ccanetwork

newsletter of the children's craniofacial association   Cher—honorary chairperson   2012: Issue 1

inside

BEST IN AMERICA
CERTIFIED BY INDEPENDENT CHARITIES OF AMERICA

Children's Medical Charities of America

leigha's story

By Melanie Roder

leigha was not born the little girl I had envisioned in my dreams. The elation that I felt upon the announcement, "It's a girl!" was quickly overshadowed. I felt robbed of normal motherhood delights by our family practitioner puzzling over her looks; and I was confused by a quick explanation that her features resembled those of children born with Down syndrome. The same thoughts kept running around in my head "Down syndrome? That couldn't be right. I was tested during my pregnancy for the genetic mutation. Besides, I was only twenty-three and babies weren't born to mothers as young as me with Down syndrome, right?"

see **leigha**, page 12

message from the executive director

as I am writing this message, we are embarking on a new year with fresh enthusiasm and determination.

In October, CCA's Board of Directors and staff gathered for a weekend to assess the progress that was made in 2011 and re-evaluate and expand our three-year strategic plan.

Among our 2011 accomplishments, CCA:

- Held the 22nd Annual Cher's Family Retreat, attended by 92 families
- Held the 3rd Annual Craniofacial Family Symposium

see **executive director**, page 9

meet avary mitchell

eight-year-old **Avary Mitchell** is one smart girl. She loves English class, creative writing and math, so it's no surprise she's made the honor roll this year.

Avary reads a lot on her own, particularly the Junie B. Jones series of books. She likes the Kit Kittredge series, too, and has not only seen the movie but also has a Kit Kittredge American Girl doll.

Apart from reading, Avary takes xylophone lessons every Thursday. She also likes to watch the Australian TV show *H2O Just Add Water*, a story about three teenage mermaids.

Avary and her older sister Audrey are very close. They even share the same birthday, September 11. They especially love to play with their American Girl dolls, Avary with Kit and Audrey with Josephina. They make houses for them and create scenes with them together. They also help take care of seven pets: two dogs, two cats, two fish and a chinchilla.

Last summer, Avary went to SeaWorld® with her grandparents and had a blast and loved all the rides. She also went to last summer's CCA retreat, where she had a lot of fun and had a chance to meet new friends.

This summer, Avary has a big surgery planned, the Le Fort procedure, which will help move her face forward. It's a major event for her, but she's taking it all in stride. Here's what she'd say to any other kid going through the same thing: "It's going to be ok."

ccakid

ccagrad

gavin mohney

hi. I am **Gavin Mohney**. I am 19 years old. Shortly after I was born, I was diagnosed with Pierre Robin syndrome. I spent my first three months in the NICU. My mom and grandma were so worried. I made it through several operations for hydrocephalous, placing a VP shunt and a tracheotomy.

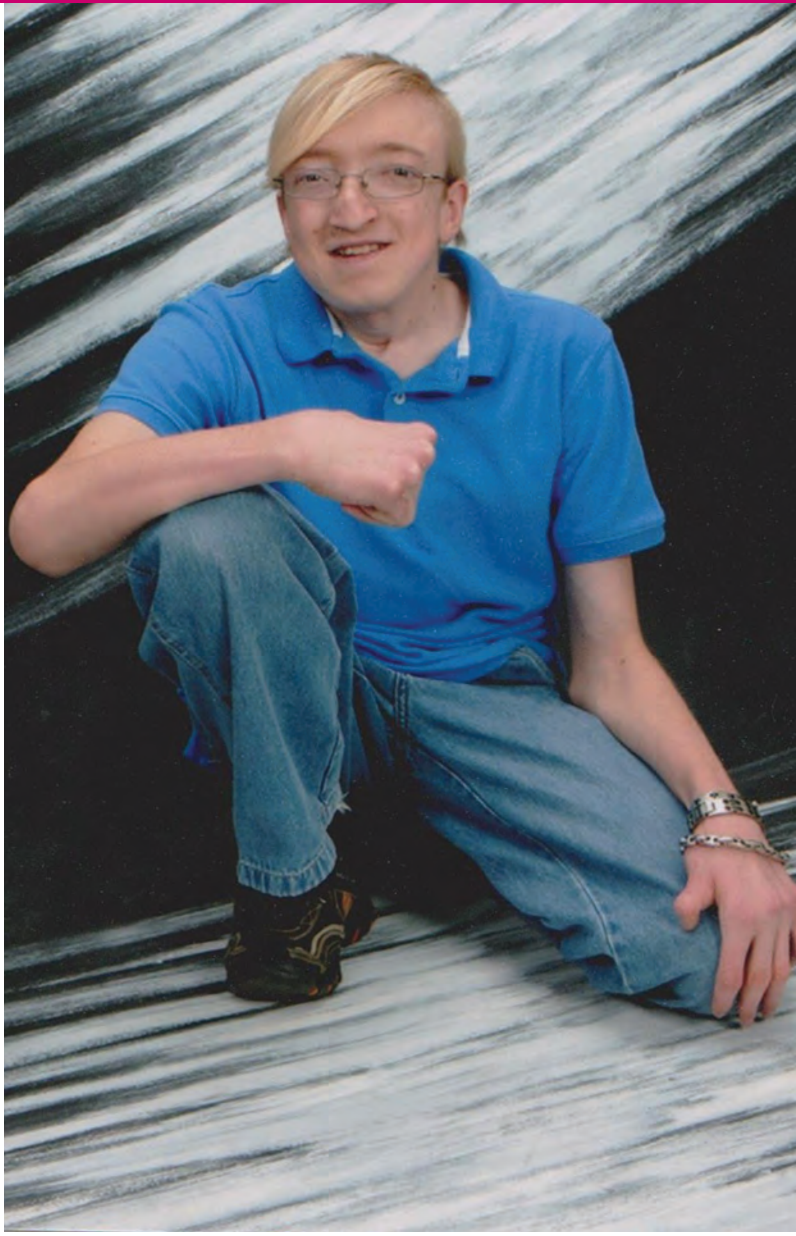
For the next two years, I had the trach and a feeding tube. I think I am making up for lost time because I love to talk and eat! I make friends everywhere I go. My mom told me I talked to the people sitting next to us on a plane for four hours straight!

Gavin, third grade

I will even sing a song once I get to know you. I was in chorus in elementary and middle school. I have had numerous operations. I have had tubes in my ears and cysts removed from my neck and mouth. I had a cervical fusion and surgeries on my feet and hands.

All these operations do not slow me down! I had a wish granted in 2002 to be a rock star! This was my "rock and roll phase." I arrived at my favorite restaurant in Phoenix by limousine and was greeted by fans and paparazzi. I soon expanded my music interests to include barbershop quartets and musicals. I sang in the Phoenix Children's Chorus.

In 2006, my mom and I moved to Florida. I enjoy going to the amusement parks and the beaches. I now live close to my grandparents, where I enjoy motorcycle rides and bonding with my grandpa. I have been to Disneyland® and Disneyworld®, dipped my toe in the Atlantic and the Pacific Oceans.



In 2009, I was diagnosed with Loeys-Dietz syndrome after a huge aortic aneurysm was discovered while evaluating my severe scoliosis. Thankfully, it was discovered and repaired.

Again, I do not let my physical impairments slow me down. I graduated from high school in Florida in 2011. I enjoyed going to prom and dancing the night away.

I still love music, techno and musicals. I've seen my favorite musical, *The Phantom of the Opera*, in four different states. I like the Oakridge Boys and Johnny Cash, too. I also love watching movies in surround sound, singing, riding my bike, and checking out Facebook. I have a dog and three cats. Someday I hope to learn to drive as well as go to college.

I was born in Phoenix and lived there for 14 years, which is why I am so excited that the retreat will be there this year.

ccasupersib

meet audrey mitchell

My name is **Audrey** and I was born September 11, 2001. I am 10 years old and in the fourth grade.

I like school, especially because I have the world's best teacher, Mrs. Polster. I also have very funny classmates. When I grow up I want to be a geologist and an archeologist.

My hobbies are drawing, watching TV, playing computer games like Poptropica and playing with my friends.

I also like going to the CCA events. At the Christmas party we met Salem, our newest little friend. We met Brisa at the Wiggles concert and Elizabeth at our first CCA event in Kentucky. I am looking forward to going to Arizona this year to meet more kids.

My sister Avary was born on my second birthday. Sometimes I think it's not good to share a birthday, because you have to agree on the party and you don't get as many presents.

Still, it's hard when my sister has surgeries because I can't go in to see her before or for a couple days after. Also, she sometimes looks different afterwards, which is hard for me. I'll be glad when she is all done with her surgeries! Avary is the funniest sister ever and that is why she is the best sister in the whole wide world!

7th annual friends of jeremy golf tournament

The 7th Annual Friends of Jeremy Golf Tournament was held last September at the **Corning Country Club** in Corning, New York. There was an incredible turnout and overwhelming support from the community, our co-workers, friends and family.

It was a record year for the tournament with 140 golfers and more than 55 generous sponsors! The tournament included a raffle, silent auction, closest to the pin, 50/50, closest to the line prize and a skins game.

There was a special raffle for a 40" LCD TV and an iPad. The silent auction included exciting items such as an autographed **Jorge Posada** baseball and autographed **Derek Jeter** photo!

A very supportive local car dealership, **Simmons-Rockwell**, was not only one of the major sponsors but also provided a new car prize for a hole-in-one contest. Unfortunately, no one won the car, but everyone had fun trying! The event was a huge success, which raised more than **$32,000** for CCA!

Jeremy was again joined this year by a few of his CCA friends and their families: **Andrew Perry** from Massachusetts; **Ryan Gulich** from Big Flats, New York; and **Trevor Larys** from New Jersey. We also had the opportunity to meet CCA kid, **Betsy Adams** and her family, from Pennsylvania.

It is so wonderful to have CCA friends join us for the tournament each year. The golfers really enjoy meeting new kids and catching up with kids they have met in the past.

We are so grateful to everyone who supported this event and the kids from CCA. For more information and to see photos from the tournament visit www.friendsofjeremy.com.

cca mugshots

Top left: George Dale, Sr. and Cathy Dale; top right: Kristine Dale and Karin Perry; bottom left: Andrew Perry and Jeremy Dale; bottom right: Erik Larys and Kim Trzanowski.

