I will admit I was not overjoyed when my daughter **Melissa** and her husband **Adam** bounced onto my bed one evening, waved an ultrasound picture at me and asked me to guess who was pregnant. It was late October, and Melissa and Adam had just married in July. I tried to guess as many people as I could think of while they sat there looking at me, grinning with excitement. I finally saw Melissa's name in tiny print in the top left corner. I was much too young at forty to be a grandmother!

Melissa learned she was pregnant earlier that day when she saw her gynecologist for high blood pressure related to birth control pills. When she described her roller coaster of emotions the doctor ordered a pregnancy test. Between breaths into the brown paper bag she was given by the nurse, she screamed at the doctor that nineteen-year-olds were not

see **lane**, page 10



message from the program director

Retreat Recap

According to many of the 2012 Cher's Family Retreat attendees, this retreat may have been the best yet! The 22nd Annual retreat was held in Tempe, Arizona. This was the third retreat held in that area, and the second at the Marriott Buttes Resort. And we were not disappointed with our choice. Everything about the resort was great, from the super-friendly staff to the delicious food to the magnificent swimming pool. **Tamra**, our hotel contact, even upgraded our

see **program director**, page 6



meet issiah eakright



ccakid

Issiah Eakright is five years old and soon to be a kindergartener. He is really looking forward to riding the bus to school every day. He had a “practice” ride on the bus when he was a preschooler, but this fall is the real deal, and he can’t wait. Also this fall, he may start baseball and wrestling classes, just

like his big brother, **Dylan**. Until then, he’ll perfect his hockey game on his Wii.

His summer has been a fun one, playing with Dylan and helping out with his baby sister, **Audrinna**. He has also enjoyed watching his favorite show, “The Wild Kratts.” He likes the character Martin, the “Blue Guy,” the best.

The highlight of the summer, however, was the retreat in Arizona — his first CCA retreat ever. Issiah had such a great time meeting new friends, including **Lexie** and **TJ**, with whom he promised to keep in touch during the year. And he especially liked the slide at the pool!

He has a birthday coming up, and to celebrate his family is taking him to see the Fresh Beat Band live in concert. He’s so excited just talking about it that he’s bound to have a blast singing along to all the

songs. Speaking of music, he is an avid air guitar player. Any type of music will do, but he insists on finding a “quiet spot” in which to play.

Issiah was born with Treacher Collins syndrome. At the moment, he has no surgeries or procedures planned. The doctors need to wait and see how he is growing to determine the next course of action. He does, however, advise fellow CCA Kids to be “brave and tough,” just like he has been—and always will be.

ccateen

meet jonathan johnson

Jonathan Johnson was born with Apert syndrome and has had more than 60 surgeries because of complications and infections. However, Jonathan loves life, and he doesn't let his medical condition get in his way. He is a special-education student at Westwood High School and will be a sophomore in the fall.

Jonathan loves his family. He has three brothers, one sister, and a mom and dad who adore him. He even named his two turtles after his brothers and his two dogs after his other siblings. He also has an extended family of cousins, aunts and uncles who also adore him, and many of

them live nearby in Mesa, AZ.

Jonathan is involved in lots of church activities. When he plays basketball with the young men, they all move back and let him have the ball until he makes a basket; Jonathan is then content and ready to leave the court. When they do service projects, they always find something for Jonathan to do. In addition to his church, Jonathan is in the process of achieving Eagle Scout status through his special ed Boy Scout troop.

Jonathan knows no strangers because he speaks to everybody he sees. It's not uncommon to hear him in the grocery



store line (with his mom) talking to the person behind him, asking how they are and how their family is doing.

He has a great sense of rhythm and often accompanies the special ed sing-a-longs with his snare drum. He loves to strum his guitar while he sings in bed. When our family sings together, we often have Jonathan direct us. We were amazed when the first song we heard him hum at age three was from "Phantom of the Opera."

Jonathan is very imaginative and always brings a lot of joy to those around him, even in stressful situations.

On one occasion, when the neurosurgeon told us that Jonathan's surgery would be the next day at 1:00, Jonathan told him, in all seriousness, that he couldn't make it because he had a volleyball game to play.

More than anything, Jonathan is a special blessing from heaven.





meet dylan
and audrinna
eakright

ccasupersibs

dylan is your typical “almost eight”-year-old boy. He loves to play baseball, go on bike rides and go to Chuck E. Cheese’s. Dylan and Issiah are also typical brothers. They play, they fight and they laugh. They love sneaking into each other’s beds at night, building forts, playing outside with their new puppy, Zizzy, and being all-around mischievous. They are brothers through and through.

With summer break well under way, the boys love spending time with their little sister, **Audrinna**. She turned one in March, and they are both great helpers as long as it doesn’t involve a dirty diaper. Audrinna

seems to enjoy picking on her big brothers. She loves to dance and stand in front of the TV when they are playing Wii. Audrinna enjoys trying to be a big girl with her brothers. Whether they are running in the yard or riding their bikes or power wheels, she is right there with them.

Dylan will be starting second grade in the fall and is really excited to take his little brother on his first bus ride and drop him off at his new kindergarten classroom. They are both very excited about this adventure. Dylan is also excited to get back to his friends.

Dylan doesn’t really notice that his brother is different. He knows

Issiah has a Baha implant and that there will be surgeries in the future. He worries about Issiah during surgeries, but Dylan has been really great with his brother. I am sure there will be hurdles with school and bullies. Dylan and Issiah are strong, intelligent, and caring boys. They are more likely to educate bullies about Treacher Collins syndrome than stoop to their level.

While the kids may fight and not always get along, I know

that they will always be there for each other and they will not let anyone or anything stop them.



First Annual Morgan Meck's Match Play Tournament

benefiting Children's Craniofacial Association



On April 19 and 20, **Bill Mecklenburg** and **Christine Condino-Mecklenburg** hosted the first-annual Morgan Meck's Match Play Tournament benefitting CCA. Ten teams participated in a 36-hole golf tournament, and the championship was ultimately decided over a three-hole, match-play contest by the top two teams. The tournament took place at **Coto de Caza Golf and Racquet Club**, and all out-of-town participants stayed at the **Marriott Laguna Cliffs Resort & Spa in Dana Point, California**. Private dinners were held at



St. Roy's at the Vine and **Capistrano Shores**, both in San Clemente.

The majority of the teams were made up of insurance and reinsurance professionals from throughout the country; however, there were some local participants

who helped fill out the field. It should be noted that **Darin Dankelson** traveled from Michigan in an unsuccessful bid to win the championship. (**Debbie Mecklenburg** continues to be ashamed of her son for winning his family's own tournament, but Bill credits the championship to the skill, tenacity and conveniently higher than usual, but legitimate, handicap of his playing partner, **John Mahoney**.)

Premier Sponsors included **Lexington Insurance** and **The Redwoods Group Foundation**. **John Mahoney** and **Tom Gillingham** of **GMI, Inc.** provided a Platinum Level Sponsorship, and Gold Level Sponsors included **Guy Carpenter & Company**, **Partner Reinsurance Company**, **TaylorMade Golf**, **Maria Amelio**,



and **Blair** and **Shelley Schrum**.

