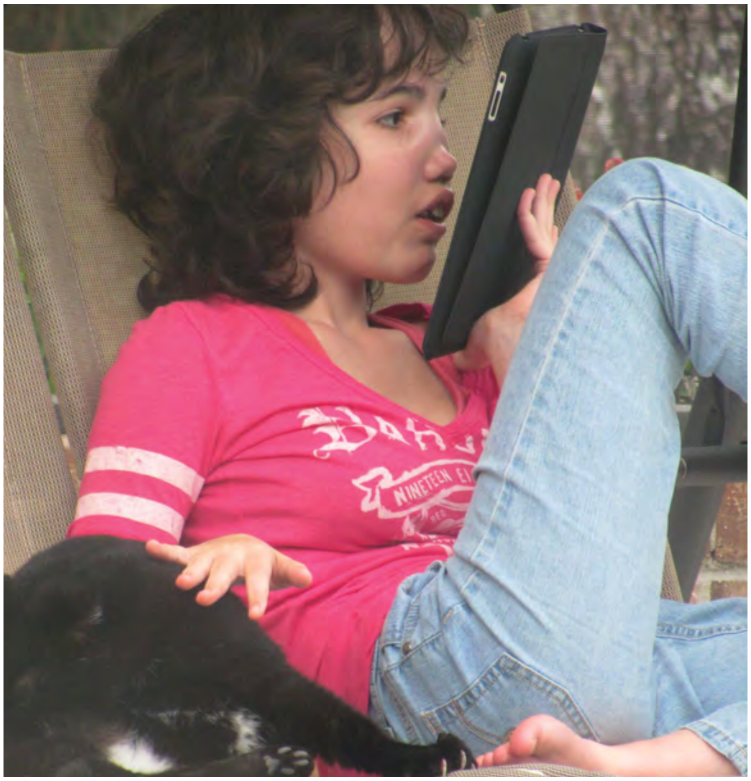
ccanetwork

newsletter of the children's craniofacial association
Cher—national spokesperson
2012: Issue 3

inside



abby's story

By Debbie Kantor

Born in Philadelphia in the fall of 1999, **Abby Kantor** was ushered in on the eve of the Jewish New Year! Anticipating a holiday in the hospital, we had no idea what our new life would involve. Upon birth, Abby had some difficulty nursing and appeared to have upper airway congestion, but otherwise was discharged in two days, with a follow-up appointment a few days later. Though I had a vague feeling that something was different—her eyes did not squint equally, and her lips looked beautiful but different—doctors did not notice anything irregular.

By four weeks old, Abby continued with congestion, and she appeared to have one-sided facial paralysis, which became full facial paralysis within the next week. She was admitted to the hospital for a week of testing and was discharged with a vague diagnosis of "bone abnormality,

see **abby**, page 14

message from the development director

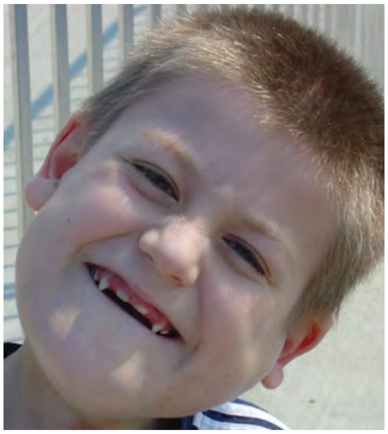
Most charities publish a donor list that includes dedications; the memorials and gifts made in honor of someone. There were only a few such gift acknowledgements on CCA's "Donor List" until **Arleen** and **Jim Heirty** stepped in to help. They got the ball rolling—and it snowballed.

Over the years, I talked to the two of them and learned the story of how they became involved with CCA. Their son, Patrick, was born with a