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.

heartfelt holidays

Our year-end "Annual Appeal" letter had a card insert for donors to send back, wishing our CCA Kids who were spending the holidays in the hospital, a speedy recovery or a message of encouragement and hope. Our supporters did not let them down. Thank you to everyone who participated! These and more were and are still being distributed to CCA Kids in need of an emotional boost.

grants to cca

We're proud to announce recent grants awarded to Children's Craniofacial Association.

The **Woodall Foundation** donated **$5,000** for General Operating needs.

Adam Carriker presents a check from the **Woodall Foundation** to CCA Executive Director, Char Smith, with Jill Patterson, Development Director & Annie Reeves, Program Director

The **Henry Bull Foundation** donated **$2,500** for Patient Financial Assistance and **The Florence Foundation** has granted **$5,000** in funds toward scholarships to attend our Annual Family Retreat. Many thanks!

dallas mav's tickets raffle winner!

Congratulations to **Kelli Park**, from Coppell, TX, who won our raffle for two "floor" seat tickets to see the **Championship Dallas Mavericks**, including an autographed team ball. Wow!

Kelli's daughter is CCA kid, **Ryan Park**, who was born with Goldenhar syndrome and is a patient of **Dr. David Genecov**. Kelli says she got on our email list through his office and started getting e-mails when Ryan was a baby. "CCA is a great organization; thank you so much for all of the work you do for these families!" Kelli received an email about our raffle and purchased 3 tickets. The happy winners attended a March game against the **Los Angeles Lakers**. Many thanks to all who supported this effort!

texas moms' 5K for cca

By Lisa Bock, mom of **Ashley** with Apert syndrome

The first-ever Texas Moms' 5K for CCA was held last October at **Lee College** in Baytown, TX. Through this event, we were able to create more awareness in the community while also helping CCA with their mission.

In February 2011, **Becky White** (Wade's mom, **Wade** has Pfeiffer syndrome) came to me and asked if I would be interested in helping her do a fundraiser for CCA. We also asked **Brenda Siebert** (Jonathan's mom, **Jonathan** has Apert syndrome).

Since Becky and I were new to fundraising, we decided to travel to San Francisco to see how **Rachel Johnson** put together **Henry's March** (held annually since 2008). We participated in the 5K and tried to soak in everything Rachel said or did. It was fascinating to see firsthand how everything came together. Thank you so much, Rachel, for all the information and for sharing your personal knowledge and experience. You are such a pro! We also talked to **Stacy Swihart** of **Seth's Stride**. She shared her invaluable knowledge as well. Thank you, Stacy!

Shortly after getting back from San Francisco, Becky, Brenda and I began to make it all happen (logo, t-shirts, sponsorship packets for donations and vendors, etc.) In August, Becky went back to a full load of college classes and asked **Lindsay Knight** (Kash's Mom, **Kash** has Moebius syndrome) to join us. Lindsay really came through for us — thank you so much!

Our event started early Oct. 8. We had more than 80 runners in our 5K. We also had a raffle for a trip to Orlando (including airfare, lodging and SeaWorld tickets) and an American Girl doll, a 1-mile walk/run, a 50-yard kiddie dash, vendor booths, food vendors, a silent auction and a live auction. There were two live bands and a kid's play area with moon walks and other fun activities.

Some attendees included **Jennifer**, **Hayley** and **Brody Lucas** (Brody has Apert syndrome) from Colorado; my cousin **Kristy** and her husband from Dallas; and **Atina Myazoe**, her husband **Bob** and son **Jamal** (Jamal has Pfeiffer syndrome) from Ft. Hood, TX. We raised more than **$20,000** and are so pleased with the results of our first event. Wooohoooo!

Many thanks to our contributors: **Lee College, Southwest Airlines**, **TCG Digital Concepts**, **Corinthian Contractors**, **Baytown Gentle Dental**, **Visible Changes**, **Fine Design, LLC**, **Funjet Vacations**, **Investment Professionals, Inc**, **Custom Websites of Clear Lake**, **San Jacinto Methodist Hospital**, **Murff Turff**, **Trattoria Italia**, **One Stop Printing**, **Candlewood Suites**, **Robson's Diamond Jewelers**, **Holly Jackson Remax/Premier**, **Filla Photography**, **Pearl Paradise**, **Thomas Markle Jewelers**, **Best Western, Dr. Jane Edmond** and **Starbucks**. There were also several generous donations from private individuals.

We also want to thank our amazing volunteers: **Wade White**, **Mike Bock**, **Karen Knight**, **John Tijerina**, **Kyle Hudson**, **Destiny Carlisle**, **Antasia Hart**, **Christopher Bock**, **Jonathan Siebert**, **Jenni Hudson**, **Elena** and **Rachel Osegueda** and **Charles Michlik**. I know there were many more. There was always a helping hand ready when needed.

Thank you all so much for helping to make this event a huge success. We hope to see you next time.

Texas Mom's 5K for CCA
Becky, Lisa and Brenda

chocolate festival

Not all the chocolate was being eaten, when the 4th Annual Chocolate Festival for CCA Kids was held last October — some of it was being worn!

What has become a signature event for **Aventura Mall** is a huge draw, not only for the worthy cause, music, fun, silent auctions, raffles and tempting taste treats, but the clever "chocolate" fashions on the runway competition that gathers the crowd and keeps the chocoholics tasting.

Creations designed by students at **Miami International University of Art & Design** have become a mainstay with the event. Mall events manager, **Laura Nichols** welcomes **Chef Rick Chiavari** and his associates, family and friends on behalf of CCA.

We're extremely grateful for their years of effort to help our CCA kids in such a "sweet" way! This year they contributed **$18,000** in funds.

We'd like to thank sponsors; **Turnberry Associates**, **Gym Kidz**, **New York Bakeries**, **Atlas Party Rental**, **BC Tacos**, and raffle and auction donors: **Turnberry Isle Hotel & Resort**, Miami; **Woodfield Country Club**; **Canyon Ranch**, **Fontainebleau**, Miami Beach; **Hobo Int'l**; **Johnny Rockets The Original Hamburgers**; **Sothys Paris**; **Pure Fiji**; **Jose Graterol Designs**; **SkinCeuticals**; music guy **D.J. Lawrence** and **High Voltage Entertainment**; and all of the restaurants, chocolatiers and businesses who donated their time, talent and wares to this fabulous event.

trevor's trip to triumph!

By Kim Trzanowski

We held our very first fundraiser for CCA last October. After being involved with CCA for just 2 short years, and attending our second retreat, we were very inspired to give back to them for all they've done for the CCA kids. We had the pleasure of attending the Friends of Jeremy Golf Tournament in 2010 after our first CCA retreat in Boston that summer and decided we needed to do something too.

Since Trevor's dad is a motorcycle guy, we decided to hold a bike run here in New Jersey. By the time I got a venue to host our actual event, we had less than eight weeks to pull it all together! (Many, many thanks to the **Freehold Elks Lodge #1454**!) We hit the pavement, spread the CCA word and managed to raise more than **$4,000** for our first event!

We would like to thank some of those who personally sponsored Trevor's Trip to Triumph, including the **Larys family**, the **Dale family**, **Mike** and **Tammy Walters**, and the **D'Amato family**. Thanks to our local business sponsors: **Complete Security Systems, Inc.**; **Pet Express Mobile Grooming**; **Dr. J's Windows**; **Extreme Machines**; **Pit Power Sports**; **Pooch Parlor** and many more — 20 sponsors total!

We would also like to thank prize donations from **Lowe's** of Marlboro, who donated a brand new BBQ grill; **Attractive Tattoo**, who donated a gift card for a nice piece of body art; **Wireless Zone** of Freehold, who donated a brand new smartphone. Many donors gave gift cards, including **Longhorn Steakhouse**, **Olive Garden**, **Bed Bath & Beyond**, **AMF Bowling**, **AMF Theaters**, **Avatar Spa**, **Gallo's Wine**, **The Hobby Shop** and many more. Food was discounted and donated by **Dunkin Donuts** and **Sorrento's Subs**.

We had a small turnout to actually ride in the event, as the weather didn't turn out as planned. However, we had an amazing first run, designed by a very good friend of Erik's, **Mike Walters**, and we are looking forward to doing this each year the Freehold Elks Lodge #1454 will have us. They have been most gracious and generous by helping support **Trevor** not only for this event, but for other times our family has been in need as well. Both the Freehold Elks Lodge and the **Old Bridge Elks Lodge** (two of our local lodges) made donations on Trevor's behalf for our run that day.

Our gratitude and thanks also go out to all our friends and family who helped us set up, clean up, take registrations, hand out T-shirts, feed the crew, announce the raffles, ride motorcycles with us and share in the joy of being able to do this fundraiser. Thank you, CCA, for your support, guidance and help through our first event too. The next one should be a smooth ride!

executive director,

from page 1

- Awarded retreat scholarships to 25 families
- Distributed *Care Journals* to 200 new families
- Over 15,000 *CCA Network* newsletters were published and mailed quarterly
- Published overviews on ten new topics
- Expanded the networking list to include an additional 765 families/individuals
- Expanded membership in social networking groups
- Held the 22nd holiday party in Dallas, TX
- Debuted CCA's redesigned brochure
- Continued to provide families with financial assistance with food, travel and lodging

All of this couldn't have been accomplished without all the hard work of the board, staff and many volunteers (both community volunteers who distribute information and fundraising volunteers). We appreciate the dedication of everyone who helped CCA achieve its goals during 2011.

Along with the many accomplishments comes a lot of expense. Unfortunately, for the past several years, CCA's expenses have outweighed income. The good news is, through careful planning, CCA has been able to retain a financial reserve that allows us to continue to provide programs and services without interruption when a deficit is incurred. However, our reserve won't last forever, and last October CCA's directors made a tough decision to strategically cut some program activities that would result in lessening the disparity between income and expenses.

The Annual Cher's Family Retreat is one program that was affected by the necessary cuts.

It has come to our attention that many families believe the retreat is funded by Cher since it carries her name. Although Cher is a very active supporter of CCA, and sends gifts to the retreat, the retreat is named for her because she is the one who conceived the idea of getting the families together once a year to share resources and make friendships with others who are enduring similar circumstances, not because she funds it.