Several individuals provided Silver Level Sponsorships, including the **Dankelson Family**, **Chris Campbell**, **Tom** and **Donna Leonhardt**, **Tracey Carragher**, and **Shelly** and **Michael Sprague**. In addition to raising **more than \$40,000** through tournament participants and sponsors, Christine Condino-Mecklenburg also raised **more than \$4,000** through a **Charity Buzz Auction** that included packages from the **Laguna Cliffs Resort & Spa**, the **Surf & Sand Resort**, the **Corinthia Hotel**, **The Grand Del Mar Resort**, **The Bernardus Lodge**, **Coto de Caza Golf & Racquet Club**, **The Los Angeles Angels**, **Disneyland** and **PGA Professional Pat Burke**.

CCA and the Mecklenburg family would like to thank all of the volunteers, participants and contributors who also include **Chip Michaelsen**, **Brad Walsh**, **Steven King**, **Heath Fisher**, **James Oh**, **Jim Dufficy**, **Ian Leisegang**, **Robert Kacer**, **Christopher McGhee**, **Michael Beasley**, **Mac Armstrong**, **Stephen Jefferey**, **John Peppard**, **Urban Koagedal**, **Steve Bouker**, **Alan Driscoll**, **Robert Reader**, **Chris McGhee**, **Mike Schnur**, **Carl Bach**, **Tate Gorman**, **Amy** and **Billy Downs**, **Betsy Robinson**, **Kathleen Philippi**, **Jerome** and **Katy Penna**, **Tatiane Cunha**, **Bob Raike**, **Helen Cressy**, **Tootsie Thomas**, **Ashleigh Fleury**, **James Steinwinder** and **Debbie "Grammy" Mecklenburg**.



Dinner Dance

program director, from page 1

tablescapes and meeting room décor to make our experience more enjoyable and festive.

There are years when all of the planets are aligned, and this was one of those years. One contributing factor is CCA's social networking. Many of our new families and those who have not attended previous retreats, have become friends on Facebook and through CCA's Yahoo Group, so the initial "get-to-know-you" period had been

taken care of before we even arrived at the retreat. Family members were glad to finally meet in person and immediately launched into deep conversations. Others met during the day on Thursday at the Annual Craniofacial Symposium.

As a result, the energy at the ice cream party on Thursday evening was so high and there was so much interaction among families, CCA staff actually had to forego some of the planned introductions because it was so hard to draw the attention from the conversations. In fact, during breakfast on Friday morning we experienced a city block electricity loss causing the lights to go out in the banquet room, but our energetic group hardly missed a beat. Immediately cell phone flashlights were on and

conversations carried on uninterrupted!

Arizona's finest talent showed up in full force for Friday Family Day. We were entertained by award-winning **Native American hoop dancers**. During this story telling ritual, shapes such as the butterfly, the eagle, the snake, and the coyote, (and even Mickey Mouse) were formed with the hoop symbolizing the never-ending circle of life. Additionally, we were amazed by the skills of **Loop Rawlins**, a gun-spinning, whip-cracking, trick-roping, Wild West performer.

The fun continued Friday evening at the traditional family night/teen party. As usual, families from across the United States and beyond brought



Meg Gray and David Storie, engaged!

themed baskets as well as goodies from their areas for CCA to raffle! We had everything from Hello Kitty and Thomas the Train, to Bath and Body works, Baseball Hall of Fame and everything in between! The generosity of our families



Native American Hoop Dancer

Henry Johnson and Derek Coleman with Cowboy Loop Rawlins





Casey Deakins during her speech at the Symposium

never ceases to amaze us. It was heartwarming to see **Eric Lucas** present the Thomas the Train raffle item he and his family had just won to his new little friend "**Jesse James**," who "just knew" he was going to win it.

Meanwhile, the teens were lounging by the pool, having dinner and doing the things teens do best!

The Buttes not only has a spectacular swimming pool, but on Saturday it was reserved for CCA. This gave kids and adults the opportunity to play together (including a pretty fiercely competitive volleyball game), share



A volleyball game during the pool party

experiences and support, and do it all in an emotionally safe environment. We were all one big, happy family!

And, all that swimming didn't slow anyone down at the dinner dance on Saturday evening. In line with the rest of the retreat we had the **best DJ ever!** He had everyone out on the dance floor, had the board members and staff don goofy chicken caps



Nick Wiese with his reptile friend

while leading the chicken dance and of course really got things on course with **Scott Guzzo** (assisted by his brother **Aaron**) rocking out to *Wipe Out!* We even had a dance-off between



John Moulton with his sister, Mary Zimmerman

young **Jalen Washington** and board member **George Dale**. George held his own against the youngster, but I'm quite certain after that "worm," George's knees will never be the same. Way to take one for the "oldsters" George! One of the sweetest moments during the dinner/dance was the dance between **Meg Gray** and **David Storie**, who are **ENGAGED!** Congratulations to you both!

We had a first at the dinner/dance when an impromptu fundraiser erupted. **Mike Wiese** of Baden, PA, came up with a plan to get **Robbie Gorecki** to cut his hair. Much to his mom's chagrin, Robbie grew his hair to shoulder length prior to the retreat. Mike saw an opportunity to make Mom happy and raise funds for CCA to boot. To read more

about how this turned out, please see page 15.

Alas, all good things must come to an end, and on Sunday morning there were lots of hugs, promises of staying in touch and,



Parker Kocsis and Peter Dankelson

as always, a few tears. We really enjoyed meeting all of the **33 new families** and catching up with our old friends who attended from 25 states as well as from Australia and Canada.

Registration is officially open for the 2013 Orlando retreat, and we hope to see you all there!

Annie Reeves
CCA Program Director

program director, from page 7



CCA Board and Staff after Chicken Dance



Scott and Aaron Guzzo doing Wipe Out



Jayden and Liam Gonzales with Kayla Rodriguez



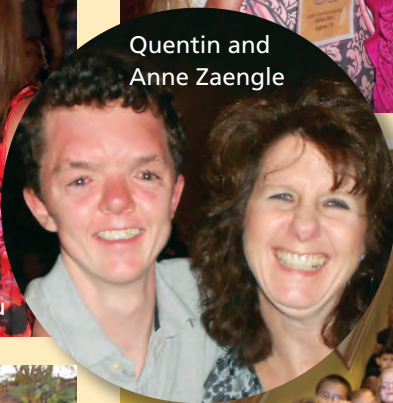
Jaci Samhammer dancing with Wade White



Ashley Bock, Olivia Sanborn and Callie Shaffer



Olivia Dean, Lia Burton, Carrie Brooks and Sabrina Robineau



Quentin and Anne Zaengle



Pool Party during Teen Night



2012 Retreat Group shot



Father/Mother,
Daughter/Son Dance



Milligan Family



Paulson Family



Tracy/Holland Family



cca mugshots Send us your
mugshots!
Betsy McBride (left) and Anne Moore (right)

Donate a Car, Boat or Motorhome to

children's
craniofacial
association

- Free pick-up
- Tax receipt given
- Easy & convenient

Call Today Toll Free:
877.570.4222



our first retreat

By Deena Dyson

It was a day before our first CCA Family retreat. My husband, **Darryl**, and I were driving with our five-year-old daughter toward Arizona, and I was starting to panic about our decision to attend. I lamented, “What if it backfires?”