see **development director**, page 7

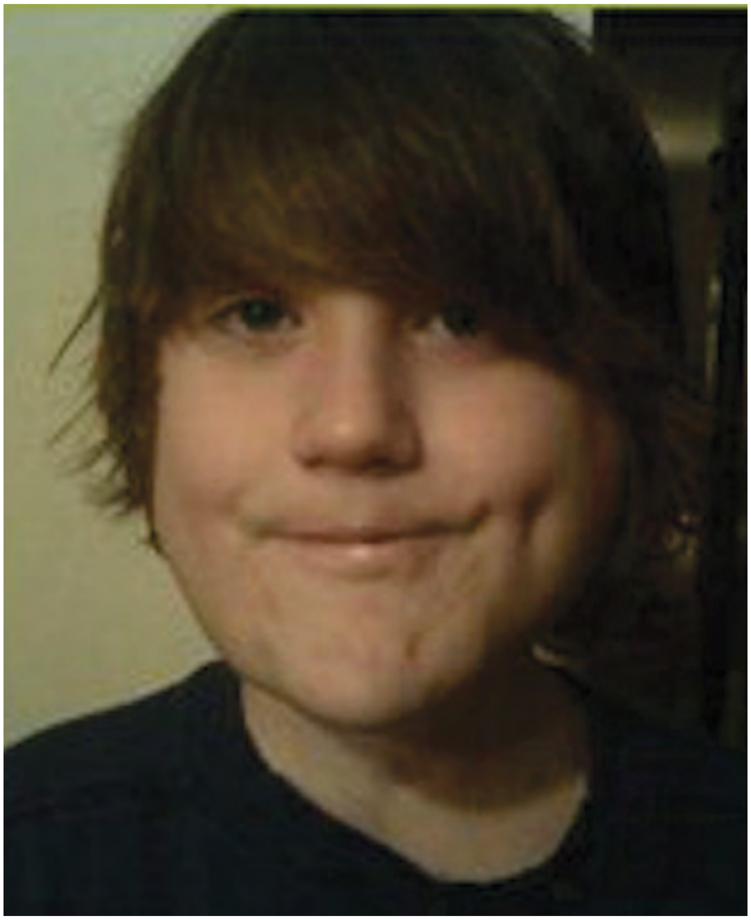
Newborn

3 years old



5 years old

7 years old



10 years old

meet trevor cunningham

Trevor Cunningham is 11 (almost 12) years old and is from Fort Wayne, Indiana. He's in sixth grade, which is considered middle school where he lives. He has a younger brother, eight-year-old **Carl**. Trevor is an A-student and is in advanced classes for both reading and math. His favorite subject, however, is social studies, where he likes the way his teacher brings each topic to life. Trevor enjoyed playing football this season and, at the time of his interview, was looking forward to trying out for his basketball team.

He's an artist, who mainly likes to draw comics. In fact, he has about three notebooks filled with his drawings. Trevor also loves to skateboard when he has the opportunity. The Discovery Channel and the History Channel are his go-to TV channels, and his favorite show is *MythBusters*.

He's even co-founded a Facebook group for kids, tweens and teens, who may be going through similar situations. It's a place online especially for them called LM Families: Second Generation. Check it out.

Trevor has lymphangiomas/cystic hygroma, where fluid-filled cysts grow in the floor of his mouth, tongue area and chin. He spent his first three months of his life at the hospital, and he has undergone dozens of surgeries and procedures, with many more to go. Still, even after everything he's gone through, Trevor's optimistic nature shines through. His philosophy is that "it'll be ok in the end" and that "it'll be worth going through."

ccakid

ccateen

meet lilli martin

hi, my name is **Lilli**, and I'm 13 years old. I was born with coronal craniosynostosis. I had two surgeries on the bones in my head before I was two years old, but I don't really remember that. What I do remember is going to the doctor, a lot, my whole life. Other kids don't really understand that because they only go once a year or when they are sick.

I am a regular kid. I love to sing and dance. I am in ballet and pointe. I also play the saxophone and viola. I am a good student. This year I am in honors English. I am also a Cadette Girl Scout; this is my eighth year in Girl Scouts. I love art, and drawing is one of my favorite pastimes.

I also love to read fiction. I have read the entire *Harry Potter* series and the *Hunger Games* series. Of course, I also enjoy watching the movies that go along with the books, but the books are always so much better than the movies. I like reading these stories, and I get so attached to the characters. One day I would love to write a fiction novel and have it published.

I live with my mom, dad and little brother, **Dante**. I also have a big brother, **Andrew**, who is 23. He is a really funny guy and I enjoy spending time with him. I have a cat named Wesa, but I really want a narwhal for a pet (but my parents say they cannot live in captivity).

It can be hard to live in a world that puts so much emphasis on being perfect. At 13, everyone wants to be just like everyone else, and it is hard to be a kid with a craniofacial difference. I get strength from knowing other kids who are like me. My parents also tell me I can do anything.

meet dante martin

My name is **Dante Martin**. I am 9 years old and live with my parents and sister **Lilli**. My sister, Lilli, is older than I am. She bosses me around a lot, but I know she loves me. She is a really great sister. Lilli was born with something I cannot pronounce, but I don't see her as any different than anyone else.

I love playing video games, and my favorite is Minecraft. My favorite TV show is *Star Wars: The Clone Wars*. I am a Webelo Cub Scout. This is my fourth year in Cub Scouts, and my favorite things about Scouts are camping and building things with real tools.

I am in the fourth grade, and really like math and reading. I am currently reading the *Harry Potter* book series, and I just started the fourth book. When I grow up I would like to read books to homeless people. I think that would be a nice thing to do. Sometimes my sister, Lilli, and I read books to people at the nursing home. They really like it when we read to them.

ccasupersib

hartley golf outing

By Nancy Michael

The 4th annual **Hartley Company** golf outing for CCA was August 7th. The event, held in honor of local Cambridge CCA kid, **Raegan Daugherty**, was a huge success, raising a total of **$29,623** for CCA. We also raised $2,259 to give directly to Raegan's family to cover medical expenses.

There were about 30 volunteers at the event, who all wore T-shirts purchased from CCA and helped with more than 94 golfers. In addition, every person attending got a CCA "Beyond the Face is a Heart" wristband to help spread awareness. Before the golfing event even began we started a fundraising raffle. **Hunt Brothers Pizza** donated the top prize of two NASCAR "Hot Passes," which created a lot of sales.

The golfers enjoyed beautiful blue skies throughout the event. We held a 50/50 drawing, and the winners kindheartedly **donated back** their winnings to CCA! Other prizes were awarded to golfers at the games we held at special holes.

After golfing, the group moved indoors to enjoy a wonderful dinner. Raegan's family joined us to say a few words regarding CCA and their daughter. We held a Chinese auction during dinner and continued the raffle sales, creating a lot of activity. **All of the gifts for the auction were donated by our suppliers and local businesses.** The auction was great fun, and music, food and support for this cause were flowing. Thanks again to all who supported the event, CCA and our own Raegan Daugherty!

thank you for choosing kind!

