

# ccanetwork



quarterly newsletter of the children's craniofacial association

Cher — honorary chairperson summer 2011

## inside

cca kid	
kieran roehl . . . . .	2
cca adult	
brittany balentine . . . . .	3
cca supersibs	
bailey & laney roehl. . . . .	4
my first retreat . . . . .	5
calendar of events. . . . .	6
craniofacial acceptance month . . . . .	6
financial assistance . . . . .	6
retreat pics . . . . .	7-9, 18
testimonial . . . . .	12
donors in the spotlight . . .	13
cca mugshot. . . . .	13
sleep apnea . . . . .	14-15
fresh start. . . . .	15
cca kids blog. . . . .	16
fundraising news . . . .	16-17
3 cheers for volunteers . . .	18
donor list . . . . .	19
chance raffle. . . . .	20



## madelyn's story

By Melissa Jurek

We were blessed with our sweet baby girl, **Madelyn Ann Jurek**, on August 23, 2006. She was just a peanut, 5 pounds 12 ounces and 19 inches long.

Following our 20-week ultrasound, we were told Maddie had a cleft lip and palate. The remaining weeks of my pregnancy were filled with numerous, lengthy visits each week to both the OB/GYN and the perinatologist. I remember little Maddie always had her hands up in front of her face.

We later learned she would be born with a bilateral cleft lip and palate and that the right side was more severe. We were completely unaware of exactly how severe it was. My husband, Jeremy, and I immediately focused on researching the best care for her. This included meeting with the program medical director for the Center for Craniofacial Services at Gillette Children's in St. Paul, Minnesota, as well as his RN.

see **madelyn**, page 10

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



## message from the program director

Louisville, Kentucky was the site of the 21st Annual Cher's Family Retreat. 92 Families from 34 states, Canada and Switzerland gathered at the famous **Galt House Hotel**, visited the Science Center and Louisville Slugger Museum and spent quality time reconnecting with old friends and meeting new ones.

For the 3rd consecutive year, the retreat began with an educational craniofacial symposium led by area healthcare specialists. We are particularly grateful to **Charlene Pell; Angela**

see **program director**, page 7



 **Children's Medical Charities of America**



# meet kieran roehl

**K**ieran Roehl is a soon-to-be sixth grader from Sterling Heights, Michigan. He said “good-bye” to elementary school this past spring, and is really looking forward to starting middle school in the fall. His favorite subject is math. And since Kieran likes to count (and collect) money, it’s a particularly good skill to have.

Hands down, his favorite sport is baseball. Kieran plays outfield, he’s a huge Detroit Tigers fan and he really likes collecting baseball cards.

Kieran also has another different, and very interesting, hobby. He loves building domino and marble runs. It can take up to an hour and a half to set one up, taking over floors, pool tables and more across multiple rooms. Yet after all that work, the dominos all fall over in a matter of seconds. Still, he enjoys the entire process.

Kieran likes the group, “Big Time Rush,” and keeps up with their show on TV. As for movies, his



favorite is *Cars*, and he wants to see *Cars 2* “so bad.”

He has two older sisters. (See the two SuperSibs articles in this issue.) He likes to hang out with them and go swimming with them in their pool.

Kieran recently got back from the retreat in Louisville and had an “awesome” time. He really enjoyed seeing his friends again and catching up. Also, being the baseball fan that he is, he loved going to the Louisville Slugger Museum. He even toured the factory where the legendary bats are made and took home a mini bat as a souvenir.

This was Kieran’s fourth retreat (and counting). He’s looking forward to seeing

everyone again in Tempe next year.

Kieran has some good tips for other CCA kids. He says to not be afraid to ask for what you want.

Also, he advised that you stay calm during a surgery or procedure. He adds that there’s always ice cream at the end of the tunnel.



ccakid



# ccateen

## brittany balentine

**h**ello, I'm **Brittany Balentine**. I recently graduated high school, and I also celebrated my eighteenth birthday this summer with a big party on the Fourth of July. This fall, I'm looking forward to taking childcare classes.

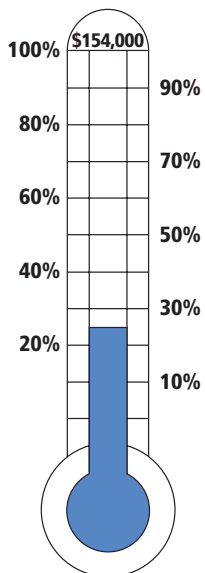
I love to hang out with my friends and family. My two favorite hobbies are Justin Bieber, of course, and dancing. I have all of Justin's DVDs, CDs and a ton of JB T-shirts. I spend my summers going to yard sales with my nana, grandma and aunt, swimming at my aunt's pool and dancing in my room.

My birthday party is the biggest party of the year. Since it falls on the Fourth of July, we get together at my cousins' house and have our family reunion the same day. We have a big cookout, and for fun we ride four-wheelers, swim in the pool, ride horses and jump around in bounce houses. Then we enjoy watching fireworks at night. Everyone looks forward to it all year.

We just got back from the CCA retreat in Kentucky, and I had a great time seeing all my CCA friends. I can't wait to see everyone next year in Arizona!






### 2011 FAMILY FUNDRAISER GOAL THERMOMETER



**BUY A CRANIOFACIAL ACCEPTANCE MONTH T-SHIRT!**  
**GO TO [WWW.PROMOTES.ME/CCA](http://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)