In an effort to make the weekend as affordable as possible, thus allowing more families to attend, CCA has tried to cover as many of the expenses of the weekend as we can. So if you've wondered why we are so diligent in keeping track of activities/meals families attend during the retreat, it's because we are charged for each person for each meal/event. So for instance, if a family of four decides not to come to a breakfast or dinner without alerting us, the charity is still responsible for paying for those meals. Additional retreat cuts were made to scholarship funds and the registration fee was increased (although still much lower than most conferences).

Other ways CCA is conserving the reserve is by cutting one edition of the newsletter. In 2012 you will receive three newsletters four months apart. The funds previously designated to research were also cut.

Even though we are cutting expenses, CCA's board and staff are focused on serving our families with the same quality programs and services, and with the help of our steadfast volunteers we know we can achieve our goal. We are more determined than ever to explore fundraising avenues to ensure our families are served to the fullest.

To that end, **we challenge our donors to dig deep and help us meet our financial goals so that once again we may run our programs at full capacity.**

Charlene Smith
CCA Executive Director

dallas holiday party

CCA, together with **Dr. Jeffrey Fearon**, hosted its 22nd annual holiday party at **Southfork Ranch**, in Parker, TX, on Saturday, December 10th. Around 500 attendees joined us for a morning full of fun!

Radio Disney was once again the entertainment, and everyone really participated in the fun, music and games. The parents had just as much fun as the kids, especially during the dance contest. Everyone enjoyed cake and punch as well as arts and crafts. The kiddos decorated their own cookies and picture frames, had their faces painted, and even had a chance to get up close and personal to some slithering snakes! They were also able to see a real fire truck, thanks to the **Parker County Fire Department**! We would also like to thank the **Dallas Cowboys Cheerleaders** for coming out.

Families went home with lots of door prizes, which were donated by several local businesses. Prizes included a merchandise package from the **Frisco RoughRiders**, tickets to the **Mesquite Rodeo**, **Dallas Zoo**, **Fort Worth Zoo** and **SeaLife Aquarium**, gift cards to **Amazing Jake's** and signed merchandise from the **Dallas Cowboys**, **Dallas Mavericks** and **Texas Rangers**.

As always, the highlight of the party was the big man himself, **Santa Claus**. Children took their picture with Santa, and everyone went home with a keepsake photo and toy.

CCA would like to thank **Southfork Ranch** for hosting, as well as their wonderful **staff**! A huge thank you goes out to our wonderful volunteers from the **Italian Club of Dallas**.

CCA would like to send a special thanks to **Tyler Hanson** and **KLS Martin** for all of their support!

midwest holiday party

Families gathered last December 3rd in Kenosha, Wisconsin, at the **Parkway Chateau** for a pizza lunch, a variety of desserts and lots of fun. The kids decorated trees and hung ornaments while awaiting their turn on **Santa's** lap for a photo and a sack of early presents. Later, Santa sang, did a little judging of the masterpieces and chatted up the crowd. Everyone left with a photo ornament souvenir of themselves with Santa and lots of gifts. This year, folks came from Wisconsin, Illinois, Iowa, Texas and Colorado! Thanks to all who joined us. Special thanks to CCA Mom, **Marla Verdone**, from Janesville, Wisconsin, who helps plan the fun each year.

Have you included **cca** in your **estate** arrangements with a **planned gift?**

leigha, from page 1

The family practitioner puzzled over what was cited as "dysmorphic features," which included low-set ears, a flattened forehead, eyes that were downturned at the corners and a slight ridging above each ear. Although she was beautiful to me, a consultation with a pediatrician did little to halt my fears. Her remarks were: "features uncertain," "most likely not Downs," "perhaps only post-delivery swelling." To hear some doubt in the words did not ease my mind when she said she was certain my daughter would begin to round out more normally in a few weeks.

So we took home my beautiful, fuzzy haired, baby girl. Every check up, every concern, was met with one pediatrician after another giving us dubious advice. As a newborn, Leigha was difficult to console, shrill crying spells would last from about 7 in the evening until around 2 in the morning, and nothing we tried would help. One pediatrician said it was colic. Each day was spent worrying about all the "what-if's" instead of focusing on my quickly growing baby girl. I would fret over my daughter's looks, although a total of six pediatricians had dismissed all our concerns for her flattened and towering skull. The initial concern of Down syndrome would always return and I didn't know if my daughter was indeed one in 800 born with 47 chromosomes instead of 46 or not. I researched the National Association for Down syndrome website many times as I fretted over Leigha's looks. I didn't believe she resembled a baby with Down syndrome, but I just knew something wasn't right.

As my daughter turned 6 months old, a new concern arose when it appeared her soft spot was closed. A seventh pediatrician dismissed it as something to "keep an eye on." Fed up with doctors who treated me as if I were an over-protective and fretting shrew or bothersome mother, I finally, after fighting my family practitioner for a referral, consulted with a craniofacial surgeon. One glance at my daughter, one feel of her non-existent fontanel, after a staggering seven pediatricians had been consulted on her head shape, a specialist finally diagnosed my daughter with Craniosynostosis. My daughter was not one in 800 after all. She was in fact one in 2000. Surgery, CT scans, neurosurgeon consult, and genetics appointments were all arranged that day.

The relief of finally knowing I wasn't crazy for worrying for so many months was eclipsed by the emotions of preparing for surgery. I was caught by a tidal wave of fear and stress, and stuck on a roller coaster ride with little knowledge of how to avoid the sudden torrent of tears that snuck up on me with little warning. Friends and family meant well but did little to quell my fears. My serenity came from virtual strangers located online through CCA and a few other craniofacial organizations. Friends on discussion boards became more of an extended family, and they were with me each late night leading up Leigha's surgery. Some even called while I waited anxiously for nine hours as surgeons cut and sculpted my daughter's skull. Not only were they there in 2001 for our surgery, they have continued to be there over the years as Leigha has grown. Without my family in the craniofacial world, the inundating task of facing the diagnosis and treatment of a craniofacial anomaly would have overtaken my sanity long ago.

Ten years ago Craniosynostosis revealed itself to us and seated itself in our lives. Some days it's the large elephant in the room and others it's the little mouse squeaking in the background. For us, Craniosynostosis is always in our lives. Leigha was initially diagnosed as having Crouzon syndrome which was later dismissed and she was then sighted as having Muenke's syndrome. Although she was not found to have the FGFR or twist mutations, there were more than enough clues that something genetic was indeed going on.

In the beginning, the Muenke syndrome diagnosis brought on the post-op fears of her midface not growing correctly, concerns on how her teeth would grow, fears of hearing loss, the possibility of learning delays, the always persistent concern of second, third, or more surgeries, and lastly the possibility of Leigha and her older brother having children with Craniosynostosis due to the 50/50 chance of passing on whichever flawed gene she has.

Leigha has been fortunate to only face two major surgeries in her little life, and for those 11 years we have been fortunate to call ourselves part of the CCA Family. Our extended families found through organizations like CCA have been there for us throughout many ups and downs. They talked us through high-stress situations such as in 2006 when we faced Nebraska Child Protective Services, due to Leigha's first grade teacher turning us in for abuse because of her lack of understanding for Leigha's odd- shaped forehead. Their love, support, outreach, and prayers were life-saving as we faced a second craniovault reconstruction in June of 2011 and traveled over 800 miles from Omaha, NE to Dallas, TX. CCA was there every step of the way. Had groups like CCA not been accessible through Facebook, emails, and websites, our lives would be much darker and our story with the misdiagnosis of a craniofacial anomaly would not have been as successful.

Since our first frustrating task of getting several doctors to take our concerns seriously, to our most recent choice to seek out a different craniofacial team, life-long friends have been made thanks to being able to reach out through email, websites, Facebook, and Twitter. I will always stand proudly as an advocate for CCA and many other craniofacial organizations. I have my own websites for craniofacial awareness and acceptance (www.beyondaglimpse.com / www.care4cranio.com) and Leigha loves to help out as much as possible. She has even been fortunate enough to make life-long friendships (and even has her first crush) thanks to our CCA family.

I have a love/hate relationship with the diagnosis of Craniosynostosis, but most of the things I hate about it can now be coped with, thanks to my CCA family. It has been a pure joy to dedicate my time for outreach and sharing. My goal is to keep as much information on the internet in the hopes that as many families as possible can find CCA and other craniofacial organizations, and be saved from facing this journey alone. We look forward to having CCA and all our extended family share in future delights such as graduations, marriages, new careers, and births of children. Our love and thanks to all who have been along on this crazy roller-coaster ride known as a diagnosis of a craniofacial anomaly, and to those just boarding… hold on tight, don't be too frightened, CCA will be there to provide the safety restraints.

Additional information for Melanie:

C.A.R.E. (card drive for Craniofacial kiddos)
http://www.care4cranio.com

My Facebook Profile:

http://www.facebook.com/profile.php?ref=profile&id=100000867709798

Beauty in Imperfection Fan Site:

http://www.facebook.com/pages/Beauty-In-Imperfection/104471209584047

Blog

http://acraniosynostosislife.blogspot.com/

Online Portfolio

http://craniomommy.daportfolio.com/

Follow Me On Twitter

http://twitter.com/CranioArt

Our Story on Youtube

http://www.youtube.com/watch?v=SwEIEBFasEQ

lily's dinner

Last September we held Lily's 3rd annual Craniofacial Awareness Dinner and Silent Auction. The event was held at **Pioneer Park** in Lindon, Utah. We had 130 adults and children in attendance this year. The silent auction was a great success, thanks to all of the generous donations and hard work put in to gather donations. We had 145 items in the auction. It was amazing! With the generosity and kindness of everyone in our wonderful community, we raised more than **$10,000** for CCA and Craniofacial Awareness! If you want to help us top this, we need your help!

Lily and her other CCA friends always look forward to their dinner and getting together with friends, family and neighbors for their fabulous cause. The kids had a wonderful time playing on the playground and making new friends. It was so much fun watching them get acquaintanced, I forgot to take pictures!

We had a BBQ theme this year. **Par Palmer** and his wonderful volunteers cooked the food. The food was donated by **BMC West**, located in Orem, Utah. We were served delicious BBQ hamburgers, hotdogs, baked beans, fruit, salad, and for dessert we had Dutch oven cobblers. The food was to die for! We all had a great time enjoying good food, great company and awesome silent auction items on a beautiful summer night.