How wonderful that the "Choose Kind" message from **R.J. Palacio's book**, ***Wonder***, is being embraced in classrooms around the country! Teaching students to be accepting of differences and choosing to act kindly toward others is a powerful lesson that will stay with these kids throughout their lives. Having them connect with real-life people who have facial differences solidifies that lesson even more.

If you have been following our blogs about *Wonder*, then you know that CCA began selling the book just a few months ago. **The Power of First Impressions** announced our endorsement of the book. We then participated in the *#WonderSchools Blog Tour*, by posting **Every Kid Needs a Hero**. A 5th grade class in Baltimore saw the blog and, after reading *Wonder*, acted on its message by choosing to give a real-life Auggie his first standing ovation. What a wonderful way of embracing the book's message to "Choose Kind." Here's the **Standing Ovation for Peter** video that **Reilly Posey's 5th graders** created.

As a real-life Auggie's Mom, I can't recall ever being so touched as I was when watching this video. I have always said that our CCA kids leave a powerful impression on everyone. As their parents, I believe it is up to us to make sure that impression is overwhelmingly positive. After drying my eyes, I told Peter that he should send a video message back to Reilly Posey's class thanking them and sharing his opinion of the book. What ensued was a great evening where my two boys wrote a skit, rehearsed, and eventually produced **Peter's Precept Video**. What a fun family project. We had a lot of laughs together that night—lots of ear humor!

Peter's Precept video has now been viewed over 500 times on YouTube, and I'm proud to say that my family is doing our part to spread CCA's message that "Beyond the Face is a Heart," while also promoting Ms. Palacio's campaign to "Choose Kind." But, it doesn't end there...

This morning, I was blown away to read the following email from **Deb Tyo** who teaches at Versailles Middle School in Ohio. "Dede—Please tell Peter how much he has inspired us. Because of Peter this is happening... **To Our CCA Friends**. I

believe the entire middle school from grades 6-7 shared the book as a school-wide read. How amazing is that?! And, how about that video? I'm still choked up and overwhelmed with gratitude. This book and these teachers are improving the lives for CCA families everywhere—the affected kids, their siblings, and their parents.

CCA parents have faced sadness, fear, grief, and anger following the birth of their child. They have spent anxious hours worrying about teasing and bullying at school. And, they have endured many agonizing days and nights sleeping in hospitals, waiting in emergency rooms, and driving to/from specialty clinics and therapy sessions. For all this, our CCA family is finally receiving some gracious acknowledgements of acceptance. Let's return the kindness by expressing our appreciation for those who are embracing the "Choose Kind" movement. Make your pledge now at www.choosekind.tumblr.com.

CCA Families created the following video at the "2012 Cher's Family Retreat" as a thank you to all of those who support and embrace our vision of a world where all people are accepted for who they are, not how they look. I can't imagine a more deserving audience for it's debut.

Thank You from CCA!

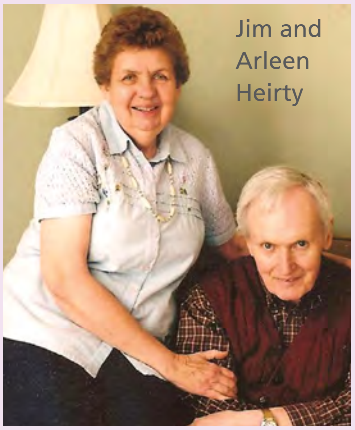
Finally, my standing ovation goes out to the following for their amazing acts of kindness...

- R.J. Palacio for writing *Wonder*
- **Random House** for creating the Choose Kind website
- **@DavidAEtkin**, the teacher from Buffalo who started #WONDERSchools
- **Reilly Posey** (@PolkaDotOwlBlog) & her 5th Graders in Baltimore for their Wonder Blog & Peter's Standing Ovation
- My two amazing boys **Peter & Jacob** for promoting the Choose Kind campaign and producing Peter's Precept
- **Deb Tyo** (@ChocolateAir) & **Versailles Middle School** for their Wonder Blog and CCA Standing Ovation
- **Sherry Gick** (@LibraryFanatic), a school librarian from Indiana, for her assistance in launching #WONDERSchools

Dede Dankelson

Dede is the Board Chair for CCA and proud Mom of CCA Kid Peter (age 12) & CCA Sib Jacob (age 7)

development director, from page 1


Jim and Arleen Heirty

craniofacial condition. They read the story that our own **Stephen Wright** had published in *Parade* magazine way back in 1992. The end of the article included contact information for CCA.

It was then they connected themselves with CCA and became lifelong supporters. Whenever we talked they even took an interest in my own CCA kid, Robbie. I wanted to feature them time and again in our "Donors in the Spotlight" section of the newsletter, but like so many of you, they wanted no special recognition.

While preparing for our summer newsletter issue, which was due out in August, I asked Arleen and Jim once again if we could feature them. I didn't hear back from them until I received the following note from Arleen in mid-August:

Jill, My husband of 52 years died in July. He was diagnosed with Parkinson's at age 58 and died two weeks short of his 75th birthday. During our marriage, we traveled to almost every state, including Hawaii and Alaska. Jim was a Boy Scout leader for over 30 years and we square danced for over 25. He had a busy life and I have lots of good memories. Give your son a hug from me! — A.