### Also Available:

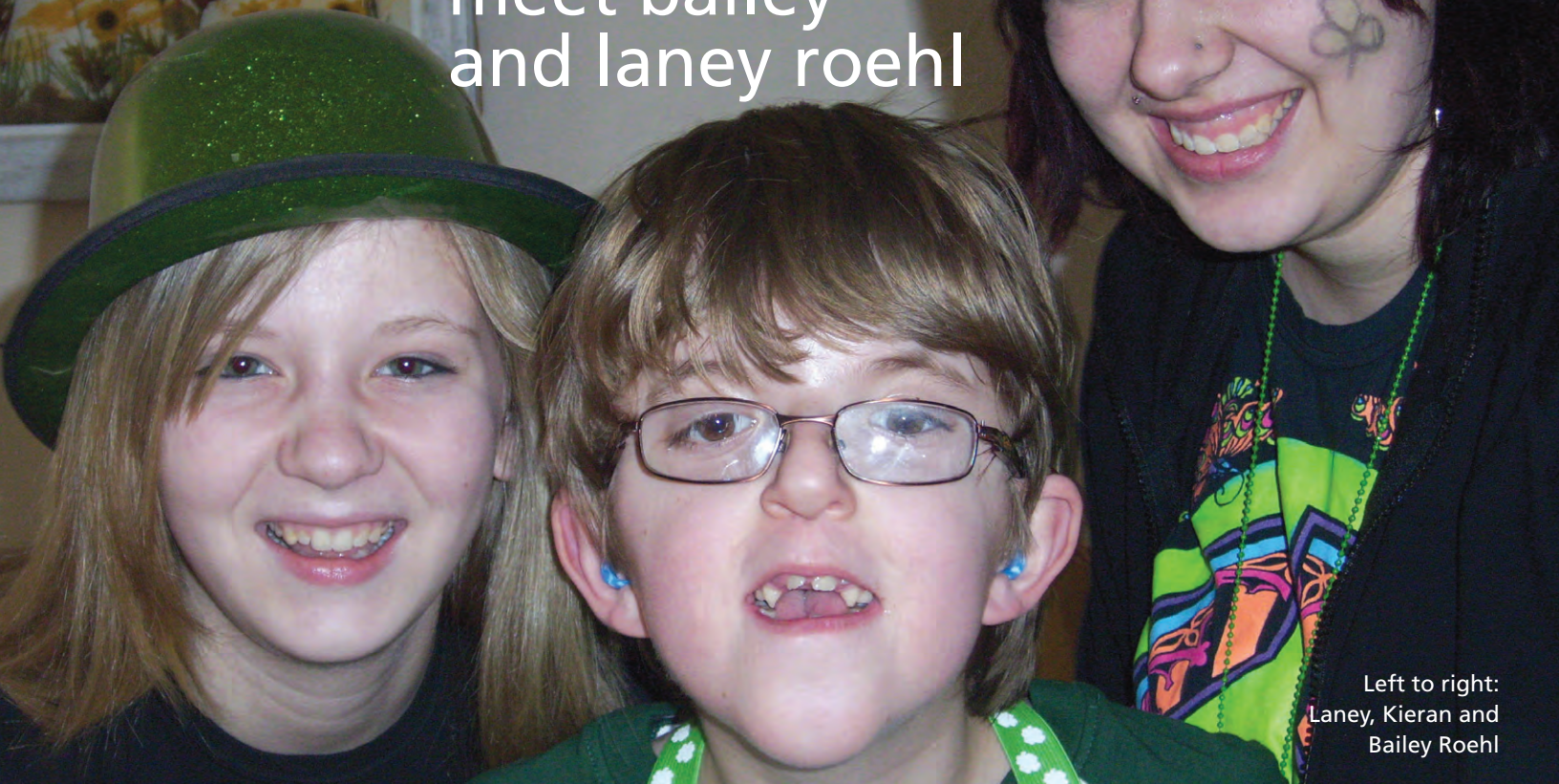


Multi-colored "Limited Edition" bracelet for September



# ccasupersibs

meet bailey  
and laney roehl



Left to right:  
Laney, Kieran and  
Bailey Roehl

**m**y name is **Bailey**. I'm 19 and a sophomore at Oakland University. I haven't declared a major yet, but this coming semester I will be taking health science courses to see if going to medical school would be right for me.

If all goes well, I plan to declare pre-med and become a forensic pathologist. If not, I want to become a social worker with a specialty in either probation or drug rehab.

I have been spending this summer working, saving money and job hunting. I also moved into my first

apartment with two of my friends, Chelsea and Shaina.

I have two cats, Tiger and Cooper, plus I love to read. And I never have more fun than when I spend time with my best friend Lynnette. My friends and family are the most important things to me in the world.

Even though my little brother has a craniofacial birth defect, it doesn't change anything. And although I worry when he has surgeries, he's still your typical, pain-in-the-you-know-what annoying little brother. However, I'm

proud that nothing ever gets him down.

**h**i, my name is **Laney Roehl**. I'm 17 and going to be a senior this fall at L'Anse Creuse High School. During school, I am a percussionist for the school's wind symphony. I also participate in the school's photography program.

Outside of school I am a member of our marching band, for which I have participated in both the front ensemble and the battery. I plan to go to college and major in physical therapy.

In my free time I love to hang out with my friends and family. My brother, Kieran, is my favorite guy ever. He can be the typical annoying little brother, but he can also be an extremely sweet and kind kid. We love playing video games together as well as pool, board games and sports. Plus we love to go swimming together.

To me, his having Apert syndrome doesn't affect anything, because I don't know any differently and neither does he. He is just my ordinary little brother whom I love.



# my first retreat

By Christine Clinton

hi, my name is **Christine Clinton**, and I had the privilege to attend the 21st Annual Cher's Family Retreat in Louisville, Kentucky. This retreat was my very first retreat, and what an experience it was!

Before I left for the retreat, I was super nervous. In fact, to be quite honest, I was having second thoughts about going. I am an incredibly shy person, so meeting new people for the first time is never easy for me. For me, having Apert syndrome makes meeting new people much more difficult.

Once I started meeting the other retreat attendees, all of my anxiety and fears were washed away. Everyone was absolutely wonderful, so very accepting, caring, loving and welcoming. I felt like I belonged there, like I was a part of a wonderful new extended family.

Everyone was just so sweet to me, and they really made me feel like I was a part of something special. I really felt accepted, cared for, loved and truly welcomed. It was a great feeling to know I was part of such a wonderful group.

On the first full day, I attended a symposium session about staring, and I'm really happy I went. It helped me gain more insight on why people stare. I also learned what to do if someone stares at me or asks me a question about having Apert syndrome. I also went to another symposium session on applying make-up correctly. Both sessions were very informative and very interesting, and I left them with a renewed sense of self.

After the symposiums, my guest Judi and I went to the Louisville Slugger Museum and Factory to walk around. That was awesome!

The next day, we went to the

## Louisville Science Museum/IMAX,

which was fun too, but we decided to go back to the Slugger Museum. There, we went on a tour of the factory to see where the actual Louisville Slugger baseball bats are made. We got a free bat, too! I think going to the Slugger Museum and touring the factory was one of the best parts of my trip to Louisville.

The next day, Judi and I went to the Louisville Zoo. The animals were so amazing, and we had a really great time. The dinner/dance that night was also extra-special. I got to meet more amazing people I hadn't had a chance to meet or talk to the first two days I was there. We took lots of pictures, had tons of fun and danced the night away. I was exhausted, but happy, when the night came to an end.

On the last day, we went to the farewell breakfast, where we took some pictures and said our goodbyes to everyone. I didn't want to go home,

though I knew that I had to. I promised myself that I would attend the next retreat in Tempe, Arizona. I also told myself that I will someday go back to Louisville. It is so calm and serene there. I absolutely loved it.