Teresa Joy doesn’t know she’s different yet! What if this puts a spotlight on it and makes her self-conscious right before she starts Kindergarten?”

Darryl didn’t share that concern, but there were hints that he was out of his comfort zone too, with his preoccupation about keeping Teresa Joy healthy, hydrated, and rested while away from home. As older parents of an only “special needs” child, we struggle with balancing her stability and protection with exposure to all the excitement and risks of a “normal” life. Though we consider our lives to be fun, we aren’t lighthearted about changes in our routine and are often referred to as “helicopter parents.”

Twenty-four hours later, Teresa Joy and I were in the pool within minutes of checking in to the hotel

in Tempe. While holding tight to her, I was scanning around at faces, curious about who might also be with CCA. I shortly noticed an adorable girl a few years older than my daughter jumping in, splashing around, and having the time of her life. I was dumbstruck to observe that this courageous and clearly fun-loving girl was swimming with a trach! It’s hard to describe why this struck me so intensely, but I think, for me, it represented letting go and trusting that one can follow their child’s lead.

Teresa Joy had a trach for the first two years of her life. During that time, fear was my constant and primary emotion. Because there was (and is) always a surgery around the corner, we were worried about germs and barely left the house. Hypervigilance became our lifestyle, and it may never entirely reverse.

What a contrast in this spunky and fearless young lady, capping her trach and hopping in the water! Recalling that moment of meeting Jayden Gonzales still brings chills to my

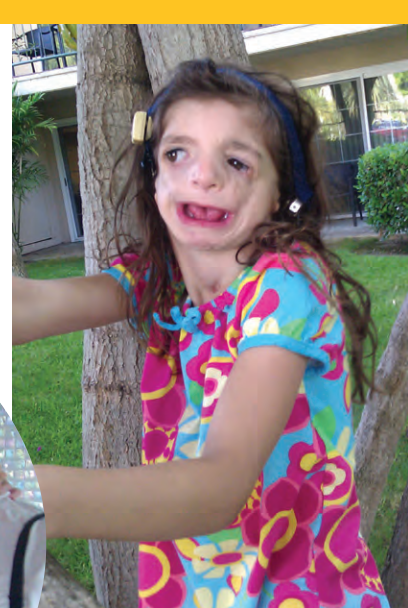
spine. **I realized in an instant that nothing negative could come out of what we were about to**

experience in Tempe. This was not going to be a weekend of limits, sob-stories, or holding back because of fear.



In fact, we had arrived in a place of joy, bravery and miracles beyond what we had ever seen. No one we encountered over the next days is living their lives as if being “different” is a tragedy.

While in Tempe, Teresa Joy had no “Aha!” moment of realizing her own differences. Or anyone else’s, for that matter (though she did have a wonderful reaction to Meg Gray, a young adult who shares her syndrome, when she exclaimed, “She has my face!” and pointed at Meg with a huge smile!) Rather than an “Aha!” moment, my fervent hope is that the experience of the retreats (plural, as we will continue to attend!) will somehow leak into my daughter’s psyche to help form how she sees the world: as inclusive, abundant and vibrant with possibility, regardless



of physical or any other types of challenges. And, of course, that she makes lifelong friends.

A few days after the retreat my family was enjoying Sea World, when a child pointed at my daughter and called her a “monster.” I couldn’t help but wonder: What is leaking into that kid’s psyche to have that harsh reaction? Why haven’t his parents taught him to be kind to others, no matter the differences? Casey Rae, a CCA young adult and Facebook friend, posted at the close of the retreat, “CCA retreats will change everyone who witnesses what goes on—100% guarantee.”

I agree with Casey and only wish I could show the whole world “what goes on” in the lives of our amazing children. By raising awareness, CCA is taking steps to do exactly that. We feel lucky to be a part of it and are committed to doing our part—for all children.



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. The need is great as we grow to provide programs and services to many more affected individuals and their families. 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** Go to GoodShop.com, an online shopping mall featuring hundreds of great stores including Best Buy, Macy's, Apple, and Orbitz. It's easy! Just go to GoodShop, click on the store's logo and then 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!



room during the delivery to record the happy event. The excitement, laughter, and joking in the delivery room came to an abrupt halt when Lane was born, shortly after midnight, with a

complete bilateral cleft lip and palate. The nurse

looked at me pitifully, batted her eyes, rolled out her bottom lip and shook her head.

Melissa sobbed as Adam consoled her and she asked me if we would still love him. I was completely numb with shock but I tried my best to reassure her that we would love him regardless. I don't know that I believed it but I said it. I honestly didn't know what to say. I did not feel anything.

Already I saw pity from the nurse, a complete stranger, and I did not like it. Did she think we were awful people that had somehow caused this? I personally was immediately consumed with shock, guilt, shame, hurt, panic, and hopelessness. I tried to recall every bad thought, everything I had ever done wrong, did I laugh at a child with a birth defect? Did I ever participate in making fun of someone who was less than perfect? There must be something somewhere in the past

that I had done to cause this. As Melissa's mother, I felt responsible to "fix" whatever was wrong for my baby, but I had no idea how to fix this.

In addition to the huge hole in the middle of Lane's face where something protruded profoundly out of his mouth at an odd twisted angle, there were angry, red, raw patches of skin scattered across the top of his shoulders, down his arms and legs and on his scalp. He had lots of dark hair but it was very odd in texture. Each raw place oozed yellow fluid. He was breathing fine but his body temperature was very low and the nurses had a difficult time warming him up. He looked as if he had been scalded and I immediately blamed the doctor and the blood pressure medication.

As soon as the nurse placed Lane in Melissa's arms, any doubt she had was gone, and she loved him instantly. She kissed him and cooed to him and proudly announced that she did not care if he had a cleft, he was her baby and she loved him.

A nurse taught us to feed Lane with the special cleft nurser and gave us a tentative time line for the surgeries to repair the cleft. The pediatrician was very concerned with the

appearance of Lane's skin and the next afternoon he made the decision to have Lane airlifted to the Children's Hospital in Birmingham, four hours away.

In the NICU, his bed was padded with saline bags covered with a blanket for comfort and only sterile water was allowed to touch his skin. There were skin biopsies, hair samples, continuous IV antibiotics and guesses by physicians and their students as to a diagnosis. I just wanted someone to talk to us about the cleft and repairing it.

An ultrasound showed a ureterocele and one kidney appeared to be much smaller and less functioning than the other. They would not agree to circumcise Lane due to the condition of his skin, the risk of infection and further skin breakdown. Nine days later Lane was discharged from the hospital with a diagnosis of "Contact Dermatitis."

Two weeks later we met with the genetics team in Birmingham, and they determined Lane's cleft to be an isolated event and as we were leaving the exam room, the doctor casually mentioned possible Ectodermal Dysplasia Type A. We had no idea what that was, and it was so nonchalantly mentioned that we really didn't pay much

attention to the term. The condition of his skin had improved tremendously, but his scalp remained thin and would break down at the slightest touch.

The breakdown across his shoulders would be very red at times, other times it appeared to be scarred, dry and flaky. (We have since learned that the breakdown of skin across the shoulders and down the arms is referred to as “the shawl” in ED.)