Our hearts sank when we read this note. However, Arleen has permitted me to tell you about the difference she and **John James "Jim" Heirty** have made for Children's Craniofacial Association. In fact their names have appeared in each issue of *CCA Network* in the donor list, proof of their long-lasting commitment. They are a wonderful couple who've honored the memory of many, many friends by helping our CCA kids. I honor Jim's memory by telling you their story here.

Jill Patterson

CCA Development Director

PICNIC

craniofacial acceptance month

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

Many of our CCA families were able to get their local newspapers to feature them, and some were even featured on their local news stations. Radio stations also ran PSA's throughout the month of September. We mailed more than 100 Craniofacial Acceptance Month packets to 30 states, Australia, Canada, England and Spain!

And, for the fifth year, CCA held National Picnic Day in September as part of Craniofacial Acceptance Month. CCA families across the nation held picnics in Arizona, Arkansas, Australia, Colorado, Hawaii, Indiana, Kansas, Minnesota, Nebraska, Ohio, Tennessee, Texas (which held two picnics), Utah, Virginia and Wisconsin. This is the best turnout we've ever had.

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

ARKANSAS

ARIZONA

ARIZONA

ARIZONA

ARIZONA

ARIZONA


DALLAS, TEXAS


DALLAS, TEXAS


DALLAS, TEXAS


DALLAS, TEXAS


DALLAS, TEXAS


HAWAII


HAWAII

see **picnics**, page 10

picnics, from page 9


INDIANA


VIRGINIA


VIRGINIA

INDIANA


VIRGINIA


VIRGINIA


VIRGINIA


WACO, TEXAS


WACO, TEXAS


WACO, TEXAS


WACO, TEXAS


OHIO


WISCONSIN


WISCONSIN


OHIO


OHIO

donors in the spotlight

This issue we highlight the **Bono family**—**Justin**, **Debbie**, **Molly** and **Sadie**—who have supported CCA in many ways since Sadie came along. We've asked them to tell you their story.

When Sadie was born and we received her diagnosis, the first piece of information handed to us was CCA printed educational material on Pfieffer syndrome. It was so nice to have a concise description of what was ahead for our family before we were inundated with material found through an Internet search.

Within days we contacted CCA to connect with other families who have a child with Pfieffer syndrome. Whether we are making extremely important medical decisions or talking about psychosocial issues, to this day these parents offer abundant support for our family. A couple of them are on speed dial the second we leave a doctor's appointment or just to talk with along our journey.

Within three months of Sadie's birth, we attended a weekend retreat hosted by CCA that just happened to be near our home in Dallas. We heard medical professionals across many disciplines talk about the surgeries Sadie would have in her future. She was just an infant with a new trach facing her first cranial vault the next month. We met families from all over the country who had been through the scary and uneasy first few months of life that we were living at that moment. Being able to discuss these impending challenges with parents who had walked in our shoes was invaluable.

Fast forward three years. Sadie has been surgery-free for two years offering her the amazing chance to grow and develop beyond our wildest dreams. Now we get the opportunity to give back, celebrate and enjoy the things CCA offers families like ours.

We are blessed beyond belief to have a community that embraces our family and wants to spread the word about craniofacial differences. We immediately think of CCA as the beneficiary of these efforts.

Our family has participated as a sponsor of the **Links of Love** golf tournament for the past four years, an event Sadie loves. Our high school baseball team recently hosted **Sadie's Night** at the ballpark, raising **more than $1,600** for CCA. Kids from our older daughter, Molly's, elementary school want to help too. They organized a walk-a-thon during PE classes one day in order to raise awareness and funds.

We feel so fortunate to have the support of our community and the families and staff of CCA. The journey we are on with Sadie is never easy, but we are inspired every day by her strength and by the kindness we experience from those around us.

A big thank you to the Bono family, this issue's Donors in the Spotlight!

how to raise funds for cca

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

- **www.goodsearch.com** (Powered by Yahoo) Enter Children's Craniofacial Association as your beneficiary charity. (You only have to do this the first time. You may add others if you wish.) CCA will receive up to a penny each time someone uses the GoodSearch search engine.
- **GoodShop.com** 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!

abby, from page 1

non-specified." My then-husband **Jonathan** was a medical student at the time, and I was a newly graduated nurse practitioner just beginning my first teaching position. Overwhelmed by the joy of our first child, but saddened to learn of her bone abnormality, we had the responsibility of finding the appropriate medical care, while also bonding with our beautiful daughter. Jonathan and I both were struggling financially, working multiple part-time jobs, and we had no family nearby.

The path to diagnosis was scary and unknown, and we were originally told she would need a bone marrow transplant to improve survival. A donor was found, though Abby was later diagnosed with an exceptionally rare condition, craniometaphyseal dysplasia, for which there was no real treatment. Her skull would develop more bone than typical and press on her cranial nerves, causing deafness, blindness, a facial difference, and more.

I later discovered that the boy in Cher's film, *Mask*, had craniodiaphyseal dysplasia, the sister condition. Years went by before I was willing to watch the movie, knowing the outcome was tragic. I tried instead to focus on the present, and have the early intervention she needed (speech, OT, PT, vision, hearing therapy…) while also doing typical activities like taking her to the zoo, playground, traveling and spending time with family. Many of my friends had children at the time, and we all played, but Abby and I were clearly different.