# calendar of events

## date event contact

### 2011

Sep	<b>7th Annual Craniofacial Acceptance Month</b>	<a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a> 214.570.9099 800.535.3643
Sep 3	<b>Raegan's Rally/Walk for CCA</b> Deerasic Park, 3 PM Cambridge, OH	Ashley Daugherty <a href="mailto:adaugherty@mvesc.k12.oh.us">adaugherty@mvesc.k12.oh.us</a>
Sep 10	<b>4th Annual Craniofacial Acceptance National Picnic Day</b> Sandy Lake Amusement Park Carrollton, TX	<a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a> 214.570.9099 800.535.3643
Sep 10 10 AM-2 PM	<b>Picnic—Brame Park</b> Bellmead, TX	Ron or Carmen Mickley <a href="mailto:carmenamickley@gmail.com">carmenamickley@gmail.com</a>
Sep 10 11 AM-2 PM	<b>Picnic—Robious Landing Park</b> Midlothian, VA	Daniel Elliott <a href="mailto:Carolina98@comcast.net">Carolina98@comcast.net</a>
Sep 10 1-4 PM	<b>Picnic—Schnelker Park</b> New Haven, IN	Jessica Eakright <a href="mailto:Jessica_debug@msn.com">Jessica_debug@msn.com</a>
Sep 10 2-4 PM	<b>Picnic—Moss Park</b> Orlando, FL	Casey Deakins <a href="mailto:caseydeakins@gmail.com">caseydeakins@gmail.com</a>
Sep 11 2-4 PM	<b>Picnic—Jeffrey Mansion &amp; Park</b> Columbus, OH	Meg Gray <a href="mailto:megitect@gmail.com">megitect@gmail.com</a>
Sep 17 Noon	<b>Picnic—Glur Park</b> Columbus, NE	Gina Matson <a href="mailto:matson@megavision.com">matson@megavision.com</a>
Sep 17 Noon-2 PM	<b>Picnic—Rambling River Park</b> Farmington, MN	Jennie Rutter <a href="mailto:Jenniej530@yahoo.com">Jenniej530@yahoo.com</a>
Sep 22	<b>Torey's Distraction Screening</b> Cranberry Cinema Cranberry Township, PA	Nick Wiese <a href="mailto:rosewiese@zbzoom.net">rosewiese@zbzoom.net</a>
Sep 24	<b>7th Annual Friends of Jeremy Golf Tournament</b> Corning Golf Club Corning, NY	<a href="mailto:gdale@stny.rr.com">gdale@stny.rr.com</a> <a href="http://www.friendsofjeremy.com">www.friendsofjeremy.com</a>
Sep 24	<b>Lily's 2nd Annual Craniofacial Awareness Benefit Dinner</b> Lindon, UT	<a href="mailto:NurseTosha@gmail.com">NurseTosha@gmail.com</a>
Sep 30	<b>Links of Love Golf Tournament for CCA</b> Woodbridge Golf Club Wylie, TX	<a href="mailto:JPatterson@ccakids.com">JPatterson@ccakids.com</a> <a href="http://www.linksofloveforcca.com">www.linksofloveforcca.com</a>
Oct 1	<b>Trevor's Trip to Triumph Motorcycle Ride for CCA</b> Morganville, NJ	<a href="mailto:kimtriz@msn.com">kimtriz@msn.com</a>
Oct 8	<b>Texas Moms' 5K for CCA</b> Lee College, 200 Lee Drive Baytown, TX	<a href="mailto:ledestiny@gmail.com">ledestiny@gmail.com</a>
Oct 9	<b>4th Annual Chocolate Festival for CCA</b> Aventura Mall Aventura, FL	<a href="mailto:ChefRick2@aol.com">ChefRick2@aol.com</a>

### 2012

Jun 28-Jul 1	<b>22nd Annual Cher's Family Retreat</b> Tempe, AZ	<a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a> 214.570.9099 800.535.3643
Jul 13-15	<b>10th Moebius Syndrome Conference</b> Sheraton City Center Hotel Philadelphia, PA	<a href="http://www.moebiusysndrome.com">www.moebiusysndrome.com</a> <a href="mailto:dawnang@moebiusysndrome.com">dawnang@moebiusysndrome.com</a> 510.304.2302 660.834.3406



## craniofacial acceptance month

This year marks the seventh 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 7th Annual Craniofacial Acceptance Month, CCA will hold its 4th Annual National Picnic Day on September 10th (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.



## program director,

from page 1

**Dixon, MA, CCC-SLP; Cara Drake-Luecking, MA, CCC-SLP; Raeko Diemer, LMFT; Lili Lutgens, LCSW; Krista Embry and Paula Guzzo** for addressing topics of importance to each family member affected by facial differences.

It seems that each year the retreat just keeps getting better. Our CCA families feel ownership of the organization and specifically the retreat. CCA staff and board organize and prepare for it, but it is the families who make the magic happen. On Saturday night when we sing and dance to “We Are Family,” we are really expressing how we all feel about each other.

It is always difficult to tell a new family, or anyone else for that matter, what the retreat means to all of us. Yes, there are educational opportunities, sharing experiences and a lot of fun, but there is something much deeper than that. I’m sure the retreat

means different things to different people. As **John Moulton** expressed in the [2009 Retreat Video](http://www.youtube.com/watch?v=sTH7MToKiJA) (<http://www.youtube.com/watch?v=sTH7MToKiJA>) “Sometimes I go home in tears, and other times I go home in laughter.” But be sure each of us goes home changed.

After this year’s retreat, **Sabrina Robineau** wrote about what the retreat means to her. I’d like to share her thoughts with you.

Annie Reeves  
CCA Program Director

## one big happy family

By Sabrina Robineau

### What the retreat means to me.

Another year has come and gone. As I sit in my kitchen back at home, I cannot believe the CCA retreat is already over once again. It was one of the best ones yet. I never grow tired of it and, honestly, I don’t think I ever will.

Even though it’s Children’s Craniofacial Association, and I’m an adult, I feel that it is still incredibly important to continue attending these retreats and be a part of this amazing social network.

One of my favorite things to do at the retreat is to

minge with the parents of a child with a craniofacial syndrome. I love talking to them about what I have been through and how far I’ve come, despite the challenges along the way. I want to give them hope that their child can do the same. Did I ever think I would make it to a university and major in a subject that I love? Never. But here I am now, doing exactly what I always dreamed of. It really doesn’t get any better than that.

Another thing that I really love is the overwhelming support I feel from my CCA friends. When I see these people every year, it truly feels like a family reunion because, in a way, we are one big happy family — there’s nothing like it. Not to mention, people with craniofacial syndromes have similar traits, so we all look alike in some way. It feels like they’re my “distant cousins.”

Going to these retreats is like entering another world, my world. I feel safe, loved, protected and accepted. I feel like I belong, which is why I look forward to it every year. I never want to miss a chance to go back to this world, even if it’s only for a short period of time. It always feels weird when I go back home after the retreat because I have to step back into the other world—reality.



Sabrina with Avery Cooper

One of the things that really stood out to me this year was the love from the fathers. You can tell just by watching them with their child how much they really care for them. When I saw these fathers, I couldn’t help but wish that my dad would want to be there too. Even though I have an amazing mom, in the back of my mind I wondered what it would be like to have my father there too. When a child is born with a craniofacial syndrome, they are going to need all the support they can get. Support from both parents is the most important.

### Growing up, it wasn’t so easy.

Life is like a stack of cards, and you’re stuck with the cards you’re dealt. When your child is born with a craniofacial syndrome, you have to either accept it or deny

see **program director**, page 8



Sabrina and her Mom, Jo-Anne Perras



Sabrina dancing with Joe Brooks

that it's happening. Unfortunately, my dad chose to deny it. Growing up, I never felt the "unconditional love" from him, I always felt that he wanted to hide the "Pfeiffer" part of me and pretend that I was "normal." Sure, I was normal in some ways, but in other ways I was not.