We worked diligently to learn all we could about cleft repairs, the methods, techniques, looked at photo after photo of before and afters, knew all of the terms, and felt pretty prepared when we met with the cleft team in Birmingham.

The surgeon was not enthusiastic about using any of the appliances we had researched. He was not in favor of taping the premaxilla and told us to “tape if we wanted to.” His plan was to pull the lip segments over the protruding premaxilla and hope for the best, his goal being to make Lane “school pretty” at age four.

That was not in our plan at all. There had to be a better way but we were not sure if there were any other options available to us for Lane. Where else could we go? It would have to be

out of state, and we didn’t know if that was possible. We spent countless hours on the computer, talked to everyone we could find, contacted the insurance company and finally decided to meet with a surgeon in Georgia, another four-hour drive.

Before the appointment, I met a mom from Georgia online through Cleft Advocate. Her son was born a year before Lane with the medical team in Georgia. She urged us to consider traveling to Boston as she had done. I assured her the four-hour drive was going to be difficult enough and we could not financially consider Boston. She met us at the consultation appointment with her son. His repair was very impressive but it was the comfort, peace, faith and trust in the surgeon



that impressed us. Still, it was too much and too far to consider. Could we let money and distance hinder us from seeking the best for Lane without even trying?

The surgeon in Georgia agreed that an appliance to reposition the premaxilla was very necessary for a successful repair, explained the procedure and how the appliance would work. He then explained that it was his opinion that Lane’s lip segments were too small and the prolabium, center portion of the lip, did not give him enough tissue to completely close the cleft. He wanted to schedule a procedure called an Abbe Flap. He would sew the lip segments closed from top to bottom to allow an overgrowth of tissue. The lips would be separated after a few weeks and the excess tissue transferred to close the cleft. Melissa dissolved into tears at the thought of additional surgeries and creating scars when we could barely imagine the ones we had prepared for. We made the appointment for the Latham molding and finally the placement. Managing the Latham appliance required weekly, eight-hour roundtrips to Georgia for six weeks.

I remained in contact with the mom I met from

Georgia, and she continued to urge us towards Boston. Late one afternoon, at my wits end, worried, depressed, stressed, still struggling to “fix” all I could, I sent an email to the surgeon in Boston with Lane’s pictures attached. Five minutes later my email was answered. He asked for my phone number and immediately the phone rang. I was so shocked I am not sure to this day exactly what I said to him. A small-town country girl from Alabama, talking to a Harvard Professor!

He was very concerned, extremely kind, and genuinely interested in Lane’s repair. He felt there was no place for an Abbe Flap in Lane’s plan of care. Peace flooded over me like a warm blanket. I knew in my heart he was the answer to our prayers but I had no idea how we would get to him. Somehow we had to get Lane to Boston.

One week later, the doctor in Georgia placed the Latham and repaired the ureterocele. After that, Lane had tubes placed in his ears in Birmingham. The consultation in Boston was scheduled for late October. I contacted CCA at my friend’s insistence, requested financial assistance with traveling and, to our

see **lane**, page 14

lane, from page 13

surprise, the request was granted! We had contacted CCA for support shortly after Lane's birth but had no idea of the opportunity they would afford him in the future. In addition, we received many gifts from our family members and friends in our small community. We held a huge yard sale, a bake sale and a 50/50 raffle giving the winner half of the proceeds (a small way to give something back we thought). We were on our way to Boston!

I had never flown before, but I happily packed my bags along with Melissa, Barbara (Melissa's mother-in-law) and my sister-in-law, Rita. (I'm sure you have heard of the country going to the city. Well, that sure describes our trip!) We met with the surgeon, who thoroughly examined Lane and said he would "fight" for a date for Lane's surgery as soon as possible. He would do a one-step repair taking care of the lip, the gum and the nose. We could have flown home without a plane! How good it felt to finally have a plan.

Many tears, worry, sleepless nights, appointments, packing, unpacking and traveling followed the consultation. The Georgia team was less than supportive with our



decision, but we had to do what was best for Lane.

The date for Lane's surgery was set for January, 2007. We contacted CCA right away and were generously granted the financial assistance needed for traveling that would make the trip possible.

The surgery, which included an osteotomy to set the premaxilla back into its natural place when the Latham did not or was not allowed to work, was a nine-hour procedure and worth every second. Lane's sweet face was restored, whole, and beautiful — the face we grieved for.

One of my favorite photos is of Melissa and Adam leaning over Lane with his new little face. Their expression was the one we expected in the delivery room. Tears of joy and relief poured from the eyes of

everyone who was present to witness the miracle of plastic surgery and the abilities and talents of the surgeon we know God directed our paths to find.

Six weeks later we returned to Boston for a post op visit. Lane's palate was repaired in March, 2007, in Boston. Since then, we travel back to Boston once a year for Cleft Clinic appointments, and each trip has been made easier through the caring and generosity of CCA.

Lane was officially diagnosed with Ectodermal Dysplasia (Hay-Wells syndrome) at a National Foundation for Ectodermal Dysplasias Conference in 2009. The characteristics

of the ED are very evident today in the structure and shape of his teeth; thin fingernails and toenails; pale, dry skin; thin, coarse, sparse, light colored hair; a very sensitive scalp and the inability to sweat. He had no tear duct in his left eye and had surgery to create one. We have learned the ureterocele and the cleft are characteristic of ED.

Despite all he has been through, Lane is a happy, healthy five-year-old who just started kindergarten! His favorite TV show is Bonanza. He enjoys swimming, playing t-ball, going to the beach, tractors, hunting with his PeePaw (Peeps) and working with his dad's tools. His favorite foods are brownies, chicken nuggets and yellow rice—in that order.

We will be forever grateful and indebted to CCA for giving Lane the opportunity to receive the best medical care available. I cannot imagine what our lives would be without them. To any and everyone who supports and funds this organization, THANK YOU! You truly have given our family and Lane a miracle.

Click on
DONATE
at ccakids.org

robbie's \$5,000 haircut for cca

There was an unplanned event held to raise funds for CCA at the annual family retreat this year in June. When **Rob Gorecki** showed up with his hair longer than usual, some of our CCA dads came up with a plan to get him to cut it. **Mike Wiese** talked him into consenting to the deed if families would pool at least \$1,000 for CCA. After an announcement from board member, **Bill Mecklenburg** at the Saturday night dinner dance, over \$2,000 was collected in about five minutes! DeeJay Matt Figueroa announced that Mike would get to make the first snip under the direction of another board member, **Janis Macut**, who (fortunately for Rob) happened to be a hair expert.

Mike grabbed the microphone and challenged the crowd to get the funds up to \$3,000 and said he'd add another \$2,000 to it to



Board member, Janis Macut, just getting started on Robbie's \$5,000 haircut

make it \$5,000. You can guess the rest... in another 5 minutes or so, Rob was sitting in a chair receiving a **\$5,000** haircut thanks to our CCA retreat attendees who love this organization! Thank you Mike, Rob, Janis and ALL who contributed!



Above 1: Robbie and Mike Wiese

Above 2: Brendan O'Brien takes a snip

Left: Robbie and Janis AFTER the haircut!