By age six months, Abby was diagnosed as hearing impaired for which she wore hearing aids. By the time she was one year old, we realized she would likely become blind. As the craniofacial condition appeared more reconstructive than medical, it was not our focus. We deliberated whether to have risky skull surgery to salvage her vision, and opted not to due to the risk of complications. The blindness and her progressive condition were challenging, and she had continued medical appointments, and attended various schools for the visually impaired. For socialization, she also attended typical preschools and still today has a wonderful friend from when she was four years old.

During this time, her adorable brother, Elliot, was born in 2003, and Abby was thrilled to have a best friend. The friendship today is wonderful, as they respect and love each other. As her sibling, Elliot is extra compassionate and helpful, though they still have a very typical sister-brother teasing, playful friendship.

In 2005, our family chased warm weather and found a school for the blind in north Florida. Despite Abby's challenges, she is a social, intelligent, and vocal girl. We transferred her to public

school after one year at the School for the Blind. Despite continued medical issues, and a shunt surgery, she has thrived in public school. With a dedicated one-on-one assistant, Abby has been a straight-A student, won the school spelling bee, sung solos in school plays, sings in her middle school choir and loves life!

However, within the last month, Abby went through one of the scariest episodes she's ever had to endure. I called 911 when she appeared to have a stroke, with slurred speech, neck pain and hand numbness. She in fact had a TIA (transient ischemic attack), considered a mini-stroke. Thankfully, she recovered fully, but it is a reminder of the constant challenges she faces. On her ride home from the hospital three days after the episode, Abby cheerfully said "Now it can be a Happy Friday!"

Abby remains a joyful, loving sympathetic, smart and wonderful girl who loves life and those around her! She inspires me every day that "It's OK to be different" as we all are meant to be. Her confidence helps her stay strong, despite her medical and facial differences.

raegan's rally

by Ashley Daugherty

this year marked the third year for Raegan's Rally, and it didn't disappoint! Every year we set our goal higher in hopes of continued growth of the event. We met our goal again, even surpassing last year's goal by netting **over $7,000**!

This year's event was held at the **Deerassic Park Whitetail Deer Education Center.** General Manager **Mark Meeker** and his wonderful staff assisted us in organizing the event and collecting items for our Chinese and silent auctions.

We kicked off the day with a field of 5K runners and walkers of all ages. After the race, we began our auctions. Some of the Chinese auction items included 31 gifts, gas cards, primitive decorations, Ohio State memorabilia, oil changes, Target gift cards, several restaurant gift cards, pet grooming gift cards, a gift certificate for web design and numerous other items.

This year, for the first time, we implemented a silent auction, and it was a huge success. Some of the items for this included a flat-screen TV, hand-carved wooden bench, drag race tickets, and a Super Fan race package for Charlotte Motor Speedway (two suite tickets to nationwide and cup races, driver introduction tickets, garage passes, and VIP parking—valued at more than $2,000!). Many delicious dishes and desserts were also up for bid.

The 50/50 raffle, in which we raised **more than $400**, was very popular again this year. And we were very fortunate to have **Megan Miller** from **Picture This Photography** donate her time and skills to capture this magical day for us.

We absolutely could not make this event the success that it is without the help of all of our family and friends — we cannot thank them enough. Then there is our amazing community. Every year we are astonished by our community and their support for Raegan and her Rally. She is our "Rae" of sunshine, and she spreads her warmth to all who know her and even those who don't! CCA's tag line, "Beyond the Face is a Heart," is a true testament for Raegan.

As we meet more families and truly see what drives Children's Craniofacial Association, it drives us every year to aim higher and higher for this wonderful organization.

links of love for cca

The 5th Annual Links of Love Golf Tournament took place on September 21 at **Bear Creek Golf Club**, Dallas, Texas, raising **more than $11,000**. All 18 tee signs featured local CCA kids, and some of them were also sponsored on pin flags—John Gorman by Bill and Nancy Gorman; Rob Gorecki by Micetic Insurance; Sadie Bono by the Bono Family; Elizabeth Dalton by the Dalton Family and Luke Bowen by Arden and Judy Kemler.

Morning coffee and bakery goodies were provided by **Starbucks**, and golfers were treated to box lunches from **Corner Bakery** before the shotgun start. Volunteers helping with registration, photos and course contests were **Beverly Butera**, **RaeGene Mungioli**, **Tracy** and **Reid Smith**, **Cinde Keller**, **Jane Monell**, and **Sylvia Reeves**.

A special thanks to the family of CCA kid, **Oliver Bench**, whose photo was on one of the tee signs. They came out to help with the event, as did **Sadie Bono** and her Mom, **Debbie**—Sadie's dad, **Justin**, and his crew played in the tournament. The day rounded off with another great dinner catered by **Spring Creek Barbeque**, auctions, raffles and awards, emceed with the assistance of board member **Tate Gorman**.