When my younger half-sister was born, I felt even more out of place. To me she was perfect. She had no abnormalities and no medical problems. This was hard for me to go through because once she entered the picture, I was no longer the only daughter in my dad's life. He now had a "perfect" daughter, and I felt like the odd one out.

There was a point in my childhood where I didn't want to deal with Pfeiffer syndrome. I didn't want any part of it; I just wanted

to live a normal life. I realize now that this attitude was brought on by the way my dad always treated me: "There's nothing wrong with you. You're perfectly fine. You're the same as your brothers and sister."

So sometimes he made me feel that it was wrong to think that I was different, but yet deep down, I always felt different from my siblings. Since my dad saw me as "normal," he always belittled my accomplishments in school. It took a lot of strength and effort to get through school while having surgeries at the same time; therefore it would upset me when my dad would shrug it off and say, "Well you could have gotten a higher grade." This made me try even harder to do well in school so I could make my dad proud. However, nothing I did was ever good enough for him.

#### How I see it now.

Even though it hurts not to have support from my dad, now I finally realize I don't need it. I have to focus on the fact that I have the love and support from my family, my friends and, more important, my friends from CCA.

I feel sorry for my dad (and my siblings) for missing out on this

amazing event every year. I feel so blessed to be a part of CCA and I wouldn't trade this for anything. I'm even thankful to have this syndrome, so I can use my experiences to help others who are going through difficult times.

This is exactly what CCA is all about — being proud of who you are and helping others feel the same way about themselves. I am so grateful for my mom who has helped me become the woman I am today. I love myself just the way I am. I am not ashamed, and I definitely don't want to "hide" the unique side of me.

Unfortunately, not everyone in our lives will be as supportive as others, but this is where you have to choose whether or not to let it bother you. I hate that I can't share the CCA world with my dad and my siblings, but I am working on letting it go and just



Sydney Garcia, cheesing for the camera.

enjoying this part of my life.

**My advice is to always be true to yourself and be proud of what you accomplish.** And, as Eleanor Roosevelt so wisely said, "No one can make you feel inferior without your consent."







Francis Smith and Melissa Giltz



Donna and Victoria Green at the swim party



Ethan, Taryn and Aiden Skees, and Bridget Hospodka

Many thanks to the Jorge Posada Foundation for sponsoring the dessert social!



Left: Retreat attendees looking over the raffle baskets



Above: Kids enjoying the magic show; Below: the Dinner Dance



Julie Baird with her nephew, Cubby Baird





**madelyn**, from page 1

We immediately felt comforted and have continued our care with them, along with the medical geneticist, pediatric dentist, orthodontist, and speech-language pathologist.

At 8:21 AM on August 23, Maddie was born *via* caesarean section. The delivery room was packed and ready to help. Maddie made her presence known when she was born—she was very vocal, screaming almost immediately. She was then whisked away to an adjoining room where Daddy followed her.

The extensive team was well prepared for the unexpected and took great care of her. I was able to briefly meet my baby girl before the staff and Jeremy left the delivery area and headed for the special care unit with Maddie. It was immediately evident that she had more than the cleft lip and palate and the hospital initiated additional testing to be done in order to evaluate all that was going on with her.

During Maddie's initial stay, we met with the genetic counselor at Children's of Minneapolis who provided us with her diagnosis of Goldenhar Syndrome. For her, this includes a bilateral cleft lip, a bilateral cleft palate, a cleft nose, a cleft skull, cleft ears, and a cleft



eye. Maddie is blind in her right eye and deaf in her left ear. She was also born with dermoids on her eye, without an eyelid, and skin tags on her nose and ears.

During her initial hospitalization when she was born, she underwent numerous vision tests, hearing tests, an ultrasound of her bladder and kidneys, a CT scan of her brain and skull, and an echocardiogram of her heart. Other than the vision and hearing losses, all tests came back normal.

Her main issues at birth centered on feeding. She worked so hard at trying to figure out how to suck using the special bottles. But she just did not have enough energy, and feedings were not pleasant. With help from the occupational therapist from Children's, we were eventually able to get her to learn how to drink from a Pigeon baby bottle and were discharged after 15 days. She later even figured out how to suck on her middle

three fingers to soothe herself.

My leaving the hospital without Maddie was one of the toughest things I have ever done. We left in the evening and returned the following morning. It was so emotional and we were so uneasy with it that we chose not to leave her again (not the initial hospitalization, nor any of them that would follow). We lived out of luggage in our car, and we slept on cots, in chairs or on pull-out couches. Jeremy took the bus to work from the hospital. Our neighbors took care of our house, and our family took care of us, including bringing us most of our meals up to the hospital. And we took care of Maddie.

Including her initial stay, Maddie has had 15 hospitalizations, many of which included numerous surgeries during each stay. Maddie has had an eyelid reconstruction, eyelid muscle shortening, cleft lip repair, numerous ear

tube placements, skin tag removals, endoscopy, G tube placement, bronchoscopy, laryngoscopy, a dermoid on her eye shaved down, G Tube replacement, ABR exam, cleft palate repairs, cleft nose repair, conformer placement, ear lobe correction, tonsillectomy, and, most recently, a velopharyngeal flap reconstruction.

Throughout all of her doctor visits and hospitalizations, we have continued to devote ourselves to being by her side. After being away from her that one night, we vowed to do everything in our power for her to never be alone in the hospital again.

Just days after Maddie started daycare and I returned to work, Jeremy and I made the decision to fully support her care at home. He ended up quitting his full time job to be a stay-at-home daddy and work part time. Since then, he has found a full-time job and I have changed jobs, allowing us to work opposite shifts keeping daycare to a minimum.

Our lives continue to be busy with doctor appointments. In addition to her team at Gillette, she also sees her normal pediatrician, two ophthalmologists and an ocularist. In the past, she also saw a gastroenterologist. Maddie also started wearing eyeglasses when she was just six months old and is currently looking forward to getting "big girl" glasses



just in time for kindergarten. Additionally, when Maddie was a baby, we tried to get her to develop vision in her right eye by patching her left, which unfortunately did not work. We are blessed to have a fantastic local ocularist, and Maddie received her prosthetic eye just before Christmas in 2009.

When Maddie was about four months old, she started Early Intervention through our school district. Numerous teachers and personnel would come out each week to meet with us and work on things such as getting Maddie to sit up, to follow objects, speech, etc. Once Maddie turned 2 and a half, she then started attending preschool in the Deaf/Hard of Hearing classroom at the district's learning center. And when Maddie turned 4 and a half last January, she was mainstreamed into a School Readiness Preschool class. She absolutely loves going to school and riding the bus.

Maddie turns 5 in August and is very excited to start

kindergarten and attend our local elementary school with the neighborhood kids. She loves to keep busy with playing (especially with her baby doll), doing crafts, reading and singing. She also loves swimming, dancing, gymnastics, t-ball,



friends, including Children's Craniofacial Association. Everyone took care of us so we could focus on taking care of Maddie, especially when she was first-born and throughout all of her surgeries.

