ccanetwork

quarterly newsletter of the children's craniofacial association

Cher — honorary chairperson

spring 2011

inside

a mother's perspective

By Lisa Moore

We moved to Tampa when I was 8 months pregnant with **Katie**. I was polyhydric (extra amniotic fluid), and they were concerned that her head was measuring larger than her age. At the follow-up ultrasound they also took note of her feet and toes. I knew in my heart something was wrong. Without knowing what we would be facing at her birth, Tom and I were blessed with an 8 lb 9oz baby girl with Pfeiffer's syndrome.

We thought we were very fortunate there was a doctor coming out of the OR who noticed Katie immediately and told my husband that she had a craniofacial syndrome. (We would later read that some families experience a long period without identifying their child's syndrome or condition.) He said that surgery would correct her head, she would be

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message from the chairman

It is an honor to write this as the newly elected chair of the Children's Craniofacial Association Board of Directors. If you're reading a **CCA newsletter** for the first time, my hope is that you will want to seek a relationship with CCA and become a part of our wonderful family. If you're a regular reader and already a part of the CCA family, thank you for your continued involvement and support. I hope your needs are being met and that you are motivated to remain a vital part of the organization, where our vision is a world where all people are accepted for who they are, not how they look.

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Q&A with camryn berry

Tell me a little bit about school.

I am in the sixth grade at Livermore Falls Middle School in Livermore Falls, Maine. Something interesting about my school is we are preparing for consolidation between my school and the school from the next town over. Next year, I'll be going to a new school and will meet a lot of new kids. I am also on the Student Council, so I get to help organize things.

What are your favorite subjects?

I like language arts, gym, math and art. But I probably like gym the most because I get to let out all my energy!

Do you have any after-school activities?

I am a member of the school newspaper, which meets after school. I also participate in youth group at my church. I play soccer in the fall (I didn't get to this past season because of surgery) and basketball in the winter. I'm looking forward to trying track for the first time this summer.

Any hobbies?

I like to write, paint, draw and read. My favorite books right now are the *Hunger Games* series, the *Percy Jackson* series, the *Sisterhood of the Traveling Pants* series, and the *Peter and the Starcatchers* series. I love all these books and read them over and over.

I love to write and am currently writing a book called *The Falls*. It is about a girl who locks eyes with the new boy, but he is trying to avoid her as much as possible. Little does she know that he is part of a secret society along with her brother trying to fend off evil in the world.

I also like to paint landscapes more than anything else and love to draw my own anime characters.

What kind of music do you like to listen to?

I enjoy all types of music — it's just a matter of what's playing on the radio! But above all, I think I like Christian Alternative the best. Some of my favorite bands are TobyMac, Switchfoot, and Joel and Janna. Joel and Janna is the name of my cousin's band. My father plays the guitar for the band. It's great because every summer they play at a Christian music festival called Soulfest, and I get to go to see my favorite bands.

I also love to sing and am on the worship team at my church. One time I even sang for a crowd of hundreds at my school for a concert last year. I sang the song "Castle on a Cloud" from the Broadway classic *Les Miserables*.

What are your favorite TV shows?

I like the shows *Victorious* and *iCarly*. I also like repeats of older shows like *Full House*, *The Brady Bunch* and *Bewitched*.

Any favorite movies?

I love ALL Disney movies, old or new. My favorites being *Mulan*, *Tangled*, *Pirates of the Caribbean* (I can't wait for the new one to come out), *The Princess and the Frog*, and the *Toy Story* series.

Do you have any brothers or sisters?

Yes, I have one brother named **Caleb**. He just turned 15 a few days ago, which makes him about three and a half years older than me. Caleb and I like to play music together. I sing and he plays piano. My brother and I also like to play outside and ride bikes. We like to make videos of us together having a comedic newscast or making silly commercials. It's a lot of fun!

Have you been to a CCA retreat?

I have been to one CCA retreat. It was this past summer in Boston, Massachusetts. All my medical care is in Boston, which means it's normally pretty stressful to be there. But this time it was so great to go there just to have fun. It brought a new way of how I viewed Boston. We got to go to an aquarium and stayed in a humungous hotel that was beautiful.

Do you have any advice for kids going through similar situations?