And an extra special thank you to this year's sponsors:

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

Ben E. Keith /Firemans #4 Blonde Ale/Real Ale Brewing Co.
Corner Bakery
Spring Creek Barbecue

Silver Sponsors ($500 or more)

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FairLease
Hudson & Marshall
Impact!Chemical Technologies, Inc.
Jack FM
Mark Hagan
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Peace Family
Sirius Computer Solutions
Starbucks (Inwood & Willow)
Team Margaret

Auction Sponsors

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Top Golf
Nordstrom Dallas Galleria Lancôme
Macy's
Geoff and Lori Gunn
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JoAnn Morley
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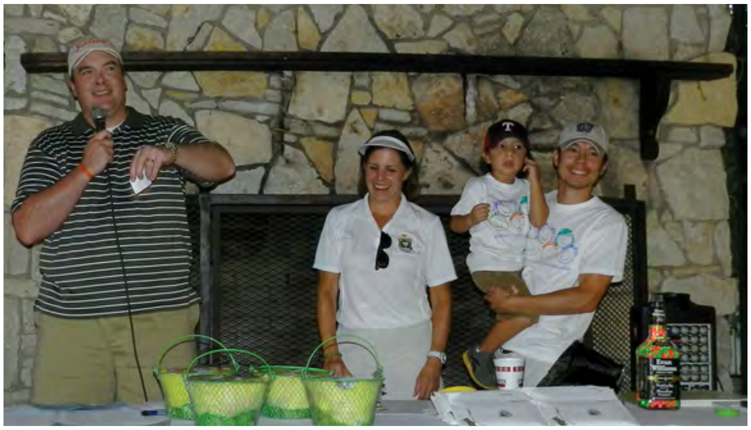
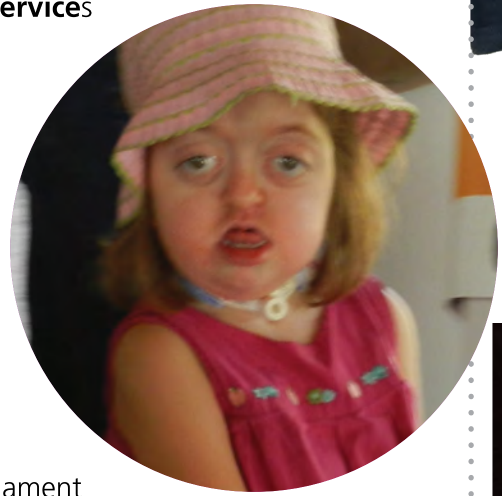


Three Eleven Designs
Whole Foods Market
Williamson Creative Services



We are extremely grateful, as always, to all who had a hand in our planning, participation, fun and success this year. We extend a warm invitation to everyone to join us next year for the 6th Annual Links of Love Golf Tournament to benefit CCA kids! Thank you, all!

Click on

DONATE

at ccakids.org

FREE SHIPPING

new items at the **cca** web store

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

New colors for our CCA Wristbands!

Because of the change in our logo, we've dropped 2 colors of our wristbands as well, teal and royal blue, and added red for the heart in the logo! So, order your lime, orange, violet and red wristbands today in Adult 8" or Youth 7"– $1 each

good news

Tate Gorman, Jill Patterson, Jon Alspaw

CCA Kids are extremely grateful to **The Exchange Club of Lake Highlands** in Dallas. To commemorate Craniofacial Acceptance Month in September, they made a generous contribution of **$1,000** toward CCA's Retreat Scholarships. The club was made aware of our cause by some of their members who also happen to be CCA parents! Thank you!!

calendar of events

date	event	contact
2013		
Jun 27-30	**23rd Annual Cher's Family Retreat** Orlando, FL	AReeves@ccakids.com 214.570.9099 800.535.3643
September	**9th Annual Craniofacial Acceptance Month** Nationwide	AReeves@ccakids.com 214.570.9099 800.535.3643

matching gifts

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

financial assistance

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

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

testimonial

Our daughter, **Lacey**, who was adopted from China, was born without the left side of her nose. We decided **Dr. Genecov** in Dallas would be the plastic surgeon to help us, and CCA helped make it happen.

We have been so blessed by the financial assistance CCA provided on our trip from Colorado to Texas. And we were so happy that one of the visits coincided with one of the CCA Craniofacial Awareness Month picnics!

Thanks again for your help!

Gary, Marie and Lacey Sollinger

more fundraising news

The **Students with Disabilities and Their Allies (SDATA)** club at the University of Mary Washington (UMW) is designed as a support network for students with disabilities. SDATA aims to raise awareness about all disabilities. They held a bake sale to raise funds for their club, and they are also donating **$27** to CCA kids. Club member **Joe Brooks** may have had something to do with that! Joe is very active in both organizations!

Nick Wiese held another Film Festival for CCA in September at the Cranberry Cinemas, where he works. The films *Torey's Distraction* and *Mask* were screened, raising **$583** for CCA kids. Thanks, Nick!

CCA mom **Deena Dyson** of San Jose, California, whose daughter, **Teresa Joy**, was born with Treacher Collins syndrome, organized an online fundraiser and "book party" event with **Barefoot Book Ambassador Kathleen von Raesfeld**. They've raised more than **$200** so far for CCA kids, and Kathleen has been so kind to extend it as an **ongoing** effort for all to participate at www.enjoybarefootbooks.com. **Check it out for holiday giving and help our cause!**

CCA mom **Carmen Mickley** held a Craniofacial Acceptance Month picnic with a fundraising component. She and the folks at **Central Christian Church** in Waco sent more than **$700** for our cause. Thank you, Carmen, and all who participated!

more fundraising news

go, griffin!

By Nikki Davies

griffin is a 10-year-old boy with Goldenhar syndrome. He had always wanted to do a fundraiser for CCA, as well as bring awareness to his classmates who know he looks different, but are not sure why.