Even with all that she has been through, Maddie is a very smart, friendly, caring and happy little girl. She doesn't fear going to the doctor and takes everything in stride. She even enjoys going to see her favorite doctors! She is the most resilient person I know. We are extremely proud of Maddie and how far she has come.

Although our road is still long and there are many unknowns, we concentrate on taking it just one month at a time and sometimes just one day at a time. We have truly been blessed to have our little miracle in our lives. And for that, we are forever grateful.

soccer and attending Sunday school. She is a doting big sister to Hannah, who will be turning 2 in October. We continue to not only work on managing her medical journey, but we also focus on giving her the tools to take care of and stand up for herself as well.

Throughout our entire journey, we have been extremely lucky to have such great medical care. We are also completely blessed to have the support of our family and



## 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**





July 2011 – Rosemary and mommy after most recent surgery, tracheostomy and anterior cranial vault remodel

September 2009 – Rosemary gets her weight checked by the midwife.



another surgery to repair a growing skull fracture on the right side of her skull.

During our initial visit to Dallas in February 2010, we visited Annie, Char and the rest of the gang at CCA. That’s when we learned about the possibility of getting financial assistance for our next trip. This time we knew we had to get back to Dallas quickly, so thanks to CCA, within a couple of weeks we were back in Dallas for surgery in March. Annie worked with us to get a hotel close by the hospital so we could get some rest while Rosemary recovered from her surgery.

In April 2011, Rosemary had an MRI and a sleep study, and we discovered that she would need an anterior cranial vault remodel and a tracheostomy, so I contacted Annie and asked if we could get assistance again. We were approved for a car rental and a hotel stay.

Rosemary’s surgery was successful, but her tracheostomy didn’t heal as expected, so we ended up staying four days longer than expected. Originally we thought we would be going home on a Monday. Monday came, and we were told Wednesday. Wednesday then turned into Friday. CCA was able to help us extend our hotel and our car rental the entire time. Not only did this make our stay much more tolerable and manageable, it put our minds at ease, so we could focus on Rosemary’s healing.

We are so grateful to CCA and to everyone who’s donated to CCA for all that they have done to help us care for our daughter. We don’t know what we would have done without your help. Thank you.



February 2010 – Rosemary before first surgery in Dallas. Growing skull fracture on left temporal side.

## testimonial

**Rosemary Elliott** was born on Labor Day in 2009 (September 7) at our home in Midlothian, Virginia. She is our fourth child. As soon as she was born, we knew immediately that something was just not right, so we quickly worked on a plan with our midwife to seek further medical care for our daughter.

We decided to spend the night at home to give Mom and baby some time to bond. Early the next morning, I took Rosemary to the pediatrician’s office. That’s when we “fell through the rabbit hole” and began our journey to understanding life with craniofacial anomalies.

We were introduced to specialists in Dallas, Texas, and we intended on seeing them as soon as possible. However, the pressure on Rosemary’s brain was too high for her to travel, and she needed lifesaving skull/brain surgery right away.

At four-weeks-old, our daughter had a craniotomy, cranial vault remodel and Arnold Chiari malformation decompression. Three major surgeries later (Rosemary was four and a half months old at the time), we thought Rosemary was stable enough to travel, so we went to see the craniofacial experts in Dallas, 1,200 miles from home.

We really didn’t have the funds to afford such a trip, but we knew we had to go, so we went on faith that somehow God would provide the resources we needed — and He did. While we were there, the doctors were alarmed about some things that were going on with Rosemary. Our doctors at home in Richmond were not concerned about the things that our Dallas doctors brought up, so we sought a third opinion. Within a couple of days, we discovered that Rosemary urgently needed





CCA KidsKlub members, Peter and Jacob Dankelson, doing one of their favorite summertime activities, Junior Golf

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

## cca mugshot



**Send us your mugshots!**

Rick and Laurie Chiavari of Coral Springs, FL "Chef Rick" spearheads the Chocolate Festival to be held October 9th for CCA



## donors in the spotlight

This summer we want to highlight the donation of time and talent by **Tisha Blood** and her husband, **Matthew Taylor**. They created and produced the wonderful PSA for our 2009 retreat birthday celebration ([youtube.com/electrafidelis](http://youtube.com/electrafidelis)) and were again present at our 2011 retreat in June to record our families' stories and document the event for a new PSA.

Tisha and Matthew first became involved with Children's Craniofacial Association when they were introduced to our organization by **Andrea Harrah, Torey's** mom. Tisha directed and produced the award winning documentary, **Torey's Distraction**. CCA is among the organizations designated to benefit from funds raised by the film.

This September they plan to take the film on tour to a few select cities across America with CCA families serving as hosts for a theatrical screening and fundraiser. If anyone wants to get involved and host an event, please get in touch with them at [matthew@electrafidelis.com](mailto:matthew@electrafidelis.com).

To find out more about *Torey's Distraction*, please visit [toreysdistraction.com](http://toreysdistraction.com) and help spread the word.

When not involved in filmmaking and fundraising, Tisha runs **Buffalo Casting** and Matthew is a touring musician with his band **Bellini**.

Thanks again for all you do for Children's Craniofacial Association, Tisha and Matthew, our Summer 2011 Donors In The Spotlight!

Click on **"Donate"** at [ccakids.org](http://ccakids.org)

# craniofacial related sleep apnea

By George Varkarakis MD and Jeffrey A. Fearon, MD • The Craniofacial Center, Dallas Texas

**Sleep apnea** (AP-ne-ah) is a disorder in which one or more pauses in breathing, or shallow breaths, occur during sleep. These breathing pauses can last from a few seconds, up to a number of minutes, before normal breathing resumes; sometimes with a loud snort or choking sound. When sleep apnea does occur, it often causes the person to shift out of a deep sleep into a lighter sleep stage, which results in poor sleep quality. In children, sleep apnea can cause: hyperactivity, poor school performance, angry or hostile behavior, and learning and memory deficits. Sleep apnea may even possibly lower IQ scores. Some of the signs of sleep apnea in children are: unusual sleeping positions, bedwetting, and breathing through the mouth instead of the nose during the day. Sleep apnea typically produces different effects in children than it does in adults. For example, in adults severe sleep apnea often leads to weight gain, while in children it does the opposite, and may even result in a condition called “failure to thrive.” The poor growth that may occur in children with sleep apnea is thought to be the result of two things: first, it takes more work to breathe at night so calories are burned at higher rates. Second, blockages in the nose and throat make food more tasteless, and rarely even physically uncomfortable to swallow. There are two basic types of sleep apnea: obstructive sleep apnea and central sleep apnea. Obstructive apnea is the result of a blockage somewhere along the airway, and central apnea is the result of “forgetting” to take a breath.