Stay positive. Whether it's staying positive about how you see yourself or about long trips, stressful hospital visits or surgeries, life is so much more enjoyable when you have a smile on your face!

ccakid

strength and courage

By Beth Wenger, N. Bethesda, MD

Long after the corrective portion of my life was behind me, and right in the middle of trying to figure out the woman I am supposed to be, I had a great need to find someone I could *really* relate to. I needed to find someone who had endured craniofacial defects and reconstructive surgeries like I had. So, as any modern girl would do, I turned to the Internet.

In my search, I stumbled upon the CCA website. CCA didn't exist when I was growing up and going through most of my surgeries (and neither did the Internet). Before I discovered this vast resource, I knew of no one who had experienced anything like I had. For the first time, I found that the lonely part of me so inherently tied to the medical issues of my past was no longer alone. In the faces and stories posted on ccakids.org, I not only found good company, I found a common bond as well.

Enduring facial differences and massive reconstructive surgeries from the age of 6 weeks to 22 years gave me strength and courage. Through stories written in CCA newsletters, I have since found this strength to be quite common among young people who endured the same or similar procedures (and in many cases significantly more). These children—and probably all children who have craniofacial differences—have incredible grit.

The grit I developed so early in life through my medical hurdles overflowed into all aspects of my life. It has propelled me forward through many challenges and into many great experiences and rewarding opportunities. At the same time, I have always loathed that I was "different," that I had a defect and that I had all that stuff to deal with as a result of it. (And, boy, there is a lot of stuff!)

In spite of all that stuff, the summer before I entered sixth grade I became so determined to not be the girl with the birth defect, regardless of how well doctors could make me look "normal." I worked like crazy from that time forward to become the girl and later the woman who "did all this and had all that going on." The birth defect and the facial differences would just be a fact of life, a side note for those who really had to know.

From that point, defining myself as I saw fit became my life's goal. In fact, it has been my only true, deep-in-my-core goal. It has been a goal that has pushed me forward to have many, many remarkable and fun adventures and experiences.

With a no-limits attitude, most days it has been easy to get up and try and do, win or lose, succeed or fail, or just be satisfied with the effort and outcome. And some days, even still, I have to remind myself of the strength and courage I possess—and where it comes from—before I can take those big bold steps to go after whatever I desire.

Through all my pursuits, I have learned that having craniosynostosis will always be a part of me. But it is, just as I had long ago hoped, not at all who I am.

Beth Wenger is Program Manager for KEEN Greater DC, a nonprofit organization providing free recreational opportunities to children and young adults with disabilities. Beth is also a professional writer and editor with a B.S. in Psychology and Marketing/Business Administration from Albright College in Reading, PA, and a Publication Specialist Certificate from George Washington University.

ccasupersib

meet caleb berry

Caleb is a 14 year-old sophomore at Livermore Falls High School in Livermore Falls, Maine. He is quite humble and not one to brag about his accomplishments. However, he is very outgoing and personable. He enjoys many things and is involved in several extracurricular activities. He plays soccer in the fall and runs track in the spring. His track events include the 800 and 1,600 meter run, the long jump and the triple jump.

Over the winter, he participates in "One Acts," which is a theater competition. He gets to hang out with kids that love theater and have fun. In December, Caleb was in the musical *Annie* with his sister, **Camryn**. She played a sassy orphan named Duffy. Caleb played four different roles: a dogcatcher, a lawyer, a judge and Henry Morgenthau, Jr. (a member of FDR's cabinet). Other extracurricular activities include the student senate and the Envirothon team.

Music is a very important part of Caleb's life. He started at a young age, playing piano before grade school. He plays the drums (the "quints") in the marching band, xylophone and bells in the concert band, and piano in the jazz band. He also plays the drums for the worship team at Emmanuel Assembly of God Church.

Caleb excels in school and his passion is math. Last year, he won a trophy for the highest scoring freshman in the Mountain Valley Conference meet for the High School Math team.

Also, Caleb took high school Algebra I when he was only in the 6th grade! He skipped the 8th grade and started high school at age 13. He is now in honors pre-calculus and absolutely loves it! He'll often remark, "Math is the reason I get up in the morning."

Caleb also loves photography, computers and technology, and he is the family resource for any computer-related question. He hopes to attend MIT for a degree in Aerospace Engineering.

Caleb volunteers at Rumford Hospital, where his mom works as a cardiac and pulmonary rehabilitation nurse. He is employed at his dad's store, Mt. Blue Agway, as a clerk. He attends youth group and Sunday school at his church.