I would like to especially thank each and every person who came out to support this worthy cause and I am so grateful to everyone who helped out with this incredible night.

We had so many great sponsors and donations and each of them is very much appreciated. I would also like to thank **Lindon City** for donating the park, Par Palmer for working so hard to serve us delicious food and for getting all the food donated. A big thank you to everyone who participated and volunteered in any capacity. We appreciate it very much! I am very passionate about these kids and the overwhelming support, love and charity shown to them by attending and donating is awe-inspiring. Thank you!

calendar of events

date	event	contact
2012		
Jun 28-Jul 1	**22nd Annual Cher's Family Retreat** Tempe, AZ	AReeves@ccakids.com 214.570.9099 800.535.3643
Jul 1-6	**Camp About Face** Bradford Woods Martinsville, IN	iuhealth.org/campaboutface 317.274.2489
Jul 13-15	**10th Moebius Syndrome Conference** Sheraton City Center Hotel Philadelphia, PA	www.moebiussyndrome.com dawnang@moebiussyndrome.com 510.304.2302 660.834.3406
Sept	**8th Annual Craniofacial Acceptance Month** Nationwide	AReeves@ccakids.com 214.570.9099 800.535.3643
Sep 8	**5th Annual National Picnic Day** Sandy Lake Amusement Park Carrollton, TX	AReeves@ccakids.com 214.570.9099 800.535.3643
Sept 21	**5th Annual Links of Love Golf Tournament** Bear Creek Golf Club at DFW Airport Dallas, TX	JPatterson@ccakids.com 214.570.9099 800.535.3643

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

testimonial

My husband and I had our beautiful little girl **Averi**, but we felt like something was missing. We decided, as many couples do, to add another child to our family. We anxiously waited to find out the sex of our baby after we announced our pregnancy.

At our 20-week gender ultrasound my husband and I found out our baby was not only a boy but that he would be born with a cleft lip and palate. We were devastated. As parents you assume that your baby will be healthy, but sometimes God works in mysterious ways.

We spent the next 19 weeks worrying if something else might be wrong with him and why we were given this burden to bear. At that point in life nothing else, except our family, mattered. We knew that we were given this little boy for a reason and that he would have a very special purpose in life.

We started researching areas with craniofacial clinics and doctors in the southeast and found a great clinic in Atlanta along with a great plastic surgeon. We met with Dr. Williams, and it was a great and pleasant experience. The first encounter I remember about him was asking if our baby had a name while holding his ultrasound picture. At that point we knew we wanted him to be our doctor.

My next challenge was the fact that his office and the children's hospital was more than two hours away. How was I, a stay-at-home mom, going to afford all the medical bills, gas, lodging and everything else on one salary? How would our three-year-old daughter react to all the attention focused on the baby? Would she love him?

After 19 long weeks, **Adisen** was born a week early and weighed 8 pounds and 0.6 ounces. He was otherwise healthy except for his cleft lip and palate. We made our first trip to Atlanta when he was three days old and continued biweekly trips until he was three months old.

Adisen was fitted for a NAM device, which is like a retainer that helps pull the tissue together to get his mouth ready for surgery. This device had to be adjusted two times a week. He had his lip repair at three months and then his palate repair at six months. Since his previous two surgeries, he has been seen twice a year and recently had another surgery on his nose.

CCA has been so warm and welcoming to our family and my son. Without them I would have had to drive a three-year-old home after his outpatient nose surgery. Instead, they paid for us to stay in a hotel. They also are willing to help with our gas to and from appointments and lodging during appointments and checkups. I am very thankful for them. They have helped a tremendous amount, and I am so grateful for everything they have done for the Gibson Family.

James, Kristi, Averi and Adisen Gibson

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.

fostering tolerance: ways parents and kids

by Katy Hopkins • Doctoral Student in Counseling Psychology
University of Louisville • Louisville, KY

As a parent I often worry, as I know many parents do, how I will keep my child safe from all the "bad stuff" out there. All one has to do anymore is turn on the news to hear yet another heartbreaking story of a child being bullied by their peers, with sometimes tragic consequences. Many parents come to me for advice as to how to help their kids navigate the often rocky road of peer relationships. More and more children report being bullied, not only at school, but on the playground, the bus, and after school on sports teams and other extracurricular activities. So what exactly is bullying and what can parents and kids do about it?

Normal conflict vs. bullying

Conflict between children is normal and developmentally appropriate. Children need to engage in conflict in order to build much-needed skills to face and manage adversity throughout their lives. So what is the difference between a normal conflict and bullying?

NORMAL CONFLICT	BULLYING
Equal power	Imbalance of power
Happens occasionally	Happens repeatedly
Not purposeful	Purposeful
Equal emotional investment	Strong emotional reaction of victim
Not power seeking	Seeking power and control
Remorse	No remorse—blames victim or negates purpose
Effort to solve problem	No effort to solve the problem or make amends (the bully doesn't recognize the problem)

What is bullying?

Bullying is a repeated behavior, either physical or verbal, that occurs over time in a relationship where there is an imbalance of strength or power. This imbalance is either a real or perceived power between the bully and the victim. When many of us think of this power, we may conjure up images of the big kid picking on the little kid. However, power can come in other forms, such as popularity, socioeconomic status, and ability level. The victim does not intentionally provoke bullying. It can be expressed directly *towards* the victim, such as name-calling and physical aggression. Bullying can also be expressed indirectly *about* the victim, such as social exclusion, rumor spreading and cyber bullying.

Roles in bullying

Bullying does not just occur in one-on-one situations. Bullying can involve more than one bully, more than one victim, and multiple bystanders. Children who are bullies tend to have more positive attitudes towards using aggression than their peers. They may have difficulty following or conforming to rules. They may also be popular with their peers and teachers, and have friendships with other kids who bully. Bullies often show little empathy for others.

Children who are victims may be quiet, cautious or sensitive. They may feel insecure and have low self-esteem. They may have little confidence in social situations. They may also find it easier to associate with adults than with their peers.

What can kids and parents do?

Common feelings victims may experience include:

- "This is my fault. I deserve to be bullied."
- "There must be something wrong with me because I get picked on all the time."
- "I don't know what to do to make this stop."
- "If I tell someone that this is happening to me, then I am a bad person for tattling."
- "I'm really sad."
- "I'm really angry."

can STAND UP TO BULLYING

- "I'm really embarrassed."
- "There isn't a way for me to make things better."
- "I'm too scared to go to school."

So what can kids do when they find themselves a victim of bullying?

Positive self-talk

The first thing they can do (and parents can reinforce this) is begin by telling themselves that it's not their fault that they're getting picked on. Parents can help kids practice saying:

- "It's not my problem he's so mean."
- "I don't have to let her hurt me."
- "Don't get upset. Stay calm and decide what to do."

Take action

After empowering themselves with positive self-talk, kids can then try one or more of the following:

- Walk away from the bully.
- Ignore the bully. (Don't take the bait!)
- Change the subject to something else. (A neutral topic that isn't about themselves or the bully.)
- Get support from a friend.
- Ask for help from a teacher, parent, or other trusted adult.
- Tell the bully how they feel and ask him or her to stop.

Many children do not report bullying to adults. Older children and boys are less likely than younger children and girls to report being victimized. Parents can empower their child to handle bullying by helping them practice speaking and behaving assertively (not aggressively).

Encourage kids to voice their feelings and avoid attacking or being negative towards the bully. Help them describe the bully's behavior and how it bothers them. Doing so will help kids, not only by empowering them to stand up for themselves but also help them to accurately report bullying to adults who can help them.

Teach kids to defend others

Bystanders to bullying can serve a variety of purposes. They may come to the aid of the bully by reinforcing or assisting them. They may avoid or ignore the bullying. They may also be a defender and come to the aid of the victim.

Just as important as teaching kids to stand up for themselves is teaching them to stand up for others. Parents can engage their children in conversations that encourage them to think that bullying is mean, not funny, and that someone is getting hurt. Have children ask themselves what they would want someone to do if they were being bullied and what they can do in bullying situations to help. Encourage children to only do what they feel comfortable and safe doing.

Ways that defenders can help other kids being bullied include:

- Comforting the victim during or after the bullying happens.
- Tell an adult immediately or after the bullying happens.
- Get the victim out of the situation.
- Distract the bully.
- Tell the bully directly to stop.

The ultimate solution

Many parents feel, and rightfully so, that it is their child's school's responsibility to keep their children safe in their hallways. Unfortunately, many well-intentioned school districts have responded to this by instituting zero-tolerance bullying policies. These policies often have unintended consequences such as large periods of missed school because of out-of-school suspensions, court appearances and other overly punitive measures.

I propose, and research supports it, schools and parents should be responding not with *zero tolerance* but rather, *fostering tolerance*. We need to teach our children how to stand up, not only for themselves, but also for others. We need to teach children to recognize when they have hurt someone's feelings and work to make meaningful amends. As adults, it is our job to instill values of resiliency, empathy, compassion, understanding, and acceptance. Foster the belief that, as CCA encourages, *beyond the face is a heart.*

indoor flea market

CCA Mom, **Anjolene Whaley** sponsored an indoor flea market to raise funds for CCA. The event was held on February 4th in District Heights, MD at 2100 Oakwood Lane. The event brought in over **$300** in just a few hours! She had thirteen vendors who donated $20 each to CCA in order to show their wares.

In addition, folks gave cash donations as Anjolene also provided information about CCA. Anjolene says she could not have done it all without the help from her good friend, **Laverne Thompson**, who also spent time and energy on the event, in addition to recruiting vendors. She would also like to thank the following donors who provided food, drinks and gift cards for vendors.

- **Safeway** ($25 gift card) Ms. Sedgewick, 8735 Branch Ave., Clinton, MD
- **Starbucks** (coffee discount) 3550 Donnell Dr., Forestville, MD
- **Shoppers** (drinks and snacks) 2950 Donnell St., Forestville, MD

tamale sale

by Abigail De Los Reyes

It was a pleasure to coordinate another successful Tamale Sale for CCA. With the **Community Partnerships & Philanthropy** (CPP) team from **Booz Allen Hamilton** and the ladies' group from **Aldine Church**, we successfully raised **$655** in support of Craniofacial Acceptance Month and in honor of **Natalie Wardlaw**.