FREE SHIPPING

cca web store

\$15 each

Millefiori glass heart
No two alike!
Leather w/CCA logo tag



Stainless steel w/ braided leather; round, heart or dog tag style; "Beyond the Face Is a Heart" on reverse



"Swarovski-type" genuine Austrian crystal stretch bracelets with stainless steel CCA logo tag



Alexandrite "Purple"



Apricot "Orange"



Chrysolite "Lime"



Gold Beryl "Teal"



Light Sapphire "Royal"



Multi "Limited Edition" for September (still available)

Children's Craniofacial Association held a successful online auction through www.CharityBuzz.com in coordination with "Morgan Meck's Match Play Tournament for CCA" (see page 5) and we're looking to do this every time we gather twenty items for auction. If families or friends of CCA have items for donation worth at least \$500 which are one-of-a-kind celebrity-related merchandise or "experiences," please get in touch with our office. Anything raised from your donations counts toward the family retreat room award.



Board member and CCA dad, Tate Gorman and wife April welcomed their third child, Greta Blythe, on April 20. Congratulations Gorman family including big brother John and big sister, Rory Cate!



CCA Mom and Blogger, Taryn Skees and husband Ricky, welcomed their third son, Hudson on July 18. Congratulations Taryn, Ricky, and big brothers, Ethan and Aiden.

calendar of events

date	event	contact
2012		
Aug 18	2nd Annual Trevor's Trip to Triumph Motorcycle Ride for CCA Freehold, NJ	kimtriz@msn.com
September	8th Annual Craniofacial Acceptance Month Nationwide	ARees@ccakids.com 214.570.9099 800.535.3643
Sep 1	Raegan's Rally/Walk for CCA Deerasic Park, 3 PM Cambridge, OH	Ashley Daugherty adaugherty@mvesc.k12.oh.us
Sep 8 11 AM-1 PM	5th Annual National Picnic Day Sandy Lake Amusement Park Carrollton, TX	ARees@ccakids.com 214.570.9099 800.535.3643
Sep 8 11 AM-1 PM	Picnic-Robious Landing Park Midlothian, VA	Daniel & Leslie Elliott Carolina98@comcast.net
Sep 8 Noon-3 PM	Picnic-Bexley Recreation and Parks Bexley, OH	Meg Gray megitect@gmail.com
Sep 8 2 -6 PM	Picnic-Main Park LaSalle, CO	Gaby Guevara victorsraffleforcca@yahoo.com
Sep 15	Ahmie's Blackberry Bash to benefit CCA Vinton, VA	ashley.arriaga@hcahealthcare.com
Sep 21	5th Annual Links of Love Golf Tournament Bear Creek Golf Club at DFW Airport Dallas, TX	JPatterson@ccakids.com www.golfinvite.com/linksoflove 214.570.9099 800.535.3643
Sep 22	8th Annual Friends of Jeremy Golf Tournament Corning Golf Club Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com
Sep 27	Barefoot Books for CCA San Jose, CA and online San Jose, CA	deenstrick@aol.com
Sep 29	Jonathan's Strive for Acceptance 5K for CCA Oroville, CA	freedomfromadd2@yahoo.com
Oct 5	Pete's Oktoberfest to benefit CCA Highland, MI	dededankelson@gmail.com
Oct 14	5th Annual Chocolate Festival for CCA Aventura Mall Aventura, FL	ChefRick2@aol.com
2013		
Jun 27-30	23rd Annual Cher's Family Retreat Orlando, FL	ARees@ccakids.com 214.570.9099 800.535.3643

GO PAPERLESS and view the newsletter online in FULL COLOR! Email ARees@ccakids.com and let her know you want to save the environment and save money for CCA.



testimonial

CCA has been an incredible blessing to our family. Our son, **Bauer**, was born with an incomplete bilateral cleft lip and cleft palate. He has had both his lip and palate successfully repaired. As our journey began and we were praying and seeking the Lord concerning surgeons, hospitals, travel, and of course, finances, we chose to take Bauer to Children's Hospital Boston.

Now four years after his initial procedures we are still traveling to annual clinics. It goes without saying that since the first day our little guy arrived, finances have been a concern. In the last two years, CCA has been a great support system for our family and helped to relieve some of the tension.



CCA has provided the cost for one plane ticket each year. While some people may not see this as significant, we could not be more appreciative.

As we are in the season of small children, diapers, and daycares, every penny counts! Having one of our plane tickets covered has given us room to breathe and allowed us to continue saving for future surgeries and travel. Thank you for loving on our family!

Adam, Stacy, Bauer and Aubrey Smehyl



craniofacial acceptance month

This year marks the eighth year CCA will observe September as Craniofacial Acceptance Month across the nation. CCA families, friends, volunteers and related support groups will be widening 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 8th Annual Craniofacial Acceptance Month, CCA will hold its 5th Annual National Picnic Day on September 8th (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 the communities.

It's not too late; 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.

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.

family dynamics

by Raeko Diemer, LMFT

new babies in the house can be a time of both joy and transition. This transition is intensified when a child is born with a difference, such as a craniofacial anomaly. Parents are often thrown into a period of intense grief as they struggle with their fears of what the future will be like for their child and anger about why their child is different. How parents get through the challenges of parenting a child with differences depends on many factors.

Gender differences can create tension as mothers and fathers sometimes have different ways of coping and communicating. Women typically reach out to others for help and want to process feelings by talking about their fears and frustrations. Men often look for solutions to problems and tend to avoid sharing feelings that make them feel vulnerable. This can lead to frustrations if one partner throws themselves into research, therapies and support groups while the other wants to downplay any challenges.

Parents can get frustrated and feel the other parent does not understand them. It is sometimes too easy to think that the other person is the problem rather than the stress and vulnerability that is at the heart of the issue. It is important for parents to realize that there are limits to how many therapies and treatment in which they can participate and that they need to make the time for other relationships and other activities.

A common dynamic that often arises is the desire for parents to protect their child from teasing or other social challenges. All parents desire that their children are loved and accepted. Parents will sometimes avoid social situations or limit social situations to try to protect their child. This can often lead to conflicts as one parent wants the child to learn how to cope with social difficulties while the other parent believes that protecting their child from teasing is the way to help the child's self-esteem.

Another dynamic that is challenging for parents is dealing with anger and frustration about their child's issues and some of the demands it places on the family, such as surgeries, support groups and therapies. There can be increased financial pressures and difficulties at work because of excessive time off. Parents often feel very guilty

about being angry at their child or at the situation, and this leads to conflicted emotions that parents try to deny. Parents worry about the impact of abnormality on siblings and worry that other siblings are getting less attention. This can lead to feelings of isolation since sharing these perceived negative emotions could create a sense of embarrassment and shame.

Despite the challenges of raising a child with craniofacial abnormalities, most couples are not more likely to divorce. However, having such a child may highlight pre-existing tensions and poor coping within the family. "It is not the child's disability that handicaps and disintegrates families, it is the way they react to it and to each other" (Dickman and Gordon, *One Miracle at a Time*, p109).

Relationships within family systems with a child with a disability typically need extra work to thrive. Good communication and honesty about feelings, even painful ones, are essential in addressing these strains. Therapy and support groups can help families sort out their feelings and create a safe environment, but it is important to remember that it can take time to develop positive coping skills.