Last summer, Caleb and his family attended their first CCA retreat. Since Boston is where his sister gets her medical care, the family is used to going there, but never to just have fun. The four-hour trip to Boston always meant anxiety and stress. But going there for the retreat meant fun! He even got to tour MIT since it was just walking distance from the hotel where he and his family stayed for the retreat.

Caleb is very close to his sister, Camryn. He enjoys showing her how to use technology. They make video projects, acting out scenes from the news or made-up funny commercials. Caleb states, "Camryn has been through a lot and has met each challenge with bravery. She has kept a positive attitude through all of it. She is also the most generous person I know."

rick's raffle

CCA supporters, **Ann** and **Doug Burgin**, have established a raffle in memory of their beloved grandson, Rick Dornier. Rick died from meningitis on Christmas Eve 2009 at the age of 3 and a half years. They honor Rick's memory while helping other CCA kids.

Since Thomas the Train was one of Rick's favorites, the Burgins plan to donate a "Thomas" toy each year for an annual "Rick's Raffle."

This year's table included a 100-piece track and accessory set and two engines, a talking Thomas and a talking Percy, to go with the set. CCA held the drawing on Rick's birthday, April 25th. The lucky winners were **Dr. and Mrs. John B. Burgin** of Crowley, Louisiana, who supported the effort by buying 45 chances to win, for some pretty good odds! They plan to surprise their four-year old grandson who, they say, will cherish the prize in Rick's memory.

This inaugural raffle brought in **$2,330** and, in accordance with Rick's grandparents' wishes, funds from the raffle will be used for patient financial assistance.

We would like to take this opportunity to thank all of you who were able to participate this year. It means more to us than we are fully able to express since we began Rick's Raffle in hopes of easing our grief by helping other CCA children and by giving another child a happy surprise on Rick's birthday.

Rick's Raffle will become an annual event with the raffle of a Thomas the Train toy each year on his birthday – April 25. Rick loved Thomas the Train and he loved other children so it seems fitting to honor his memory by raising money to help children by raffling a Thomas toy. We hope you will consider participating in Rick's 2012 Raffle next spring.

Thanks again,
Ann and Doug Burgin

Randy, Julia, Luke and I thank you all as well. It means so much to us that so many people love Rick and honor his memory. We remember his sweet smile, his heart-warming laugh, his beautiful blue eye, his tight hugs and soft kisses, his outgoing personality, his zest for life and most of all… the love he shared with us and many others. We remember all the happy times we shared with Rick, as the grief and pain of missing him still breaks our hearts.

~Jessica Dornier

Kevin Monaghan from a neighboring suite stopped in at the CCA office to draw the winning ticket for us.

We are extremely grateful to Ann & Doug Burgin and to Rick's family for making this gift of Rick's spirit to all CCA kids and their families in his memory. His life truly did make an impact and now, because of their selflessness and caring for others' kids, his memory will make a difference for other children like him.

And, to all the participants who helped make this effort a success, thank YOU!

calendar of events

date	event	contact
Jun 23-26	**21st Annual Cher's Family Retreat** Galt House (galthouse.com) Louisville, KY	AReeves@ccakids.com 214.570.9099 800.535.3643
Jul 10-15, 2011	**Camp About Face** Bradford Woods Martinsville, IN	317.274.2489
Aug 27	**Jaci's Country Dance Bash** Morrisville, PA	Countrygirl28567@gmail.com
Sep 2011	**7th Annual Craniofacial Acceptance Month**	AReeves@ccakids.com 214.570.9099 800.535.3643
Sep 2011	**Lily's 2nd Annual Craniofacial Awareness Benefit Dinner** Lindon, UT	NurseTosha@gmail.com
Sep 2011	**Trevor's Trip to Triumph Poker Run for CCA** Morganville, NJ	kimtriz@msn.com
Sep 3	**Raegan's Rally/Walk for CCA** Deerasic Park, 3 PM Cambridge, OH	Ashley Daugherty adaugherty@mvesc.k12.oh.us
Sep 10	**4th Annual Craniofacial Acceptance National Picnic Day** Sandy Lake Amusement Park Carrollton, TX	AReeves@ccakids.com 214.570.9099 800.535.3643
Sep 17	**5th Annual Seth's Stride for CCA** Canton, OH	mythreekids@neo.rr.com **Stacy Swihart** www.firstgiving.com/sethsstride
Sep 24	**7th Annual Friends of Jeremy Golf Tournament** Corning Golf Club Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com
Sep 30	**Links of Love Golf Tournament for CCA** Woodbridge Golf Club Wylie, TX	JPatterson@ccakids.com
Oct 8	**Texas Moms' 5K for CCA** Lee College, 200 Lee Drive Baytown, TX	ledestiny@gmail.com
Oct 9	**4th Annual Chocolate Festival for CCA** Aventura Mall Aventura, FL	ChefRick2@aol.com
Oct 24	**6th Annual Wendelyn's Course of Dreams Golf Tournament** Pleasant Valley Country Club Little Rock, AR	wendelynosborne@gmail.com
Jun 27-Jul1	**22nd Annual Cher's Family Retreat** Tempe, AZ	AReeves@ccakids.com 214.570.9099 800.535.3643