The following folks from Aldine Church helped tremendously in making more than 750 tamales: **Janeth Perez**, **Graciela Guzman**, **Rosie Martinez, Alan Martinez**, **Maria Mendez**, **Blanca Vargas**, **Maria Jimenez**, **Magaly Reyes** and **Luzy Vega**.

And many at Booz Allen participated in the fundraiser, including **Charllot Dunnbier** and **D'Lexis Kernan**. Additional support and coordination was provided by **Bebe Watkins**, **Michael Franco**, **Kyle Richard**, **Christine Ekre** and **Kiki Walters**.

The CPP Booz Allen team donated all the items required to make the tamales. The Aldine Church volunteered many hours to prepare and cook the tamales. Booz Allen, **NASA** and other contractors purchased the tamales.

Thank you all!

in her own words

Auria with her sister Emma

My name is **Auria Wilson**. I would like to tell you about how I raised **$50** for CCA. I thought about it and decided I wanted to make a donations bucket for CCA. I put it in **Holiday Foods** in Ferdinand, IN, at the beginning of September, because September was Craniofacial Acceptance Month.

At the end of the month, I picked up the bucket. When I got home I asked my siblings to help me count up all the money, and I was excited to see there was **$50** I could donate to you! I am glad to help. — Auria Wilson

Thank YOU, Auria!

on the border

With the help of her sister-in-law, **Gina**, CCA mom, **Kellie Dowd** held a funder at her local **On The Border Mexican Cantina** in Livonia, MI. She also raised money at her daughter **Josie's** school, **Coolidge Elementary**, where they held a team spirit day. The kids donated $1 for our cause, and they got to wear Detroit Lion or Tiger wear. Funds from these efforts totaled more than **$300**! Thanks so much!

clear lake 8 ball

The **Clear Lake 8 Ball Pool League** held their annual holiday party with a host of wonderful food and players. Since 1998, the Clear Lake 8 Ball has been led by **Pat** and **Mac Vereen**, and they have created a steady fellowship among pool players and have dedicated to giving back each year. For the third year, the league chose CCA Kids as their charity of choice and presented **Jennifer Ausmus** with a check for **$1,000** in honor of CCA kid **Natalie Wardlaw**, who is diagnosed with Pfeiffer syndrome. The members of the League were very generous to help out CCA! A special thank you also goes out to **Legend's Billiards** in League City, TX, and its owners **Mindy** and **Craig Cohen** for hosting the event. A great time was had by all!

cranberry film festival: *torey's distraction* screening

Filmmaker **Tisha Blood**, her husband and film producer **Matthew Taylor** and Torey's mom, **Andrea Harrah** (**Torey** couldn't make it because of school), joined us with **Nick Wiese** in Cranberry Township, PA, for two screenings of the award-winning documentary, ***Torey's Distraction***. The tickets were $10, and Nick had a great turnout of friends, family and walk-up moviegoers. All proceeds came to CCA Kids, totaling **$1,760**!

Nick is a 24 year-old CCA volunteer and ardent supporter who himself has Apert syndrome. He attended his first retreat at age 18. For 10 years the film crew followed the life of Torey Harrah (who also has Apert syndrome) and her family. Nick jumped at the opportunity to educate others about their condition as well as to help raise funds for Children's Craniofacial Association. Thanks to his manager, **Jessica Levine**, and Cranberry Cinemas—where Nick works—it all came together. Thank you, everyone!

rick's raffle

The 2nd Annual Rick's Raffle kicked off on February 14, 2012!

CCA supporters, **Ann** and **Doug Burgin** established an annual raffle in memory of their beloved grandson, **Rick Dornier**. Last year's raffle raised over $2,000 for CCA and the winner's grandson, **Phillip Dicks**, is enjoying his Thomas train table.

This year, the Burgins have chosen a "bundle" of Thomas the Tank Engine toys, as the prize for the memorial raffle. They include a Power Wheels Fisher-Price Thomas Ride-On toy, the Blu-ray/DVD Combo "Thomas & Friends: Misty Island Rescue" and the Fisher-Price "Rescue from Misty Island."

Take-n-Play playset plus 4 Extra Thomas & Friends Die-Cast toys including Ferdinand, the newest character! The total bundle retails for over $250.

The Thomas toys were Rick's favorites and the winning ticket will be drawn on Rick's birthday, April 25th. The Burgins and Rick's family remain steadfast in their wish that the funds from the raffle be designated for CCA's Patient Financial Assistance program which will help families defray expenses while seeking medical care for craniofacial conditions.

Tickets remain $5 each, 5 tickets for $20 (1 free!), or 15 tickets for $50 (5 free!).

Phillip Dicks, winner of last year's Thomas train table.

Call NOW to purchase your tickets! Contact Jill at jpatterson@ccakids.com or 214.570.9099 or 800.535.3643.

cca's newest resource for craniofacial families:

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

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

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

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

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

www.ccakidsblog.org

Find us on Facebook – CCA Kids Blog

Brothers, **Griffin** (top left) and **Jackson Standridge** (lower left) made ornaments and sold them at their holiday market to benefit CCA kids. Proceeds came to **$80**! Thanks boys! You are a couple of Christmas angels!

Click on

DONATE

at ccakids.org

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

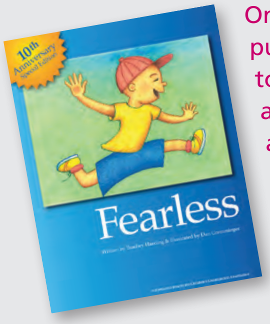
CCA is now offering support groups for 3 ages!

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.



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

2012 annual cher's family retreat announced

June 28-July 1 in Tempe, AZ

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

We hope to see you there!

donors, january 1 – september 30, 2011*

Gifts from Individuals

CCA Supporters

(up to $100)

Marcia & Wayne Abbott
Dianelis Adams
Mike & Susan Akin
Ashley Alford
Carolyn Alloway
Amy Altman
Dr. & Mrs. Chester Amedia
Jacqueline & Mark Angelilli
Anonymous
Fernando & Ilda Arcari
Stephanie Ornelas Archuleta
Bill Ash
Barbara Augenblick
Max & Jo Baer
Morgan Bates
Norma Batley
Tom & Marianne Baird
Andrew Bartkowski
Laura Beeler
John Ben & Marcy Kelley
Tammy & Andrew Berry
John Bertolucci
Kathleen Best
Christian Billman
Donna Blair
Joel & Yael Blasberg
Mike Bosko
Colin Boylem
Cynthia & James Bratcher
Philip & Judith Bressler
Rich & Clare Brill
Thomas & Sharon Brockhaus
Joe Brooks
Jeffrey Brown
Christopher Burnett
Catherine Burzio
William & Olivia Butler
Shaun Callaghan
Rene Campbell
W. Reid & Kerry Carlisle
Joseph Cattell
Dorothy Chegwidden
Barbara Chernetz
Maureen Cleary
Christine Clinton
Harold & Gail Cohen
Elvera Colon
William Core
Nellie Coudare
Timothy Cox
Joe Allen Crabtree
Thomas Croft
Harvey & Venita Crowson
James & Nance Cutler
Felicia Damato
Kathleen Danielson
Joyce & Horace Davies
Milton & Yvonne Davis
David & Patricia DeLong
Joseph & Suzanne Demalik
Josephine & Frank Deronja, Jr.
Greg & Theresa Deville
D'Gerolamo, Chad & Shannon
Camilla Diaz-Perez
Robert Donnes
Robert & Amanda Dornier
Dan & Lisa Durkee
Thomas & Lana Elliott
Diane Embry
Pauline Fallon
Lori Faust
Michelle & Joseph Ferguson
Diana Feuer
John & Carrie Follett
Jennifer Ford
Elizabeth & Lawrence Forte
Anna Fowler
Vikki Freeman
Mike Fuhrman
Therese & Michael Gabriel
Dr. John & Florence Galida
Dawn Garrity
Robert & Joyce Gallant
Frank & Maryann Gilson
Melissa Giltz
Harold Glaser
Max & Pamela Goldstein
Reynold Gravina
Marsh & Josephine Hansbrough
Alfred Harf
Kevin & Ellen Haugh
Dovie Heavrin
Carole Helring
Lisa Heral
John & Kathryn Hibler
Beth Higgins
Mandie Hiznay
Jane Hoffman
Eileen Hofmeister
Angela Hohl-AbiChedid
Marjorie Hough
JoAnn Hricenak
Albert Hughson, Jr.
Daniel Ingram
Margaret & Edward Irving
Jennifer Jaffe
Jenny Jett
Maureen Johns
Ernest & Judith Jones
Mark & Barbara Jones
Natasha Joshi
Theodore Kalivas
John & Betty Keller
Eugene Kessler
Michael & Kathryn Kevany
Thomas & Barbara Kochendorfer
Michael Kogut
Kevin Eugene & Ellen C. Kolkhorst-Haugh
Michele Koushan
James & Sandra Kovach
Pamela & Lee Kramer
Bethany Kusterman
Paul Kyle
Isabelle & Fred Lance
Lisa Latona
Mika Lawson
Diana Lesko
Arthur & Judith Levan
James & Lisa Levan
Janice Liddic
Wayne & Margaret Loebsack
Joseph & Veronica Logan
Duane Long
Tye & Michele Long
James Lonzenia

Listed are **monetary donations through 4th quarter, 2011**. We are extremely grateful for these and all other fees, purchases, fundraisers and in-kind donations not individually recorded here.