Griffin had to undergo jaw distraction this summer and had to return to school with the distracters on. He thought this would be a great time to bring awareness. We then contacted the principal and got a fundraiser in motion.

He really loved the idea of his classmates having something to take with them to keep the awareness up, so when he saw the CCA wristbands, he knew this was exactly what he wanted. Griffin also knew he wanted to raise **at least $1,000**.

He started the school year by hanging the Craniofacial Acceptance Month posters all around school. At the end of the first week of school, there was an assembly for his grade to talk about craniofacial differences, the surgery Griffin has been having, and the fact that, though he looks different, he is just a normal kid like the rest of them. The kids were amazing. They asked a lot of questions and were very supportive of Griffin.

Then, for the next week, we sold wristbands every day before school, during lunch and after school. We were overwhelmed with the number of students that lined up to get a wristband, and the parents coming back to purchase them for friends and family.

Griffin did not stop there. We spent the morning with our local **Knights of Columbus** and continued to sell wristbands to them, and also received many generous donations. We also hung posters at **Beaumont Children's Hospital**. One of the doctors purchased wristbands for the nurses and residents to wear.

With the help of our family and friends, **Griffin exceeded his goal** and is looking to set a bigger goal next year. We would like to thank CCA for helping make all of this possible. *We* know "Beyond the Face Is a Heart," and now our community knows too!

cca's newest resource for craniofacial families:

children's craniofacial association
ccakidsblog.org
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

looking for a reliable shipping Company?

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, AReeves@ccakids.com.

registration open for 2013 annual cher's family retreat

June 27-June 30 in Orlando, FL

Please join us for an educational symposium, pool party, ice cream social, dinner/dance and much more! For more information, please contact Annie Reeves,
AReeves@ccakids.com
We hope to see you there!

donors, january 1 – october 31, 2012*

Gifts from Individuals

CCA Friends

($100 +)

Anonymous
Carol Jean Anthony
Terry Lynne Ausmus
Michael Beasley
Yvonne & David Boon
Steve Bouker
Larry Carpenter
Jeffrey Lloyd Christian
Michael Clay
Judith Clonan
George Dale Sr.
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Vicente Farina & Leigh M. Soda
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Dean Spanos
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Dwight Vaughn
Mark & Natalie Weaver
C.M. & Leila Wiley
Robin Williamson
Reed Wills

CCA Companions

($250 +)

Beth Abel
Anonymous
Carl Bach
Erik Bauman
Eric Berglund
Lorrell Bush & Colleagues
Judith Cunningham
Beverly & Jim Butera
Amy & William Downs III
James Dufficy
Deena Dyson
Richard Faulkenberry
Heath Fisher
Fred & Judi Freeman
Martin Grupp
Sarah Hall
Christopher Hood
Arie Krie
Roger and Carolyn Lamb
Christopher McGhee
Joe & Alison Morrissey
James Oh
Greg & Jill Patterson
Dale & Kathleen Philippi
Jeoffrey & Elizabeth Robinson
George Rodriguez
Michael Schnur
Charlene & John Smith
Gary Uttke
Marcia Weber
Andrew & Amy Weinraub

CCA Extended Family

($500 +)

Jessica Blue
Martha Brown
Tracey Carragher
Roger S. Chin DDS, PS
Diana Critchlaw
M. Brian Evans
Fred & Judi Freeman
Kim & Urban Koagedal
Mary Lytle
Janis Macut
Joe & Allison Morrissey
Katherine Olsen
Matthew Osburn
Jana & Hugh Peace
Paul Pokladnik
Ann Sickles
Jennifer Webber

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($1,000 +)

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Molly & Robert Lytle
Carl & Kathy Michaelsen III
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Blair Schrum
Michael & Shelly Sprague
Heather Switzer
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CCA Patron

($2,500 +)

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Dede & Darin Dankelson
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The Estate of Jean Pond
E.C Styberg
Marty & Mike Willson

CCA Benefactor

($5,000 +)

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George & Kristine Dale
Bob & Paula Guzzo
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 Alice Athena Esparza
Anonymous, in honor of Meg Gray's birthday
Anonymous, in honor of Roy Dennis
Anonymous, in honor of Francis Smith's birthday
Anonymous, in honor of Nick Wiese
Anonymous, in memory of Kevin Wilson
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
Judith Cunningham, in honor of Elijah Dinsmore
Luis Davilla & Lucy Torres, in honor of Jaylin Davilla
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
Mary Kay & Thomas Gardin, in honor of Natalie Wardlaw
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 Jean Johnson
Jim & Arleen Heirty, in memory of Sharon Minor
Jim & Arleen Heirty, in memory of Mildred
Jim & Arleen Heirty, in memory of Ann Marie Sansone
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
Kimberly Martin, in memory of Ellery Walker
Susan Martin, in memory of Ellery Walker
Ellen McPadden, in honor of Jeremy Dale
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
Jill & Greg Patterson, in honor of Melanie & Chris Pipkins nuptials
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
John Steffen, in memory of Kevin Wilson
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

Ables Electrical
American Express Charitable Fund (employee giving)
American Legion Knowles Doyl
AT&T (United Way Employee Giving Campaign)
Bank of America (United Way Camp(Matching Gifts from 2012 North Texas Giving Day)
Cambridge Chapter Women Moose
Cameron Manufacturing & Desing
Dell Employee Giving / Matching through "Your Cause, LLC"
Directed Technologies
The Elena Melies Technologies
Exchange Club of Lake Highlands
Funding Factory
Hargrove Oil Company, LLC
Heart of Illinois United Way, Inc.
Interludes
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)
Steve's Discount Muffler
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)

Listed are **monetary donations of $100 or more through October 31, 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.)