2012 annual cher's family retreat announced

June 27-July 1 in Tempe, AZ

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

We hope to see you there!

craniofacial acceptance month

this year marks the seventh year CCA will observe September as Craniofacial Acceptance Month across the nation. CCA families, friends, volunteers and related support groups will be widening the circle of acceptance for individuals with facial differences. The goal is to create awareness of craniofacial differences and to get people to see that "beyond the face is a heart."

As part of the 7th Annual Craniofacial Acceptance Month, CCA will hold its 4th Annual National Picnic Day on September 10th (or other date in September of your choice). CCA families across the nation will hold picnics giving them a chance to get together with other families in their areas, while promoting awareness in the communities.

It's not too late; if you would like to hold a picnic contact CCA Program Director Annie Reeves. CCA will invite all of the families in your area and help you organize your picnic.

In addition to raising awareness and acceptance, CCA is raising funds to support programs and services available to all individuals with facial differences and their families. Contact CCA Development Director, Jill Patterson for materials about this year's fundraising events.

We hope you will join this important effort! Please call 800.535.3643.

financial assistance

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


henry's march

By TJ and Rachel Johnson, Turlock, CA

Our fourth annual Henry's March was a great success! The runner response was incredible. By race day we had more than 400 runners preregistered, the most that we have ever had. We had some incredible race sponsors including, **Foster Farms**, **Turlock Pediatric Medical Group**, **Gallo Winery**, and the ***Modesto Bee***.

Our very special sponsor, **Little Caesars**, helped with donating pizzas, including pizza for a year for each of our two Pizza Chase winners, **Mike Boyer** and **Trent Hulbert**! Both were first to catch the pizza delivery person in the one-mile race.

Even in the light rain the event was a lot of fun, and the participants seemed to revel in cool conditions. We heard over and over again that the rain made the race more fun! Our one-mile winners were **Mike Boyer** with a time of 5:44 and **Destiny Silva** with a time of 6:30! Our 5K winners were **Shawn Darmousseh** with a time of 19:31 and **Mellissa Minjarez** with a time of 20:50. Amazing!

Because of the weather, we decided to turn the Mascot Race into a Mascot Dance-Off, which was really entertaining. The Kids Dash was so adorable and exciting; it's such a blessing to see the joy on the kids' faces as they were going for the gold. Overall, the event was very rewarding for all involved. We raised more than **$21,000** for CCA! We would like to give a big thank you to all of our volunteers and committee members.



free 2012 hotel stay!

Any family raising $5,000 or more for Children's Craniofacial Association through December 31st of each year will be awarded **one free hotel room** for their stay at the following year's retreat (i.e. 2011 fundraising counts toward the 2012 retreat).

This invitation is extended to all CCA families, including those already holding annual events throughout the year and it includes any type of effort.

All families who wish to participate are asked to sign a confirmation form in order that we may track your success and budget for your room. Please contact the CCA office at 214.570.9099, toll-free at 800.353.3643 or email Jill at JPatterson@ccakids.com for more information.

Try creating your own firstgiving page

A free, CCA-customized "firstgiving" site is available for anyone who wants to help raise funds for CCA. Log onto firstgiving.com/ccakids and tell your personal story about why you support CCA or post an event you're having. Then, email your link to everyone you know and ask them to support your cause! This is an especially easy way to "ask" for donations if you're uncomfortable with the face-to-face approach.

chairman, from page 1

First, let me share a little bit of my story: During my 7th month of pregnancy, almost 28 years ago, **Bob** and I were told that we would be giving birth to a child with hydrocephalus who probably would not live, and if the baby lived, there would be an unknown quality of life. There was no such thing as the Internet or search engines. We felt very alone.