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)

Kenneth Luby
Renee Lucckino
Doris & Norbert Lustine
William J. Luyben
Joan Maddock
James Macaulay
Jimmy Mangus
Debbie Maples
Anthony & Patricia Marino
Carol Martino
Marty Mashe
Albert Mata
David & Patricia Matula
Warren McAllister
Stephen & Lisa McBride
Mary & Edward McCarthy
Kelly Burks McDade
Ellen McPadden
Marion McPadden
Carol Melton
Edward & Sandra Menard
Jennifer Miller
Margaret Mitchell
James J. & Mary Jo Montalbano
Jessie & Theodore Morgan
Mary Ellen & Gerard Morgan
Cynthia Morris
James Morris
Virginia & Luke Mulherin
David & Paula Mullins
Diane Myazoe-Debrum
Jasmine Myazoe
Melissa Chancey Najera
Paula Naquin
Janell Nelson
Arthur Nendza
April Newton
Jeffrey Nicholson
Paul Niebruegge
Rob & Jackie Nierman
Ralph Nuchols
Michael & Marti O'Brien
Matthew Osburn
Miguel & Claudine Pacheco
Richard & Sylvia Pallman
Robert & Ottie Paslay
Emmons Patzer
John & Diane Pelletier
Barb Petruck
Tracy Popescu
Thomas & Carol Porter
Vicky Porter
Joan Poston
Joseph Propri
Robert Raike
Doris Repshis
J. & B.L. Riese
Joseph & Marilyn Roche
Mona Roche
Michael Rodell
J.C. Rogillio
Allan & Lisa Ross
Heather Ruegg
Sonya Saladine
Elie Saliba
Mark Sanborn
Fayeann Sandstrum
Nicholas & Mary Sarcinelli
Thomas Sauer
Paul Savage
Patricia & Jeffrey Sharpe
Kimberly Shepard
Stephen Shields
Lillian Showalter
Leonard Siegel & Julia Pogach
Rafael Ignacio Sierra
Ann & Anthony Silano
Kathy & Curtis Skropits
Solange Skyer
Charles Sluman
Cheryl Smith
D.J. & P.S. Smith
Dennis Smith
Marilyn & James Smith
Katherine Snyder
Steven Sokach
Francis Stanford
Daryl & Allison Standridge
Gregory & Geralyn Stark
Kristina Stege
Thomas Stephens
Michael & Susan Stoudt
Daniel Strack
Eleanor Strony
Sandra & Ronald Strony
Frances Stanford
Kristina Stege
William & Nancy Suwalski
Elizabeth Sweeney
Beth Szela
Jasmine Tangcay
Marc Taylor
Truman & Mary Terrell III
Anita Tharp
Sherry Thompson
Renee Thurston
Anne Tibbals
Neva Tomlinson
Timothy & Brenda Tompkins
Richard & Lori Urso
Edgar & Joan Vallar
Kay Van Cleave, PH.D.
Peter & Patricia Vantil
Dwight & Carrie Vaughn
John Yorio
Robert Yusinski
Heather Ward
Karen Waring
Judy & Ronald Warunek, Sr.
John & Benita Wasilisin
Jennifer & Paul Wayne
Natalie Weber
Barbara Weideman
Harvey Weiner & Susan Kava
Amanda & William Willet
Rebecca Williams
J.B. & Cynthia Wills
Reed Wills
Tammy Blessinger Wilson
Dr. John & Mary Wittgen
Chris & Nancy Wyant
Cheryl Youngs
Blanche & Jean Zabady
David Zweier

CCA Friends

($100 +)

Beth Abel
Chris Abel
Anonymous
James Antoun & Jamie McMillin
Carol Jean Anthony
Tim Ayers & Christine Smith
Eleanor & Charles Berglund
Robert & Julia Boyce
Cynthia & James Bratcher
Jeffrey M. Brown
Mike & Mary Ann Budish
Ann & William Burgin
Todd & Eileen Burrous
Kelley Butler
Michael Cahill
Larry Carpenter
Robin Chapurtinov
Madeleine Cherry
Mary Ann Clark
Judith A. Clonan
Ann Connolly
Kimberly Constantine
Declan Cook & Paul Tremblay
Susan Cooper
Michele Cotignola-Eifert
Richard Cullen
Ruth & Gerald Dankelson
Casey Deakins
Yumi Debrum
Robert DeVille
Maura Dewan
Louis C. Difabio II
Debbie Dornier
Denise Duby
Keith Eckel
Antonio Estrada
Alan & Jennifer Farmer
Deirdre Farrell
Frances Fisher
Heath Fisher
Roland & Dorothy Freeman
Mary & Harry Froehlich
Lucia Garcia
Gail & Raymond Garvin, Jr.
Max & Pamela Goldstein
Ruby Gorman
Bernadette Gutgsell
Sarah Hall
Linda Hanes
Rosemary Hanrahan
David Heisler
Andrea Horsch
Clayton & Kathy Huck
Mr. & Mrs. Walter Humann
William Hunter
Robert Jacobson
Abigail B. Jaffe
Jerry & Katherine Jandres
Holly M. Jenkins
Russell & Carol Jenna
Clifford Jericho
John & Maurita Kapp
Richard Kinas
Mary King
Kathryn J. Kitchens
Jan Koren
Esther Krieger
Beverly Lacaillade
Sylvia & C.K. Lawson
Jess Leyva
Sie Min Lie
Samuel & Kathleen Lowery
S.F. Luhrs
Alvin & Betty Macko
Doug & Janis Macut
Kimberly Martin
Lisa McBride
Kevin McNulty
Frank & Patricia McPadden
Laurie Monnier
E. J. Morrissey
Robert Muller
Claudia Airaudi Myall
Emerson North
Mose & Marcia Nowland
Brad & Ann Orcutt
Jackie Halpin-Osteen
Ann Patterson & Howard Langner
Greg & Jill Patterson
Andrew & Andrea Potash
Brenda Powell
Ann Ranfranz
Jessica Roche
Joanne M. Roosevelt
Marie Rourke
Nancy Rumore
Roberta & Robert Schini, Jr.
William Schuler
Barry Scurran
Fred & Rose Seitz
Wayne & Susan Sherman
Stephen Shields
Michael Slusher
Dean Spanos
Erin Stephens
Jane Stickney
Christopher Stokes
Rebecca Sunda
Michael Thomas
Irene Tunanidas
Llisa Uken
Gary Uttke
Dwight Vaughn
Jon Welles
Max White
C.M. & Leila Wiley
Robin Williamson
Eva & Steven Willms
David & Nancy Winters
Michael Wilson

CCA Companions

($250 +)

Anonymous
Erik Baumann
Michael & Lisa Bock
Beverly & Jim Butera
Roger S. Chin DDS
George Dale, Sr.
Randy Dale
Dede & Darin Dankelson
Mike & Maria Estrada
M. Brian Evans
Martin Grupp
Jackie Halpin-Osteen
John & Arleen Heirty
Arie Krier
Roger & Carolyn Lamb
Deborah Mecklenburg
Ron Micetic
Jacob & Erica Mossholder
Steven L. Page
Joseph & Gloria Pike
Chris Riener
Fred Siyufy
Ray & Ellen Stevenson
Leona Vitolo
Priscilla Voss
Marcia Weber

CCA Extended Family

($500 +)

Anonymous
Mario Adamo
Veronica Boyd
Martha Brown
Fred & Judi Freeman
Elizabeth W. Jones
Paul & Fran Leatherwood
Ann & Don Lucas
Joe & Allison Morrissey
Katherine Olsen
Jana & Hugh Peace
Paul R. Pokladnik
Mason Rymal
Ingrid Swenson

CCA Sponsor

($1,000 +)

Anonymous
Joseph Broderick
William Burns for Friends of Jeremy
Michael Carr
Diana Critchlaw
Karen Condino, for Decade of Difference
George & Kristine Dale
Ann & Ari Deshe for the Chocolate Festival

Jeffrey Fearon, MD
Krishan K. Goel, MD, Inc. for Henry's March
Molly & Bob Lytle
Robert Reader
John & Lora Sessions
E. C. Styberg, Jr.
Kenneth Wilson
Sarah Zimmerman for the Chocolate Festival

CCA Patron

($2,500 +)

Andrew Bustillo for Decade of Difference
Charlene & John Smith
Marty & Mike Willson

CCA Benefactor

($5,000 +)

Bob & Paula Guzzo
Greg Luetkemeyer
John & Sheryl Paul

CCA Guardian

($10,000 +)