Parents also need to find a balance between the needs of their child and their own needs. Spending more time together as partners, not just as parents, can be helpful in restoring relationships. As Dr. Laura Marshak wrote in an article on the website Disaboom, "One of the first things couples can do is make a decision to protect their marriage, they must understand that they are entitled to a decent marriage no matter how many needs their children have."

Raising a child with a craniofacial anomaly can often be both challenging and rewarding. Fortunately, time and emotional support helps with the grieving process as families learn ways to cope with the "new normal" of their lives.

Here is a list of helpful books that address marital issues as well as the challenges of raising a child with a difference:

- *Married with Special Needs Children* by Dr. Laura Marshak
- *The Special Needs Child* by Dr. Stanley Greenspan
- *The Seven Principles for Making Marriage Work* by John Gottman

rick's raffle results / donors in the spotlight / chance raffle



Our Donors in the Spotlight for this issue are **Ann and Doug Burgin**, who were regular supporters of CCA. Then they became founders of Rick's Raffle, in memory of their grandson, **Rick Dornier**. All proceeds from the raffle are added to our Patient Financial Assistance fund.

Rick loved Thomas the Tank Engine toys, and his spirit and joyful nature live on through a legacy of helping all CCA kids. The Burgins asked us to publish a family photo of **Jessica, Randy, Julia, Luke** and **Rick** instead of one of themselves. Thanks again for all you do for CCA!

On Rick's birthday, April 25, our building engineer drew the winning ticket. And more good news for

CCA Kids: The winner, **Melanie Benedict**, donated the Thomas toy bundle back to our retreat Chance Raffle in June. Thank you, Melanie!

The Chance Raffle had many exciting items, as the families brought baskets of goodies and things from their hometowns. There was also a coveted quilt of past retreat T-shirts from **Meg Gray**. The Thomas toys were among the top choices along with a few other contenders, including the quilt and a "Football Hall of Fame" package. We had so many tickets we had to transfer all of them to a bigger bag, so we could shake them up for the drawing!

One of the most touching moments was when CCA dad, **Eric Lucas** and his

family won the Thomas Power-Wheels ride-on toy, and the audience found out his family had dropped their many tickets in the bag to win it for **Jesse Bridgins**. This year's Rick's Raffle tallied just over **\$1,400**, but donating the toy bundle to our June retreat helped us raise a record **\$2,500** at our chance raffle! CCA kids are the big winners!



more fundraising news

sadie's night

In March the **Lake Highlands High School baseball team** held "Sadie's Night" in honor of CCA Kid, **Sadie Bono**, who threw out the first pitch. Led by **Coach Corey Tucker** who has made service and acceptance of all people a priority for his high school boys, and assisted by his wife **Ginny** who made commemorative bracelets crafted of authentic baseballs to be sold at the event, CCA became the beneficiary of a spontaneous "family fundraiser" centered around sweet Sadie! All of the proceeds from concessions, bracelets sales and an old fashioned passing of the bucket that night added to over \$1,200, but donations kept coming in and were



deposited at our doorstep by Sadie's mom, Debbie, a few days later amounting to approximately **\$2,000!!** Thank you to this entire caring community & to **Sadie**, big sister, **Molly**, **Debbie** & **Justin Bono**, and **Grandmother** too!

planned giving

CCA's Legacy Society welcomes new members, **Mr. and Mrs. Rod Strickland**. For more information, contact our Children's Craniofacial Association office.



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!

**BUY A CRANIOFACIAL ACCEPTANCE MONTH T-SHIRT!
GO TO WWW.PROMOTES.ME/CCA**

Youth S, M, L – \$15 • Women's S, M, L, XL – \$20
Men's S, M, L, XL – \$20 • 2XL – \$22
SHIPPING ON T-SHIRTS IS FREE

Colors Available:



Black



White



Yellow

(Men and Youth sizes only)

Buy and/or sell "Beyond the Face is a Heart" wristbands for Craniofacial Acceptance Month

more fundraising news

CCA "Volunteer-at-large," **Jaci Samhammer**, held two more funders to raise funds for CCA Kids:

The **Knowles Doyle Post 317** in Yardley, PA hosted a Christmas party last December and folks paid a stipend to have photos taken with Santa. That money was donated to Children's Craniofacial Association. Jaci repeated the idea at a Valentine's Day dance taking photos of the attending couples, and the total for the two events came to **\$267**. Thanks so much, Jaci and all who participated!

CCA Mom, **Michelle Bridgins**, held a Garage Sale for CCA and donated **\$175**. Thanks so much from all CCA Kids to Michelle and her CCA kid, Jesse!

CCA Volunteer **Alie Cobo** recruited her co-ed fraternal community service organization at **St. Thomas Aquinas College** to sell our CCA wristbands last April, spreading awareness while helping raise funds of **\$50** for CCA kids! Thanks so much to Alie and **Alpha Phi Omega: Alpha Eta Alpha Chapter**.

CCA Mom, **Stacy Swihart**, donated her Pampered Chef party hostess credit amounting to almost **\$100** to Children's Craniofacial Association. Thanks Stacy!

The **Lindenhurst High School Students** in Lindenhurst, New York, helped to spread awareness and understanding of facial differences at their school. They also sold our CCA wristbands, raising **\$300** for Children's Craniofacial Association! Many thanks go to everyone who participated, as well as to **Assistant Principal, Linda Flannelly**, who coordinated the effort.

Justine Humphrey held another Yoga for Good effort and sent in **\$115** for CCA. Thanks again Justine!

A Dodson's (www.adodsons.com) held an event with **Nora Fleming** to raise money for her favorite charity and she selected Children's Craniofacial Association. CCA received over **\$300** in donations from the customers of A. Dodson's in Suffolk, VA. Thank you Nora and friends!



Principal Sonya Lail at **Flower Mound High School** gave the go-ahead for yet another "**Luke Bowen's Jammin' Jeans Week**" to benefit Children's Craniofacial Association, headed up by our favorite volunteer-at-large, Luke's grandma, **Judy Kemler**. Judy's generous colleagues contributed over **\$1,000** for CCA kids! Special thanks to all who contributed to the effort in honor of Luke!



**Join us on September 21, 2012
at Bear Creek Golf Club in Dallas, Texas
for the 5th Annual Links of Love Golf
Tournament Don't miss the fun!**

**For more details & Registrataion:
www.golfinvite.com/linksoflove**

cca's newest resource for craniofacial families:



ccakidsblog.org
children's craniofacial association
support. experience. inspiration. empowerment.

Not familiar with the "blogosphere"? Let us explain...

Blog [blawg, blog] –noun
a website containing a writer's or group of writers' own experiences, observations, opinions, etc., and often having links to other websites.

The CCAKids Blog was developed by CCA families and staff to give those affected by craniofacial conditions a place to find support, inspiration and insight into the experiences of others on a similar journey. With important documents, useful tools and frequently updated blog posts, it is CCA's hope that this becomes a go-to spot for craniofacial families.

We welcome and encourage feedback about this new endeavor! So check it out and let us know what you think.

www.ccakidsblog.org

Find us on Facebook – CCA Kids Blog



Road Scholar is an asset-based motor freight company based out of Scranton, PA with terminals throughout the Northeastern United States. Their staff is waiting to provide you with the highest level of service. They represent their

customers from the belief that: "Our Point of Delivery is Your Point of Sale." If you are looking for custom freight solutions that save you money and service that exceeds your expectations, then give Road Scholar a call today at 800.542.2301, or visit their website, www.roadscholar.com

become cca's "friend" on facebook and twitter!