I was working as a professional medical representative for a pharmaceutical company, and Bob worked in marketing and sales support for a nutritional company. So, we spent countless hours in medical libraries and on the phone both before and after Scott's birth. When **Scott** was born, we were told that he had multiple congenital anomalies.

When he was almost 11, he was finally diagnosed with the oh-so-rare Crane-Heise syndrome. By then, we were involved with CCA and the Internet was available (sort of; it was still pretty new). My family's journey with CCA began 17 years ago when my son's craniofacial team at Riley Children's Hospital in Indianapolis was the local host to the **Annual Cher's Family Retreat**. The patient liaison for the team gave my husband, Bob, and me the information about the Family Retreat during one of our many clinic visits.

While we were intrigued with the prospect of spending a few days with other families who also had a family member with a unique face, life happened and we forgot about the information. The patient liaison phoned us with a gentle nudge a couple of weeks before the event. She explained that she thought we would get a lot out of the Family Retreat and that we had much to offer CCA.

Little did we know when we made arrangements to attend that first retreat where it would take us in the future. We will attend our 13th Family Retreat in Louisville in June, have written a few newsletter articles, referred countless families to CCA, spent many hours talking with other families in similar situations, served on focus groups, helped with fundraisers and, well… here I am writing this article.

To paraphrase an old saying, "You get out of CCA what you put into CCA." So yes, we've gotten a lot: support, empowerment, hope and lifelong friends. Gee, that sounds much like the CCA mission: "Empowering and giving hope to individuals and families affected by facial differences." It's very safe to say that many of us measure our involvement with CCA on the Annual Cher's Family Retreat.

The Guzzos of Evansville, IN, at Little Fire, Big Heart in Louisville, KY
Standing, left to right: Paula, Bob and Aaron Guzzo
Seated: Scott Guzzo

My family — **Scott**, **Bob** and **Aaron** — and many other families look forward to those four days in June when we all watch with awe as CCA kids and siblings, including our own Scott and Aaron, grow into CCA adults.

It takes a lot of resources and effort to maintain and grow our CCA family. While the retreat is our marquee event, CCA, through its wonderful staff, is there serving families all year long. **CCA is blessed to have one of the most dedicated staffs you'll ever find in a nonprofit organization.** I've often said that one can't legislate or buy a person's attitude. Thank goodness we don't have to because Char, Annie, Jill and Jana "get it." Their insightful, caring attitude is the anchor of the organization's way of providing services to the tens of thousands of contacts each year.

CCA is proud to be the premiere organization addressing a broad range of medical, financial, emotional, psychosocial and educational issues related to craniofacial conditions. CCA services and resources are intended to help smooth bumps and prepare families to make the best possible informed decisions for the family member with facial differences. In this effort, CCA has published **14 booklets** in *A Guide to Understanding* series for parents. These booklets explain craniofacial conditions/ syndromes, their treatment and craniofacial-related issues. They are written in easy-to-understand text in a question-and-answer format.

Another successful effort to inform families has been the **Craniofacial Symposium**. This is held in conjunction with the Annual Family Retreat and gives families more information on craniofacial-related topics. The third annual Craniofacial Symposium will be at the Galt House in Louisville on June 23, 2011.

Since I earlier mentioned feeling so alone when Scott was born, it's been rewarding to watch CCA utilize the Internet to provide various opportunities for **social networking** for CCA kids and adults. After last year's Family Retreat in Boston, CCA's Facebook page, Children's Craniofacial (CCA Kids), was busy with much "friending."

CCA's **Yahoo Group** is a good place on the Internet for families to support each other 24/7. The CCA **Kids Klub** is for kids of all ages. It's for kids with facial differences, their siblings and their friends. Monthly activities encourage the expression of thoughts and feelings while at the same time providing the sense of belonging that comes from being in a club.

The **Care pages** offer an easy way for families to let everyone know how a child is progressing while they are in the hospital, thus allowing more time for parents to focus on the child's recovery.