Cher
Bill Mecklenburg & Christine Condino-Mecklenburg

CCA Legacy Society

Dede & Darin Dankelson

Memorials / In-Honor Gifts

Chris Abel, in honor of the Abel Family
Mario Adamo, in honor of Annie Reeves' birthday
Mike & Susan Akin, in honor of Wendelyn Osborne
Ashley Alford, in honor of Luke Bowen
Dr. & Mrs. Chester Amedia, in memory of Katherina Seitz
Anonymous, in honor of Josie Knight & Flynn Family
Anonymous, in honor of Luke Bowen
Anonymous, in memory of Hank Deily
Anonymous, in honor of Jeremy Dale, in memory of Henry T. Deily
Anonymous, in honor of Annie Reeves' birthday
Anonymous, in memory of Rick Dornier
Anonymous, in honor of Nick Wiese
Amy Altman, in honor of Jamal Jericho's birthday
Stephanie Ornelas Archuleta, in honor of Annie Reeves' birthday
Barbara Augenblick, in memory of Hank Deily
Britt & Colleen Balkcom, in honor of Solomon Glenn's 10th birthday
Laura Beeler, in honor of Nova Cox
Black Sheep Organization, in memory of Hank Deily, in honor of Jeremy Dale
Michael Bock Family, in memory of Rick Dornier
Robert & Julia Boyce, in memory of Rick Dornier
Colin Boylem, in honor of Avery Lytle
Rich & Clare Brill, in honor of Jeremy Dale, in memory of Hank Deily
Joe Brooks, in honor of Annie Reeves' birthday
Ann & William Burgin, in memory of Rick Dornier
Catherine Burzio, in honor of Annie Reeves' birthday
Andrew Bustillo, in honor of Morgan Mecklenburg
Larry Carpenter, in honor of Cher
Larry Carpenter, in honor of Cher's birthday
Brenda Catalanatto, in memory of Rick Dornier
Dorothy Chegwidden, in honor of Luke Bowen
Mary Ann Clark, in memory of Hank Deily, in honor of his grandson, Jeremy Dale
Maureen Cleary, in honor of the Cronin Family
Christine Clinton, in honor of Annie Reeves' birthday
Michele Cotignola-Eifert, in honor of Jeremy Dale
Kimberly Constantine, in memory of Hank Deily
Thomas Croft, in memory of Hank Deily
Timothy Cox, in memory of Rick Dornier
Harvey & Venita Crowson, in honor of Megan Cronin
Richard Cullen, in memory of William Mecklenburg
Ruth & Gerald Dankelson, in memory of Mary Ann Sennish
Yumi Debrum, in honor of Jamal Jericho's birthday
Josephine & Frank Deronja, Jr., in honor of Alison & James Hawse
Robert DeVille, in memory of William Mecklenburg
Maura Dewan, in memory of William Mecklenburg
Debbie Dornier, in memory of Rick Dornier
Denise Duby, in memory of Hank Deily
Keith Eckel, in memory of Henry Deily, in honor of Jeremy Dale, his grandson
G.L. Estrada, in honor of Tony's birthday
Mike & Maria Estrada, in honor of Tony's birthday
M. Brian Evans, in honor of Erica Mossholder
Pauline Fallon, in memory of Hank Deily, in honor of Jeremy Dale
Jeffrey Fearon, in honor of colleagues
Michelle & Joseph Ferguson, in honor of CCA kid Jeremy Dale, in memory of his grandfather, Hank Deily
Diana Feuer, in honor of Lynn Keiner
Heath Fisher, in memory of William Mecklenburg
Anna Fowler, in honor of our 2 sons who were both born with clefts
Roland & Dorothy Freeman, in honor of Robbie Gorecki
Vikki Freeman, in honor of Jeremy Dale, in memory of Hank Deily
Therese & Michael Gabriel, in memory of Hank Deily, in honor of Jeremy Dale
Dawn Garrity, in memory of Rick Dornier
Brandon Gibson, in honor of Soloman Glenn
Melissa Giltz, in honor of Annie Reeves' birthday
T.J. Jr. & Mary Lib Burgin Guercio, in memory of Rick Dornier & Mrs. Odella Arboneaux
Bernadette Gutgsell, in honor of Ralph Royer
Bernadette Gutgsell, in honor of Wendy Caten
Jackie Halpin-Osteen, monthly giving, 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 Heirty, in memory of Agnes Butler
Jim & Arleen Heirty, in memory of Diane Cody and Kay Cody
Jim & Arleen Heirty, in memory of Al Dippold
Jim & Arleen Heirty, in memory of Dolores Carroll
Jim & Arleen Heirty, in memory of Connie Fedorski
Jim & Arleen Heirty, in memory of Virginia Haase
Jim & Arleen Heirty, in memory of Ralph McCarthy
Jim & Arleen Heirty, in memory of Janet Mueller
Jim & Arleen Heirty, in memory of Ed Pitchkolan
Dovie Heavrin, in honor of Rocky Dennis
David Heisler, in honor of Jeremy Dale, in memory of Hank Deily
Carole Helring, in honor of Jeremy Dale, in memory of Hank Deily
Beth Higgins, toward financial assistance for cleft lip and palate, in honor of Mary Clarke
Beth Higgins, toward financial assistance for cleft lip and palate, in honor of Kim Grant
Jane Hoffman, in memory of William Mecklenburg
Carey Hough, in honor of Nova Cox
Angela Hohl-AbiChedid, in honor of Jeremy Dale, grandson of Hank Deily
Andrea Horsch, in honor of Jeremy Dale, in memory of Hank Deily
JoAnn Hricenak, in memory of Henry (Hank) Deily, in honor of Jeremy Dale, his grandson
IMCO Carbide Tool, Inc., in honor of Matthew Osburn
Daniel Ingram, in honor of Chase Ingram
Interludes, in honor of Jeremy Dale
Margaret & Edward Irving, in memory of Hank Deily, in honor of Jeremy Dale
Abigail B. Jaffe, in honor of Jen & Adam Kellogg
Jennifer Jaffe, in honor of Jennifer & Adam Kellogg
Jerry & Katherine Jandres, in memory of Hank Deily, in honor of Jeremy Dale
Clifford Jericho, in honor of Jamal Jericho's birthday
Jericho/Myazoe Family & Friends, in honor of Jamal Jericho's 4th Birthday
Jenny Jett, in honor of Elaine Gumbiner
Ernest & Judith Jones, in memory of Hank Deily, in honor of Jeremy Dale
Maureen Johns, in memory of Hank Deily, in honor of Jeremy Dale
Yukiko Johnson, in honor of Henry Johnson
John & Maurita Kapp, in memory of Hank Deily, in honor of Jeremy Dale
Mary King, in honor of Jeremy Dale, in memory of his grandfather, Henry T. Deily
Kathryn J. Kitchens, in honor of granddaughter, Brisa Dougan
Paul Kyle, in memory of Rick Dornier
Isabelle & Fred Lance, in memory of Hank Deily
Lisa Latona, in memory of Rick Dornier
Mika Lawson, in memory of Rick Dornier
Paul & Fran Leatherwood, in honor of Char Smith
Arthur & Judith Levan, in memory of Hank Deily, in honor of Jeremy Dale
James & Lisa Levan, in memory of Hank Deily, in honor of Jeremy Dale
Janice Liddic, in honor of Jeremy Dale and in memory of Henry Deily
Joseph & Veronica Logan, in memory of Rick Dornier
Duane Long, in honor of Casey Deakins
Ann Lucas, in honor of Don's birthday/"Be Brody's Angel"
Ann & Don Lucas, in honor of their anniversary/"Be Brody's Angel"
Ann & Don Lucas, in honor of Brody/"Be Brody's Angel"
Don Lucas, in honor of Ann's birthday/"Be Brody's Angel"
Molly & Bob Lytle, toward Retreats, in honor of Avery Lytle
Jimmy Mangus, in honor of Luke Bowen
Kimberly Martin, in memory of Ellery Walker
Kelly Burks McDade, in honor of Annie Reeves' birthday
Ellen McPadden, in memory of Hank Deily, in honor of Jeremy Dale
Frank & Patricia McPadden, in memory of Hank Deily, in honor of Jeremy Dale
Marion McPadden, in memory of Hank Deily, in honor of Jeremy Dale
Jennifer Miller, in memory of Odella Arboneaux
Anne Milneck, in memory of Rick Dornier
Margaret Mitchell, in memory of Hank Deily
Laurie Monnier, in honor of Jeremy Dale
James & MaryJo Montalbano, in honor of Jennifer
Cynthia Morris, in memory of Rick Dornier
Virginia & Luke Mulherin, in memory of Hank Deily, in honor of Jeremy Dale
Robert Muller, in memory of Stephen John Krasusky
Diane Myazoe-Debrum, in honor of Jamal Jericho's birthday
Jasmine Myazoe, in honor of Jamal Jericho's birthday
Melissa Chancey Najera, in honor of Annie Reeves' birthday
Paula Naquin, in memory of Rick Dornier
Jeffrey Nicholson, in memory of Rick Dornier
Jill & Greg Patterson, in memory of Hank Deily, in honor of Jeremy Dale
Tracy Popescu, in honor of Luke Bowen
Vicky Porter, in honor of Ellasyn Bergman
Andrew & Andrea Potash, in memory of William Mecklenburg
Joan Poston, in memory of Odella Arboneaux
Brenda Powell, in honor of Hank Deily
Christen M. Price Memorial Fund of the Martin County Community Foundation, in honor of Dr. Jeffrey Fearon
Robert Raike, in memory of William Mecklenburg
Robert Reader, in memory of William Mecklenburg
Doris Repshis, in memory of Hank Repshis, in honor of Jeremy Dale
Mona Roche, in memory of Henry T. Deily
J.C. Rogillio, in memory of Odella Arboneaux
Nancy Rumore, in memory of Rick Dornier
Ann Schafer, in loving memory of William Mecklenburg
Schott North America, Inc., in memory of Hank Deily
Fred & Rose Seitz, in honor of Frederick Seitz's high school graduation
Patricia & Jeffrey Sharpe, in memory of Rick Dornier
Kimberly Shepard, in honor of Juliana Wetmore
Wayne & Susan Sherman, in memory of Hank Deily
Stephen Shields, in honor of Peter Dankelson
Leonard Siegel & Julia Pogach, to CCA from Rhoda with love.
Solange Skyer,in memory of Rick Skyer, Jr.
Charles Sluman, in honor of Seth Swihart
Charlene Smith, in honor of Sharon Allbright's birthday
Charlene Smith, in honor of Annie Reeves' birthday
John & Charlene Smith, in memory of Hank Deily, in honor of Jeremy Dale
Smith Middle School of Fort Hood, in memory of Stephen Krasusky
Katherine Snyder, in memory of Odella Arboneaux
Steven Sokach, in memory of Hank Deily, in honor Jeremy Dale
Dean Spanos, in honor of Paige Spanos
Gregory & Geralyn Stark, in memory of Rick Dornier
Kristina Stege, in honor of Jamal Jericho's birthday
Jane Stickney, in honor of Caroline Dale in the name of her grand aunt, Iris Schell and grand parents, Patricia and William Powell
Eleanor Strony, in honor of the wedding of Dr. & Mrs. Alan Gillick
Sandra Strony, in memory of Henry T. Deily, to honor his grandson, Jeremy Dale
Ingrid Swenson, in honor of Robbie Gorecki
Jasmine Tangcay, in honor of Cher for Christmas
Sherry Thompson, in honor of Luke Bowen
Renee Thurston, in memory of Hank Deily
Anne Tibbals, in honor of Amy and Evan Beale
Neva Tomlinson, in memory Harry Surratt
Llisa Uken, in honor of Sophia Weaver
Kay Van Cleave, PH.D., in memory of Lola Kate Wimberly Van Cleave
Leona Vitolo, in honor of Zachary Bordonaro
Priscilla Voss, in memory of William Mecklenburg
Heather Ward, in honor of Annie Reeves' birthday
Judy & Ronald Warunek, Sr., in memory of Hank Deily
John & Benita Wasilisin, in memory of Henry T. Deily to honor his grandson Jeremy Dale
Natalie Weber, in honor of Luke Bowen
Marty & Mike Willson, in honor of Avery Lytle
Marty & Mike Willson, toward Retreats, in honor of Avery Lytle
Tammy Blessinger Wilson, in honor of Annie Reeves' birthday
Susan Wilson, in honor of Josie Knight
Reed Wills, in honor of Cynthia Wills
Thompson, Coe, Cousins & Irons, LLP, in memory of Stephen John Krasusky
Barbara Weideman, in memory of Jennifer Walker
XCD Management Services Management & Staff, in memory of Katherina Seitz
Robert Yusinski, in honor of Jeremy Dale, in memory of Hank Deily
Blanche & Jean Zabady, in memory of Hank Deily, in honor of Jeremy Dale