CCA now has its own facebook page and cause! You can look us up by simply searching for Children's Craniofacial Association!

Follow us on twitter at twitter.com/ccakids or twitter.com/ccateens.



Make your birthday wish for CCA on facebook!

cca's yahoo support groups

CCA is now offering support groups for 3 ages!

Middle School Age:

http://health.groups.yahoo.com/group/ccateens_middleschool/

High School Age:

http://health.groups.yahoo.com/group/ccateens_highschool/

Adults:

<http://health.groups.yahoo.com/group/ccakids/>

If you would like to join one of our online support groups, please visit the links above or contact CCA's Program Director, Annie Reeves, AReves@ccakids.com.



On the 10th anniversary of the publication of *Fearless*, we are proud to announce the publication of an anniversary eBook edition, now available on Amazon. All of us at CCA wish to thank our good friends, author **Bradley Harding** and illustrator, **Dan Gremminger** for making this possible. Their generosity and dedication to CCA is heartwarming!

2013 annual cher's family retreat announced

June 27-June 30 in Orlando, FL

For more information, please contact Annie Reeves, AReves@ccakids.com

We hope to see you there!

donors, january 1 – june 30, 2012*

Gifts from Individuals

CCA Friends (\$100 +)

Anonymous
 Carol Jean Anthony
 Terry Lynne Ausmus
 Michael Beasley
 Steve Bouker
 Beverly Butera
 Larry Carpenter
 Jeffrey Lloyd Christian
 Michael Clay
 George Dale Sr.
 Kathleen Danielson
 Debbie Dornier
 Vicente Farina & Leigh M. Soda
 Frances Fisher
 John & Carrie Follett
 Bunsiri Frazier
 William Gorman
 Andrea Horsch
 Dolores Horton
 William Hunter
 Abigail Jaffe
 Doug & Kirsten Jumper
 Ian Leisegang
 Ann & Don Lucas
 S.F. Luhrs
 Deborah Mecklenburg
 Ron Micetic
 Heather Miller
 Hykel & Amanuel Mulugeta
 Glenn Neubauer
 Jackie Halpin-Osteen
 Greg & Jill Patterson
 Jerome & Kathryn Penna
 Adam Perkes
 Paul R. Pokladnik
 Ann Ranfranz
 Robert & Luwana Ratliff
 Donna Rea
 Andrea Richard, D.O.
 Chris Riener
 Fred & Rose Seitz
 Dean Spanos
 Michael & Ann Steffen
 Gary Uttke
 Dwight Vaughn
 Mark & Natalie Weaver
 C.M. & Leila Wiley
 Robin Williamson
 Reed Wills

CCA Companions (\$250 +)

Beth Abel
 Anonymous
 Carl Bach
 Erik Bauman
 Lorrell Bush & Colleagues
 Amy & William Downs III
 James Duffy
 Deena Dyson
 Richard Faulkenberry
 Heath Fisher
 Martin Grupp
 Christopher Hood
 Christopher McGhee

Arie Krie
 James Oh
 Dale & Kathleen Philippi
 Jeffrey & Elizabeth Robinson
 George Rodriguez
 Michael Schnur
 Charlene & John Smith
 Andrew & Amy Weinraub

CCA Extended Family (\$500 +)

Martha Brown
 Tracey Carragher
 Roger S. Chin DDS, PS
 Diana Critchlaw
 M. Brian Evans
 Fred & Judi Freeman
 Robert Kacer
 Kim & Urban Koagedal
 Mary Lytle
 Joe & Allison Morrissey
 Katherine Olsen
 Matthew Osburn
 Jennifer Webber
 Kenneth Wilson

CCA Sponsor (\$1,000 +)

Maria Amelio
 David Armstrong
 Andrew Bustillo
 Chris Campbell
 George & Kristine Dale
 Dede & Darin Dankelson
 Adam Driscoll
 William C. Godfrey
 Tom & Donna Leonhardt
 Molly & Robert Lytle
 Carl & Kathy Michaelsen III
 Dan & Denise Paulson
 The Estate of Jean Pond
 Robert & Karen Reader
 Blair Schrum
 Michael & Shelly Sprague
 Heather Switzer
 Joslyn Verona
 Bradley Walsh
 Marty & Mike Willson

CCA Patron (\$2,500 +)

CCA Benefactor (\$5,000 +)

David Bresnahan
 John Mahoney
 Thomas Gillingham

CCA Guardian (\$10,000 +)

Anonymous
 Bill Mecklenburg & Christine Condino-Mecklenburg
 The Estate of Andrew & Juanda Seventy

CCA Legacy Society

Dede & Darin Dankelson
 Joy & Rod Strickland

Memorials / In-Honor Gifts

Anonymous, in honor of Deena Coplin's birthday
 Anonymous, in honor of Meg Gray's birthday
 Anonymous, in honor of Roy Dennis
 Anonymous, in honor of Nick Wiese
 Terry Lynne Ausmus, in honor of Natalie Wardlaw and in memory of Cecelia Guerra
 Mary & Robert Beck, in honor of Freddie Seitz
 Lorrell Bush & Colleagues, in honor of Captain Bob Ratliff
 Andrew Bustillo, in honor of Morgan Mecklenburg
 Larry Carpenter, in honor of Cher's birthday
 Maureen Cleary, in honor of the Cronin Family
 Dede Dankelson, in honor of Francis Smith's birthday
 Dede Dankelson, in honor of Meg Gray's birthday
 Michael DePalma, in honor of Deena Coplin's birthday
 Debbie Dornier, in memory of Rick Dornier
 Deena Dyson, in honor of Printer Chicks
 M. Brian Evans, in honor of Erica Mossholder
 Richard Faulkenberry, in honor of Constance Abrams
 Richard Faulkenberry, in honor of Dale D. Gorman
 Anna Fowler, in honor of her 2 sons, born with clefts
 Rabbi Jonas & Chelly Goldberg, in honor of Deena Coplin's birthday
 Joseph & Patricia Gwozdz, in honor of Kate Rogers
 Jackie Halpin-Osteen, in honor of John Gorman
 Alfred Harf, in honor of Chase Ingram
 Jim & Arleen Heirty, in memory of Milly Aske
 Jim & Arleen Heirty, in memory of Dorothy Zelanko
 Beth Higgins, in honor of Kim Grant
 Beth Higgins, in honor of Mary Clarke
 The Hitchcock Company, in honor of Kristine Dale
 Christopher Hood, in honor of Trevor Layrs
 Andrea Horsch, in memory of Stephen Haycraft
 Kristin Houstin, in honor of Deena Coplin's birthday
 Sylvia & John Loving, in honor of Ryan Holliday
 Ann & Don Lucas, in honor of Brody Lucas, "Be Brody's Angel"