Moving forward, it is the board's desire to bring greater awareness to craniofacial-related issues in an effort to foster the acceptance of children and adults with facial differences. September 2011 will be the **7th Annual Craniofacial Acceptance Month**. Our theme, "Beyond the Face is a Heart," paints a very profound picture of the importance of looking past the exterior into the real person. The truth is, though, the general public still puts the emphasis on the outside package. Fox TV Network very graciously ran a CCA **public service announcement** during *American Idol* last March. The impact was significant. Within just a few days, CCA received many phone calls, numerous visits to the website and even some donations. This speaks to the direct impact the media has on the awareness of our cause.

CCA is a national organization based in Dallas, serving families throughout the United States. The **Honorary Medical Board** is comprised of physicians from across the country, and the **Medical Advisory Committee** is made up of members of the craniofacial teams. We hope to further utilize the talents of **regional volunteers**, which would give CCA a greater presence at regional and local levels. This, in turn, will help us reach even more families.

All of these efforts take talent, time and money. We at CCA, just like any other family, have been forced to take a careful look at how we provide services while our nation is still in a state of economic unrest. We've had to ask, "How can we stretch the dollar and maximize services to families? How do we remain financially solvent while depending heavily on donations during a time when there is not as much to be given?" These are tough questions. Our CCA family is blessed through the generosity of monetary donations from individuals, corporations, foundations, as well as in-kind giving. We are truly grateful to all who have provided dollars, materials, ideas, or time to Children's Craniofacial Association so that we may go about our good work. Without any one of these, we would be unable to do what we do.

The board of directors is blessed to be a part of the CCA family. I'm blessed to be the chair. We get far more out of it than we could ever give. Thanks to all of you for the opportunity to serve. Together, we make a difference, one beautiful face/one beautiful family at a time.

Paula Guzzo
CCA Board Chairman

perspective, from page 1

fine and suggested she wear a hat until it could be corrected.

It was not the truth, but it did make us feel better. Thinking he was an angel sent from God, it was unfortunate that we placed our trust in a doctor not experienced enough to deal with the severity of our daughter's syndrome.

Katie only had two sutures that were not fused in her skull. After she lost her forehead, at age 1 and a half to a failed monobloc and bone infection, we went to Dr. Salyer in Dallas, Texas. Currently, her doctor is Dr. Barcelo in Dallas, Texas.

Katie is now a standout 13-year-old and proof that good things come in small packages. She has an amazing voice that can make people cry when she sings. She is an artist, actor, poet and writer with a wonderful spirit that can change the world.

On her journey so far, Katie has experienced the following surgeries: an occipital craniotomy, a monobloc surgery with osteogenic distracter, an osteomyelitis infection of her forehead, eight weeks of IV antibiotics, loss of her forehead, removal of the occipital bone, replacement with demineralized bone and a rebuilt forehead with the occipital bones, a VP shunt, a Chiari repair, another monobloc to repair the falling back of the facial bones, and a another forehead contouring along with expansion of her upper pallet.

Katie wears glasses to correct vision issues and a bone-conduction hearing aide because her ear canals are fused. She has been hospitalized several times for strider because of a stove pipe, caliginous trachea. She attended physical, occupational and feeding therapy through the early intervention program until age 3. She also attended an auditory verbal therapy center until age 5, where she learned to listen and speak with hearing aids. She was recently asked to speak as an alumnus at an annual event, where she sang an impromptu theme song for the organization.

Katie is blessed to have an older sister, **Anne**, who is very supportive and loving. Anne never asked if anything was wrong with Katie. She just accepted her as her sister. I remember we told Anne that Katie was special. When Anne was saying her prayers, she prayed for Katie and said she was special and then she looked at me and said "I'm not special, I am just ordinary." My heart sank because she *did* understand that Katie had a craniofacial syndrome. We told her she was special too—because she is. Being a sibling of a child with medical issues can be very difficult. We have had to spend a lot of time in doctors' offices, in hospitals and at therapy centers. Anne has been very strong and supportive; she stays calm in tense situations and is very helpful in emergency situations.

Two important events helped shape our approach to raising Katie and Anne. The first was a lovely nurse who told my husband **"Special babies are born to special parents."** The second, was when I saw the nurses whispering, knowing something was wrong with the baby, and feeling like it was my fault, my husband came in and said, "Something is wrong with the baby; she looks a little different. We are not sure what we are facing, but it does not matter because we have each other, and she has me, you and Anne."

These were magic words because instead of focusing on myself, I became focused on Katie and her development. We did all the things we had done with her sister, and all the things we had planned out to do with Katie before we found she had Pfeiffer's syndrome.