**Obstructive sleep apnea** is the most common of the two types of sleep apnea. The airway begins at the nose and mouth, continues into the throat and then goes down the windpipe (trachea) and then finally into the lungs. With each breath (inhalation), oxygen is brought down to the lungs and carbon dioxide is then blown off (during exhalation). Obstructive sleep apnea may occur with either a narrowing or complete blockage, anywhere along this airway path. When the airway becomes partially closed, airflow gets louder and may result in snoring. If the blockage is severe enough, there may be no airflow at all. Obstructive apnea is most likely to occur in very deep sleep, when the body is most relaxed. With reduced airflow going to the lungs, the oxygen levels in the blood will decrease (and carbon dioxide levels will increase) sending a signal to the brain to wake enough to open the airway. Some

of the more common causes for obstructive sleep apnea include enlarged tonsils and adenoids, nasal blockages (like a deviated septum, or a high arched palate), a longer soft palate or bigger uvula, an enlarged tongue (from benign growths, or over-growths like in Beckwith-Wiedemann syndrome), a small upper jaw (which can occur with syndromic craniosynostosis), a smaller lower jaw (which can occur with Robin sequence, hemifacial microsomia, and Treacher Collins), and airway blockages from growths (lymphangiomas, hemangiomas, etc.).

**Central sleep apnea** is less common than obstructive sleep apnea. This type of apnea occurs when the area of the brain that controls breathing does not send the correct signals to the breathing muscles. As a result, the body makes no effort to breathe until the oxygen level gets low enough that the body begins to wake up a little and starts breathing again. As with obstructive sleep apnea, central sleep apnea can result in higher blood levels of carbon dioxide, which can lead to slight brain swelling, raising intracranial pressure. Because there is no effort made to breathe, central sleep apnea does not produce snoring, and may go undetected. The most common cause of central sleep apnea in children with a craniofacial issue is a condition called “cerebellar tonsillar herniation (or a “Chiari Malformation”), which occurs when part of the brain pushes against the upper spinal cord. This condition can occur in some types of craniosynostosis (syndromic, or lambdoid) and may be either be present at birth, or develop over time.

**Diagnosing sleep apnea** usually requires a test called a sleep study (also called “polysomnography”). Just because a parent hears snoring, it does not necessarily mean that their child has sleep apnea. However, a child can sleep very quietly all night long; yet, have significant central sleep apnea. A sleep test is able to diagnose both obstructive and central sleep apnea. The sleep study results are often expressed by an apnea-hypopnea index, which is a measure of how many times breathing is interrupted. An apnea-hypopnea index greater than 1.5, or a minimum oxygen saturation level (a measure of how much oxygen is in the blood) of less than 92 percent, is generally considered abnormal in children.



**The treatment of sleep apnea** depends upon what is causing it, and how severe the apnea actually is. When obstructive sleep apnea is diagnosed, sometimes treatment can be as simple as prescribing medication. There are a number of drugs that can help to open up a partially blocked airway in order to improve airflow. If medication cannot take care of the blockage, a breathing device such as a CPAP, or BiPAP, mask may be recommended. These devices, which are worn at night, help to push air into the lungs with each breath. If children will not tolerate these masks, at the Craniofacial Center we suggest that parents first let their child fall asleep, and then put on the mask about 40 minutes later. Nevertheless, many children will still not tolerate a CPAP mask, making surgery the only solution. Various operations can be performed depending upon the specific area that is causing the obstruction,

such as: straightening the nasal septum, opening the nasal passages, reducing the tongue, performing a lip-tongue adhesion (for Robin sequence), removing the tonsils and adenoids, removing tumors blocking the airway, advancing the upper or lower jaws (with our without distraction devices), and finally performing a tracheostomy. Deciding which operation is the smallest, and most likely to solve the problem, is not always easy and may require the experienced judgment of a craniofacial surgeon. When central sleep apnea has been diagnosed, a brain scan such as an MRI is typically required to rule out cerebellar tonsillar herniation from a Chiari malformation. If a Chiari is present, then there are a number of different possible surgical treatments that are able to reduce the pressure on the brain stem. If no Chiari is present, medication can be used to help reduce the number of central apneas.

## Fresh Start

Surgical Gifts



**A Life Limiting Deformity  A LIFE WITH UNLIMITED POSSIBILITIES**  
*Fresh Start transforms the lives of children through the gift of reconstructive surgery.*

 [www.freshstart.org](http://www.freshstart.org) 

2011 Palomar Airport Road, Suite 206 • Carlsbad, CA 92011 • 888.551.1003

## 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](http://www.ccakidsblog.org)

*Find us on Facebook – CCA Kids Blog*



Jerry Lynn with her mom,  
Joan Wattenbarger

## jewelry sales at retreat

CCA's special jewelry offerings were again available during our family retreat in June.

This is always a great deal for families because they save on the shipping and can take, wear and enjoy their purchases right away! Our thanks go to **Jerry Lynn Miller** for helping sell (and for buying a lot herself) throughout the three-day period. Sales of crystal bracelets, rubber wristbands, steel pendants, and glass hearts topped out at **\$543!** If you missed out, you can still get it all... just give us a call at the CCA office!



## cd sales for cca and more

CCA Adult, **John Moulton** dedicated his talents as a gifted organist to producing an instrumental music CD for sale to benefit Children's Craniofacial Association. His sister, **Mary Zimmerman** started up the sales at the family retreat, and at just \$12 per CD they were over **\$125** by the time we left Louisville! He even gave us an autographed copy to send to fellow CCA kids supporter, Cher. Mary has also been busy throughout the year speaking at clubs and groups about Children's Craniofacial Association, spreading awareness and moving attendees to donate. Most recently she presented CCA with a **\$50** check from the **Maine chapter of the Alpha Delta Kappa Epsilon teacher's sorority**. Thank you Mary & John!

## 2012 annual cher's family retreat announced

**June 28-July 1 in Tempe, AZ**

For more information, please contact Annie Reeves,  
[ARees@ccakids.com](mailto:ARees@ccakids.com)

We hope to see you there!





## road scholar transport takes cca's message on the road!

How does it feel when a larger-than-life Children's Craniofacial Association billboard rolls into town? Just ask the 350+ persons affected by craniofacial differences who attended the 2011 Cher's Family Retreat in Louisville, KY. "When we saw this huge CCA logo pull into the Galt House Hotel parking area, each and every one of us felt ownership," said CCA Executive Director **Char Smith**.

**Jim Barrett**, owner of **Road Scholar Transport**, has taken freight delivery to a whole new level. He has decked out more than 20 of his trucks with charity logos and is spreading awareness of the charities to millions of people, one mile at a time. In fact, Jim's tagline is "**Delivering Freight to Thousands and Awareness to Millions.**"

CCA's board, staff and the families we serve wish to thank Jim Barrett for his dream to spread awareness of many worthy causes. Thanks also to all of the companies who participate in the program by using Road Scholar to haul their freight. And thank you to drivers **Jason Burton** and **Tambra Dell**, who made sure CCA's truck made it to Louisville on time for the retreat, as well as to the entire Road Scholar team. Collectively, you are making a huge impact on thousands of lives by spreading awareness across the country.