Ann Nesbitt, in honor of Megan Cronin and family
 Abigail Jaffe, in honor of Jen and Adam Kellogg
 Berlin Kaplan, in honor of Deena Coplin's birthday
 Molly & Bob Lytle, in honor of Avery
 Susan Martin, in memory of Ellery Walker
 Erica Mossholder, in honor of Meg Gray's birthday
 John Moulton, in memory of Carol Moulton
 Hykel & Amanuel Mulugeta, in honor of Amanda from LaPlata, MD
 Rose Seitz, in honor of Meg Gray's birthday
 Christine Sikes, in honor of Casey Deakins
 Charlene Smith, in honor of Francis Smith's birthday
 Thelma Kathleen Smith, in honor of Meg Gray's birthday
 Michael & Ann Steffen, in memory of Kevin Wilson
 Eleanor Strony, in honor of the 50th anniversary of M/M George Lesko, given in the name of Jeremy Dale
 Jennifer Webber, in honor of Madelyn Webber
 Andrew & Amy Weinraub, in honor of Max Weinraub
 Reed Wills, in honor of Cynthia Wills
 Marty & Mike Willson, in honor of Avery Lytle
 Greg Wood, in honor of Deena Coplin's birthday

Corporate/ Foundation Gifts

CCA Corporate/ Foundation Friends up to \$1,000

American Express Charitable Fund (employee giving)
 American Legion Knowles Doyl AT&T (United Way Employee Giving Campaign)
 Bank of America (United Way Campaign employee giving)
 Best Buy Co., Inc
 Columbia Gulf Transmission Co.
 Combined Federal Campaign / Local
 Directed Technologies
 Exchange Club of Lake Highlands
 Funding Factory
 Hargrove Oil Company, LLC
 Heart of Illinois United Way, Inc.
 Jay C. Service Inc.
 IBM Employee Services Center (employee giving)
 Lee Law Offices
 Micetic Insurance Services
 Microsoft Employee Giving Matching Gifts Program
 MissionFish (Ebay, directed donations thru percentages of sales)
 New York Life Insurance (Employee Giving)

Northrup Grumman Employee Giving
 PASCO
 PWC
 Petroleum Women's Club
 Pfizer (United Way Campaign employee giving)
 Prudential Foundation (matched gift of Diana Critchlaw)
 Prudential Foundation (employee giving)
 Random House, Inc.
 Safeway, Inc. (purchases percentage incentives)
 Thompson, Coe, Cousins & Irons, LLP
 Time, Inc.
 Truist for Qwest & UPS (employee giving)
 United Way of Greater Milwaukee (donor-directed donations)
 United Way of Tarrant County (Bell Helicopter Employee Giving)

CCA Corporate/ Foundation Sponsors \$1,000-\$5,000

BP Corporation of North America, Inc. (toward the Hartley Company fundraising effort)
 Car Inc. Trust
 The Chatlos Foundation
 Children's Medical Charities CFC 2008
 Dartmouth-Hitchcock Foundation
 Guy Carpenter & Company for MMM*
 The Hitchcock Foundation
 Orange County CFC
 Partner Reinsurance Co. of US for MMM*
 The David M. Schwarz Architects Foundation
 E.C. Styberg Foundation, Inc.
 Triangle Foundation
 Vivo Brothers

CCA Corporate/ Foundation Partners \$5,000-\$10,000

Cher Charitable Foundation
 Lexington Insurance Company

CCA Corporate/ Foundation Patrons \$10,000 or more

Fundraising Events & Other Efforts

Up to \$1,000

Cash cans /placed by Kim Rogers, Bradley, IL
 CD Sales / John Moulton
 Be Brody's Angel / Brody Lucas' Family Fundraising Effort
 Deena Coplin's Birthday Wish on Facebook / Deena Coplin
 Do Yoga, Do Good / Ananda Yoga, Justine Budhram
 Nora Fleming Fundraising Effort / Nora Fleming & Friends
 Meg Gray's Birthday Wish on Facebook / Meg Gray
 Indoor Flea Market / Anjolene Whaley
 Pete Dankelson's Fundraising Page / Firstgiving Online
 Garage Sale / Michelle Bridgins
 Francis Smith's Birthday Wish on Facebook / Francis Smith
 Wristband Sales for CCA / St. Thomas Aquinas College & Alie Cabo

\$1,000-\$5,000

CCA Chance Raffle / Annual Family Retreat Attendee Participants
 Do Yoga, Do Good in honor of Nova Cox / Ananda Yoga, Justine Budhram
 Luke Bowen's Jammin' Jeans Week / Judy Kemler & Flowermound HS Faculty
 Rick's Raffle / Raffle Ticket Sales / Established by Ann & Doug Burgin
 Sadie's Night / Bono Family with Lake Highlands High School Baseball Team

\$5,000 or more

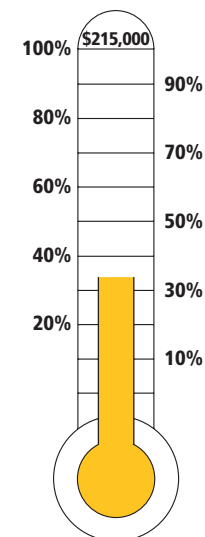
\$10,000 or more

\$20,000 or more

\$30,000 or more

Morgan Meck's Match Play Tournament for CCA / Mecklenburg Family

2012 FAMILY FUNDRAISER GOAL THERMOMETER



Listed are monetary donations of \$100 or more through 2nd quarter, 2012. We are extremely grateful for these and all other fees, purchases, fundraisers and in-kind donations not individually recorded here. (Note: For space consideration, 2012 donations under \$100, CCA "Supporters" will only be published in our year-end list. Cumulative \$100+ donations and all **In honor** or **In Memory** dedications will continue to be published in each issue.)

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

Extraordinary Fundraiser Sponsorships of \$1,000 or more are also listed. CFC (Combined Federal Campaign, federal-employee giving)

Honorary Chairperson:

Cher

Board of Directors:

Dede Dankelson, *Chair*, Highland, MI
George Dale, Corning, NY
Tony Davis, DMD, Tuscaloosa, AL
Tate Gorman, Dallas, TX
Paula Guzzo, Evansville, IN
Janis Macut, Harrisburg, PA
Bill Mecklenburg, Mission Viejo, CA
Erica Mossholder, Tuscaloosa, AL
Robin Williamson, Carrollton, TX

CCA Network Editor:

Kelly Liszt

CCA Network Design and
Production:

Robin Williamson,
Williamson Creative Services, Inc.

Executive Director:

Charlene Smith

Program Director:

Annie Reeves

Development Director:

Jill Patterson

Administrative Coordinator:

Jana Peace

voice 214.570.9099

fax 214.570.8811

toll-free 800.535.3643

url CCAkids.org

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

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

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

3 cheers

for volunteers!

Thank you, Sharon Allbright!

CCA is so fortunate to have so many wonderful families, and one of them is the **Allbright family!**

Sharon and her family live in Tempe and offered to help with the retreat. She allowed us to ship items to her house in advance to save us from paying a storage fee at the hotel. Sharon and her son,

Jonathan, then delivered everything to the hotel.

Sharon and Jonathan also helped us with anything we needed, from picking up all the supplies for our icebreaker during the ice cream social on Thursday night to buying crayons and bottled water for our families. *And she got the mayor of*



Tempe, **Hugh Hallman**, to declare September 2012 as "Craniofacial Acceptance Month" within the city of Tempe!

We are so grateful and can't thank you enough!