Corporate/ Foundation Gifts

CCA Corporate/ Foundation Friends

up to $1,000

American Express Charitable Fund (employee giving)
AT&T (United Way Employee Giving Campaign)
Bank of America (United Way Campaign employee giving)
Black Sheep Organization of the West Side
The Brotman Foundation
Cameron Manufacturing & Design
Chubb & Son, Division of Federal Insurance Company (matched gift of Jeffrey M. Brown)
Columbia Gulf Transmission Company (matched gift of Robert Schini
Combined Federal Campaign / Local
Creative Growth Counseling & Coaching
Directed Technologies
The Elena Melius Foundation
The Final Touch
Funding Factory (Ink/cell recycle rebates)
GoodSearch (purchases percentage incentives)
Hargrove Oil Company, LLC
Heart of Illinois United Way, Inc.
Jay C. Service Inc.
IBM Employee Services Center (employee giving)
IMCO Carbide Tool, Inc.
Interludes
Interpro Rapid Technologies
Kraft Foods Global, Inc.
Maine Alpha Delta Kappa Epsilon Chapter
Metal Parts & Equipment Company
Microsoft Employee Giving Matching Gifts Program
Microsoft (matched gifts of M. Brian Evans)
The Minneapolis Foundation (donor advised fund)
MissionFish (Ebay, directed donations thru percentages of sales)
Northrup Grumman Employee Giving
Opinions for Good (OP4G) (survey incentives)
Pfizer (United Way Campaign employee giving)
Printer Chicks
Prudential Foundation (matched gift of Diana Critchlaw)
Prudential Foundation (employee giving)
The Redwoods Group
Safeway, Inc. (purchases percentage incentives)
Sarah Hall Productions
Schott North America, Inc.
Swan & Sons-Morss
Thompson, Coe, Cousins & Irons, LLP
Truist for Qwest , JCPenney, Citigroup, & UPS (employee United Way giving)
Turlock Poker Room
United Way of Denton County (donor-directed donations)
United Way of Greater Milwaukee (donor-directed donations)
United Way of Greater Richmond & Pittsburg (donor-directed donations)
United Way of the National Capital Area (donor-directed donations)
United Way of the Southern Tier (donor-directed donations)
United Way of Southeastern Pennsylvania (donor-directed donations)
United Way of Tarrent County (Bell Helicopter Employee Giving)
United Way of Tucson & Southern Arizona (donor-directed donations)
VFW Post 6393
Wal Mart Foundation
Wisteria
Wright Refrigeration & Consulting
XCD Management Services

CCA Corporate/ Foundation Sponsors

$1,000-$5,000

B.B. Owen Trust
BP Corporation of North America, Inc. (toward the Hartley Company fundraising effort)
The Brotman Foundation
Children's Surgical Associates for Friends of Jeremy
Combined Federal Campaign
Corning Beagle Club for Friends of Jeremy
Epic Residences for the Chocolate Festival
E.C. Styberg Foundation, Inc.
The Foot Fetish Fraternity
Henry W. Bull Foundation
Honda Financial Services
Inshallah Trust
KLS Martin L.P. (Dallas holiday party sponsorship)
Christen M. Price Memorial Fun of the Marin County Community Foundation
Simmons Rockwell for Friends of Jeremy
Sound Impressions for Links of Love
T.A. Robinson Asphalt Paving (Nick Wiese fundraising effort)
The Rosewood Foundation
Vivo Brothers

CCA Corporate/ Foundation Partners

$5,000-$10,000

Association Works
Bank of America
Cher Charitable Foundation
Corning, Inc. (Collectively by Dept.) for Friends of Jeremy
Elizabeth Toon Charities
Florence Foundation
Foster Poultry Farms for Henry's March
Inshallah Trust
The Jorge Posada Foundation
Martin Woodall Foundation, Inc.
The Max and Victoria Dreyfus Foundation
Stemmons Foundation
The Tony Stewart Foundation, Inc.
Torey's Distraction Fund of The Dallas Foundation

CCA Corporate/ Foundation Patrons

$10,000 or more

Fundraising Events & Other Efforts

Up to $1,000

Cash cans /placed by Kim Rogers, Bradley, IL
Cash can / placed by Freeman Insurance, Tucson, AZ
CD Sales / John Moulton
Be Brody's Angel / Brody Lucas' Family Fundraising Effort
Club Italiano, Westchester Community College / Lindsay Bordonaro
Pete Dankelson's Fundraising Page / Firstgiving Online
Justin Graham's Fundraising Effort / Sherry Graham
Lincoln Heights Elementary Penny Drive / Angie Marcum
Lewis Plez IV CCA Wristband Sales Fundraising Effort /Tyeisha Jefferies
Scentsy Funder / Tony Zazza, Consultant Donor
Simple Simon's Pizza / Carol Andrews
Thirty-One Funder / Lisa Bock, Consultant Donor
Wristband Sales for CCA / Alie Cabo, CCA Volunteer

$1,000-$5,000

CCA Chance Raffle / Annual Family Retreat Attendee Participants
Do Yoga, Do Good in honor of Nova Cox / Ananda Yoga, Justine Budhram
Friends of Freddie / Frederick Seitz Fundraising Effort
Otterbein University Women's Soccer Funder
Rick's Raffle / Raffle Ticket Sales / Established by Ann & Doug Burgin
Ryan's Road for CCA 9-Pin No Tap Bowling Tournament / Gulich Family
Torey's Distraction Screening / Nick Wiese
Trevor's Trip To Triumph Motorcycle Ride / Kim Tryzanowski, Erik & Trevor Larys

$5,000 or more

Lily's Dinner / Tosha, Nathan, Lily, Tanner, Nick & Josey Walker
Raegan's Rally / Ashley, Boz, Raegan, & Drew Daugherty

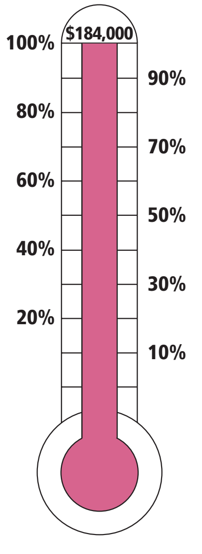
$10,000 or more

Chocolate Festival / Chef Rick Chiavari
Links of Love Golf Tournament

$20,000 or more

Friends of Jeremy Golf Tournament / Kristine, George, Jeremy, Tommy & Cody Dale
Hartley Co. Golf Tournament in honor of Raegan Daugherty / Eric Johnson
Henry's March / Rachel, TJ, Lauryn & Henry Johnson
Texas Moms' 5K for CCA / Becky White, Lisa Bock, Brenda Siebert, Lindsay Knight +

2011 FAMILY FUNDRAISER GOAL THERMOMETER



donor in the spotlight

In our first 2012 issue, we would like to highlight a very special donor, ***Mr. Joseph Broderick****. Joe gives through his workplace United Way Campaign as well as responding to our direct mail appeal letters. He's also one of our best supporters for all of our raffles. We asked him to tell us in his own words, why he started giving to CCA.*

About two years ago I was waiting in line at an Alpharetta, GA post office and in front of me was an attractive young woman with her two children, a boy about 6 or 7 and a girl about 4. The line was slow moving and I had about a half hour or so to observe them. The boy was a handsome kid, very active and friendly. He introduced himself to me and introduced his sister. The girl was shying away, crouched on the floor playing with a toy. She hardly looked up, but I could see right away that she had facial differences. I didn't know what is was exactly, but I knew it was a syndrome from birth.

By the time we had finished our business and left the line I was emotionally involved and I had to know what the girl's condition was and how she might fare in the future. I returned to my office and began searching the Internet for answers. I quickly recognized the girl's condition as Apert syndrome. My searches also found Children's Craniofacial Association. My employer, UPS, is connected with United Way and my primary charity at that time was North Fulton County (Georgia) Charities. As soon as I could, I switched most of my United Way contribution to CCA, increased the amount, and wrote a letter to NFCC informing them of my action. They responded in the kindest way. Observing that girl that day, without staring, was a very moving experience, and I'm so pleased and proud to know about CCA and to be able to be a contributing associate.

One person can make a huge difference for many. Thanks for being one of those people, Joe Broderick— our Donor in the Spotlight!

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

NONPROFIT ORG
U.S. POSTAGE
PAID
RICHARDSON, TX
PERMIT NO. 128

children's
craniofacial
association

Honorary Chairperson:
Cher

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

CCA Network Editor:
Kelly Liszt

CCA Network Design and Production:
Robin Williamson,
Williamson Creative Services, Inc.

Executive Director:
Charlene Smith

Program Director:
Annie Reeves

Development Director:
Jill Patterson

Administrative Coordinator:
Jana Peace

voice 214.570.9099
fax 214.570.8811
toll-free 800.535.3643
url CCAkids.org

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

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

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

ryan's road

By Nicole Gulich

Our son, **Ryan Jr.**, was born December 16, 2001, with Apert syndrome and has been a blessing to our family ever since. It only seems fitting to celebrate our blessing while raising awareness of craniofacial differences in the community.

Bowling is one of our family's favorite activities to do together. We decided it would be fun to host a bowling tournament to honor CCA. So, last December, we held a 9-Pin No-Tap Youth/Adult Bowling Tournament at **Crystal Bowling Lanes** in Corning, New York. This means if you were able to knock down 9 pins in your first ball you would record a strike. There were seven "300" games bowled between two shifts of bowling. It only seemed fitting that Ryan's mom bowled a 300 to finish the tournament! We had door prizes, a bowling ball raffle, and a raffle for 4 tickets to a **Buffalo Bills** game. The event was successful in, raising more than **$4,500**, with additional donations still expected to come in.

We are blessed by our family, friends, and community as year after year they come out to support CCA. We had more than 150 people in attendance, and we cannot thank them enough for supporting such a wonderful cause. A special thank you to: **Horizon Solutions**, **Realty USA**, **Crystal Bowling Lanes** and **Dandy Mini Mart** as they were our top sponsors of the event. This is our family's third fundraiser for CCA. We have been fortunate enough to raise just over **$18,000** so far, and we look forward to raising even more!