Help keep the CCA truck on the road. Visit [roadscholar.com](http://roadscholar.com) for your shipping needs.

### More Fundraising News



Carol Andrews (left) with Christina, front, and her grandmother, Katy Gras, when they attended CCA's Family Retreat in June

**Carol Andrews** of Greenwood, Arkansas, mom of CCA kid, **Christina**, held a fundraiser in June at her local **Simple Simon's Pizza** and brought in over **\$100** in just a few hours from diners who supported the effort. Thanks to Carol and Simple Simon's Manager, **Terri** for helping all CCA kids!



CA Mom, **Lisa Bock**, dedicated her commissions from her "**Thirty One**" business ([www.mythirtyone.com/lisabock](http://www.mythirtyone.com/lisabock)) to CCA Kids this summer and continues to support CCA as one of the "Moms" in the upcoming **Texas Moms 5K** event in October where some of her wares will be donated as well. Thanks Lisa!



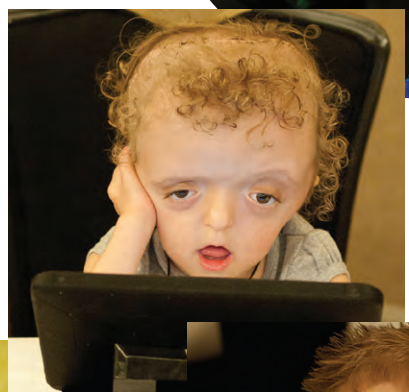
# 3 cheers

for volunteers!

Thank you, Melissa Giltz and Central KY Photographers!

CCA is so fortunate to have so many wonderful families! This year, **Melissa Giltz** and her family joined us in Kentucky for their first-ever retreat. Melissa reached out to CCA and asked if it would be ok if some of her photography club members from **The Central KY Photographers** came out to take pictures during our retreat. Not only did they take wonderful pictures and put them on a CD for us and other attendees, but they also put together an amazing DVD for CCA.

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





# donors, january 1 – june 30, 2011\*

## Gifts from Individuals (\$100 +)

Mario Adamo  
Anonymous  
Carol Jean Anthony  
Jeffrey M. Brown  
Beverly Butera  
Larry Carpenter  
Robin Chapurinov  
Madeleine Cherry  
Roger S. Chin DDS  
Judith Clonan  
Richard Cullen  
George Dale, Sr.  
Dede & Darin Dankelson  
Casey Deakins  
Robert DeVille  
Maura Dewan  
Mike & Maria Estrada  
Vincente Farina  
Alan & Jennifer Farmer  
Deirdre Farrell  
Frances Fisher  
Heath Fisher  
Fred & Judi Freeman  
Roland & Dorothy Freeman  
Ruby Gorman  
Sarah Hall  
Linda Hanes  
Rosemary Hanrahan  
Clayton & Kathy Huck  
Holly M. Jenkins  
Russell & Carol Jenna  
Kathryn J. Kitchens  
Esther Krieger  
Roger & Carolyn Lamb  
Samuel & Kathleen Lowery  
S.F. Luhrs  
Molly & Robert Lytle  
Kimberly Martin  
Deborah Mecklenburg  
Ron Micetic  
E. J. Morrissey  
Robert Muller  
Claudia Airaudi Myall  
Joseph & Gloria Pike  
Paul R. Pokladnik  
Andrew & Andrea Potash  
Ann Ranfranz  
Marie Rourke  
Nancy Rumore  
Ann Schafer  
Roberta & Robert Schini, Jr.  
Barry Scurren  
Fred & Rose Seitz  
Michael Slusher  
Dean Spanos  
Ray & Ellen Stevenson  
Lisa Uken  
Dwight Vaughn  
Leona Vitalo  
Priscilla Voss  
Marcia Weber  
Jon Welles  
Eva & Steven Willms  
Kenneth Wilson  
David & Nancy Winters

## CCA Extended Family (\$500 +)

Veronique Boyd  
Joseph Broderick  
Martha Brown  
Diana Critchlaw  
Ann & Don Lucas

## CCA Sponsor (\$1,000 +)

Krishan K. Goel, MD, Inc. for Henry's March  
Karen Condino, for Baseowl, 2011  
John & Sheryl Paul  
Robert Reader  
Marty & Mike Willson

## CCA Benefactor (\$5,000 +)

Bill Mecklenburg & Christine Condino-Mecklenburg

## CCA Guardian (\$10,000 +)

## Memorials / In-Honor Gifts

Mike & Susan Akin, in honor of Wendelyn Osborne  
Dr. & Mrs. Chester Amedia, in memory of Katherina Seitz  
Anonymous, in honor of John Gorman  
Anonymous, in honor of Josie Knight & Flynn Family  
Anonymous, in memory of Rick Dornier  
Britt & Colleen Balkcom, in honor of Solomon Glenn's 10th birthday  
Laura Beeler, in honor of Nova Cox  
Michael Bock Family, in memory of Rick Dornier  
Colin Boylem, in honor of Avery Lytle  
Jeffrey & Denise Brown, in honor of the marriage of Justin Shackelford  
Larry Carpenter, in honor of Cher  
Larry Carpenter, in honor of Cher's birthday  
Brenda Catalanatto, in memory of Rick Dornier  
Timothy Cox, in memory of Rick Dornier  
Harvey & Venita Crowson, in honor of Megan Cronin  
Richard Cullen, in memory of William Mecklenburg  
Robert DeVille, in memory of William Mecklenburg  
Maura Dewan, in memory of William Mecklenburg  
G. L. Estrada, in honor of Tony's birthday  
Mike & Marie Estrada, in honor of Tony's birthday  
Brian Evans, in honor of Erica Mossholder  
Diana Feuer, in honor of Lynn Keiner  
Heath Fisher, in memory of William Mecklenburg  
Roland & Dorothy Freeman, in honor of Robbie Gorecki