*MMM = Morgan Meck's Match Play

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)

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
Consolidated Sales and Engineering
Corning Beagle Club for Friends of Jeremy
Dartmouth-Hitchcock Foundation
The Max and Victoria Dreyfus Foundation
GMI, Inc. for MMM*
Guy Carpenter & Company for MMM*
Hardinge Inc. for Friends of Jeremy
The Hitchcock Foundation
Horizon Solutions LLC for Ryan's Road
Metal Parts & Equipment Co. for Pete's Oktoberfest
Michael Klein Foundation for The Chocolate Festival
Orange County CFC
Partner Reinsurance Co. of US for MMM*
The David M. Schwarz Architects Foundation
Simmons Rockwell for Friends of Jeremy
E.C. Styberg Foundation, Inc.
Vivo Brothers

CCA Corporate/ Foundation Partners

$5,000-$10,000

Cher Charitable Foundation
Lexington Insurance Company for MMM*
The Redwoods Group for MMM*
Triangle Foundation

CCA Corporate/ Foundation Patrons

$10,000 or more

B.B. Owen Trust

Fundraising Events & Other Efforts

Up to $1,000

Bake Sale / Kidder County Public School / Mrs. Heier's Jr.High Family Consumer Science Class
Barefoot Books Sale / Deena Dyson with Kathleen Von Raesfield
Joe Brooks' Birthday Wish on Facebook / Joe Brooks
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
Film Festival for CCA Kids / Nick Wiese & Cranberry Cinemas
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
Pampered Chef Sale / Stacy Swihart
Annie Reeves' Birthday Wish on Facebook / Annie Reeves
Francis Smith's Birthday Wish on Facebook / Francis Smith
Waco Picnic Funder / Carmen & Ron Mickley
Wristband Sales for CCA / St. Thomas Aquinas College & Alie Cabo

$1,000-$5,000

CCA Chance Raffle / Annual Family Retreat Attendee Participants
Griffin Davies' Fundraising Effort / Wristband Sales & Awareness
Luke Bowen's Jammin' Jeans Week / Judy Kemler & Flower Mound 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
Trevor's Trip To Triumph / Family of Trevor Layrs

$5,000 or more

Raegan's Rally / Ashley & Boz Daugherty
Robbie's Haircut / Mike Wiese, Janis Macut & Retreat Attendee Participants

$10,000 or more

Chocolate Festival for CCA Kids / Chef Rick Chiavari in honor of Seth Swihart
Pete's Oktoberfest / Dankelson Family

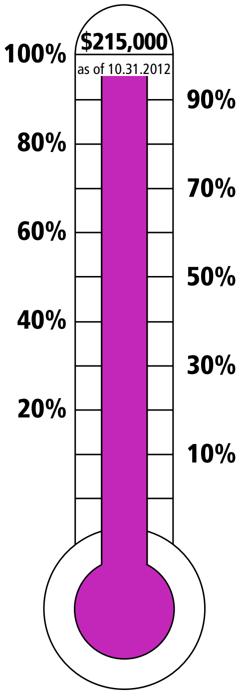
$20,000 or more

Hartley Golf Outing / Hartley Company, Cambridge, OH

$30,000 or more

Friends of Jeremy Golf Tournament / Dale Family
Morgan Meck's Match Play Tournament for CCA / Mecklenburg Family

2012 FAMILY FUNDRAISER GOAL THERMOMETER



more fundraising news

Above: Antoinette and daughter, Makena

Junior high family consumer science teacher **Antoinette Heier** (and CCA Mom to **Makena**) had her seventh and eighth graders hold a bake sale to benefit CCA, raising **more than $300**! The class wanted to help out after seeing the Little Fire Big Heart video produced by **Taryn Skees** and felt such compassion. It was their idea to have Antoinette's daughter, Makena, be their own local CCA Kid. What transpired was a lot of learning about good character, empathy, kindness and how just a smile can bring happiness to others and make them feel included.

Thanks to Mrs. Heier, her students and **Kidder County Steele School District** for their support and for spreading awareness of craniofacial conditions and widening the circle of acceptance!

Top: Wesley and Sara collecting the money

Right: Ethan proudly displaying some of the baked items for sale

Left: Jarret Wolf, Kody Bullinger, and Dillon Steinolfson enjoying a slushie

children's craniofacial association
13140 Coit Road, Suite 517 • Dallas, TX 75240

3cheers

for volunteers!

Thank you, Hugworks!

thank you **Hugworks**, for performing live music at our Dallas picnic! The kids and adults had a wonderful time, and we truly thank you for coming out and volunteering your time!

Hugworks is a 501(c)(3) nonprofit organization making a meaningful difference in the lives of children with special needs by delivering services, resources and products to help boost self-esteem and enhance a healthy expression of feelings.

Hugworks develops innovative ways to address the special needs of children through live Therapeutic Music Entertainment, Music Therapy, and other projects and programs. Through a unique, collaborative process with early childhood and music professionals, Hugworks has produced three award-winning children's audio CDs which are used in hospitals, medical camps and homes across the country.

For more information, please visit their website at www.hugworks.org.

children's craniofacial association

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