Dawn Garrity, in memory of Rick Dornier  
Brandon Gibson, in honor of Solomon Glenn  
T.J. Jr. & Mary Lib Burgin Guercio, in memory of Rick Dornier & Mrs. Odella Arboneaux  
Jackie Halpin-Osteen, in honor of John Gorman  
Rosemary Hanrahan, in honor of Kathleen Hanrahan  
Alfred Harf, in honor of Chase Ingram  
Hargrove Oil Company, LLC, in memory of Odella Arboneaux  
Jim & Arleen Heirly, in memory of Dolores Carroll  
Jim & Arleen Heirly, in memory of Connie Fedorski  
Jane Hoffman, in memory of William Mecklenburg  
Carey Hough, in honor of Nova Cox  
IMCO Carbide Tool, Inc., in honor of Matthew Osburn  
Daniel Ingram, in honor of Chase Ingram  
Jennifer Jaffe, in honor of Jennifer & Adam Kellogg  
Jenny Jett, in honor of Elaine Gumbiner  
Yukiko Johnson, in honor of Henry Johnson  
Kathryn J. Kitchens, in honor of granddaughter, Brisa Dougan  
Paul Kyle, in memory of Rick Dornier  
Lisa Latona, in memory of Rick Dornier  
Mika Lawson, in memory of Rick Dornier  
Duane Long, in honor of Casey Deakins  
Kimberly Martin, in memory of Ellery Walker  
Jennifer Miller, in memory of Odella Arboneaux  
Anne Milneck, in memory of Rick Dornier  
Cynthia Morris, in memory of Rick Dornier  
Robert Muller, in memory of Stephen John Krasusky  
Paula Naquin, in memory of Rick Dornier  
Jeffrey Nicholson, in memory of Rick Dornier  
Andrew & Andrea Potash, in memory of William Mecklenburg  
Joan Poston, in memory of Odella Arboneaux  
Christen M. Price Memorial Fund of the Martin County Community Foundation, in honor of Dr. Jeffrey Fearon  
Robert Raika, in memory of William Mecklenburg  
Robert Reader, in memory of William Mecklenburg  
The Redwoods Group, in memory of William Mecklenburg  
J.C. Rogillio, in memory of Odella Arboneaux  
Marie Rourke, in memory of Rick Dornier  
Nancy Rumore, in memory of Rick Dornier  
Ann Schafer, in loving memory of William Mecklenburg  
Fred & Rose Seitz, in honor of Frederick Seitz's high school graduation  
Kimberly Shepard, in honor of Juliana Wetmore  
Solange Skyer, in memory of Rick Skyer, Jr.

Charlene Smith, in honor of Sharon Allbright's birthday  
Smith Middle School of Fort Hood, in memory of Stephen Krasusky  
Katherine Snyder, in memory of Odella Arboneaux  
Dean Spanos, in honor of Paige Spanos  
Jasmine Tangcay, in honor of Cher for Christmas  
Anne Tibbals, in honor of Amy and Evan Beale  
Neva Tomlinson, in memory Harry Surratt  
Lisa Uken, in honor of Sophia Weaver  
Priscilla Voss, in memory of William Mecklenburg  
Marty & Mike Willson, in honor of Avery Lytle  
Susan Wilson, in honor of Josie Knight  
Thompson, Coe, Cousins & Irons, LLP, in memory of Stephen John Krasusky  
XCD Management Services Management & Staff, in memory of Katherina Seitz

XCD Management Services

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

BP Corporation of North America, Inc. (for Hartley Company fundraising effort)  
E.C. Styberg Foundation, Inc.  
The Foot Fetish Fraternity  
Honda Financial Services  
Inshallah Trust  
KLS Martin L.P. (Dallas holiday party sponsorship)  
Christen M. Price Memorial Fund of the Martin County Community Foundation  
T.A. Robinson Asphalt Paving (Nick Wiese fundraising effort)  
The Rosewood Foundation  
Vivo Brothers

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

Cher Charitable Foundation  
Elizabeth Toon Charities  
Foster Poultry Farms for Henry's March  
Stemmons Foundation  
Torey's Distraction Fund of The Dallas Foundation

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

## Fundraising Events & Other Efforts

### Up to \$1,000

Be Brody's Angel / Brody Lucas' Family Fundraising Effort  
Cash can / placed by Freeman Insurance, Tucson, AZ  
CD Sales / John Moulton  
Chocolate Festival / Chef Rick Chiavari  
Club Italiano, Westchester Community College / Lindsay Bordonaro  
Friends of Freddie / Frederick Seitz Fundraising Effort  
Lewis Plez IV CCA Wristband Sales Fundraising Effort / Tyeisha Jefferies  
Simple Simon's Pizza / Carol Andrews

### \$1,000-\$5,000

Rick's Raffle / Raffle Ticket Sales / Established by Ann & Doug Burgin

### \$5,000 or more

Nick Wiese fundraising effort

### \$10,000 or more

\$20,000 or more  
Henry's March / Rachel, TJ, Lauryn & Henry Johnson

### \$30,000 or more

## Corporate/ Foundation Gifts

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

American Express Charitable Fund (employee giving)  
Bank of America (United Way Campaign employee giving)  
Chubb & Son, Division of Federal Insurance Company (matched gift of Jeffrey M. Brown)  
Combined Federal Campaign / Local Creative Growth Counseling & Coaching  
Frugal Flower (purchase percentage incentives)  
Hargrove Oil Company, LLC  
IBM Employee Services Center (employee giving)  
IMCO Carbide Tool, Inc.  
Maine Alpha Delta Kappa Epsilon Chapter  
Metal Parts & Equipment Company  
Microsoft Employee Giving Matching Gifts Program  
MissionFish (Ebay, directed donations thru percentages of sales)  
Northrup Grumman Employee Giving  
Opinions for Good (OP4G) (survey incentives)  
Pfizer (United Way Campaign employee giving)  
Prudential Foundation (matched gift of Diana Critchlaw)  
The Redwoods Group  
Safeway, Inc. (purchases percentage incentives)  
Sarah Hall Productions  
Smith Middle School Collection by Chris Krasusky  
Thompson, Coe, Cousins & Irons, LLP  
Truist for Qwest (employee giving)  
UPS Foundation, Inc.  
United Way of Southeastern Pennsylvania  
United Way of Tarrant County (Bell Helicopter Employee Giving)  
United Way of Tucson & Southern Arizona (donor-directed donations)

Listed are monetary donations of \$100 or more through 2nd quarter, 2011.

We are extremely grateful for these and all other fees, purchases, fundraisers and in-kind donations not individually recorded here. (Note: For space consideration, 2011 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 quarterly 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:  
Paula Guzzo, Chair, Evansville, IN  
George Dale, Corning, NY  
Tony Davis, DMD, Tuscaloosa, AL  
Dede Dankelson, Highland, MI  
Tate Gorman, Dallas, TX  
Donna Gossett, Cullman, AL  
Janis Macut, Harrisburg, PA  
Bill Mecklenburg, Mission Viejo, CA  
Erica Mossholder, Tuscaloosa, AL  
Robin Williamson, Carrollton, TX  
Stephen Wright, San Francisco, CA

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@cckids.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.

## chance raffle

family night at this year's retreat in June was once again  
abuzz with excitement as everyone took chances to  
win their favorite items. Tables were filled with wonderful  
baskets and wrappings of goodies brought by families from  
their hometowns for the annual family fundraiser. This  
year ticket sales of **\$2,225** hit a new record! Thank you to  
special helper and "future development director," 9-year-  
old **Antasia Hart** and to all who participated by bringing  
items to raffle, purchased or helped sell chances to win.  
The funds from this effort will help defray some of the  
retreat expenses. Special thanks to

**Erica and Jacob Mossholder**  
who brought some extra  
incentive giveaways from  
their business, [www.  
promotes.me](http://www.promotes.me), for  
ticket purchases and  
consolation prizes!  
Let's see if we can  
top it all next year!



Erica and Jacob Mossholder of  
[www.promotes.me](http://www.promotes.me)



Dennis Gonzales and Jayden  
Parson with their "Man  
Bucket" raffle winnings



Bill, Christine and Morgan  
Mecklenberg with the much-  
coveted Hershey basket