Tom would not let me hide out with Katie as an infant. He encouraged me to keep my same routine because we also had Anne to care for. Many people had never seen a child like Katie and stared at us. I made a point to hug and kiss her when I felt people where staring and I learned that they would then respond to her with love as well.

I also learned the best response to children asking why her eyes were like that was, "So she can see." Most children were only curious. To the few that were beyond curious I would simply say she was "…a little girl and that God makes us all different but loves us the same."

I have been blessed to see the best in my older child as she deals with her sibling, and I have become a better person by being Anne's and Katie's mother. I worry for Katie every day. Yet, I have seen her change people's perceptions with her spirited personality. I have never felt such sorrow as my fears for the life she would face, and I have never felt such joy at the accomplishments she has achieved. I learned that poor vision and hearing is a good thing when everyone stares at you as you walk past them in a crowded public area. However, once people get to know Katie, they rally around her to protect her.

When Katie attended pre-school, she had to wear a helmet on the playground. Other children in the class asked their parents if they could have a helmet like Katie's. Katie felt very special in her one-of-a-kind helmet.

At our local elementary school, teachers and students loved Katie and stood up for her. She was on the morning show, won third place in the fourth-grade speech competition and won awards for her writing and art.

This year we have chosen to home school Katie, because we feel that one-on-one education is a benefit to a person with hearing and vision hurdles. She will be appearing in our local community theater as Herald in the production of *Cinderella*. Last year she was LaFou in *Beauty and the Beast*.

I also learned there were three types of responses that children had to Katie. The first would not notice until they had been playing awhile. Then they would stop and stare at her at her curiously, maybe even ask a question, then shrug and then keep playing as if everything were normal with the world. The second were the fewest, the ones that were overly curious to the point of being rude. I have only encountered three of these. Lastly were the children that would know that something was not right and wanted to mother and care for Katie.

We taught her to respond to simple questions about herself. When she was in kindergarten she told me she thought she should tell kids about herself. I agreed, and I was so nervous about what she would say. She stood up and said, "I'm different because I wear a hearing aid and glasses," and then she sat down.

We taught the girls they cannot control others, they can only control themselves; and if other people have a problem with Katie, it is their problem, not Katie's. We have tried to teach them that all people have issues, mostly on the inside where no one can see.

Unfortunately, Katie's are on the outside for everyone to see. But sometimes it gives people the opportunity to be kind. Whereas those with issues on the inside have to sometimes face them alone. Additionally, some people may strive their whole life to be noticed and remembered. We want Katie to try to use her uniqueness as a strength. People who meet Katie do not forget her.

We started coming to the CCA family retreats in 2009 because Katie asked me if there were other kids that looked like her. I was afraid to come to the family retreat because I did not know what it would be like. **I was so surprised at the wonderful sharing of positive spirits and the joining of families with common issues.**

It has been a blessing to our family to make these connections with others and a relief to be with other families with similar issues. It is a blessing to meet people with Pfeiffer's that are older than my daughter because it brings me hope; and it is wonderful to meet younger children with Pfeiffer's because it makes us feel good to share hope with others.

During her last monobloc surgery when she was 3, Katie had emotional difficulties. I was able to speak with a therapist who gave me some great advice. She said to treat her with the same level of discipline, or she will think she is dying. Never say "I'm sorry" because she will think it is my fault and it will cause her conflict because she looks to me for comfort. Instead say, "I wish you did not have to go through this," and give her a mirror to see the implanted devices. Allow her to participate in her care. This was excellent advice and really helped because we thought we were protecting her by keeping her in the dark.

As our family goes forward from here, we look to the future with hope and promise, knowing that every family faces issues, sometimes wishing it was as easy as when she was 3. I think the biggest issue facing Katie in the future, aside from more surgery and whether it will be covered by insurance, is discrimination and exclusion. I know she will face both with courage and personality. And, I know that we will be there to help her along her way.

testimonial

Our son Jaydon was born on January 28, 2008, in San Angelo, Texas, with a unilateral cleft lip and cleft palate. During a routine ultrasound at 30 weeks, we learned about his cleft and immediately sought out the best surgeon for him. Unfortunately, the town we live in has limited medical specialists, and we knew we would have to seek help elsewhere.

After thorough research, we located an excellent surgeon in Dallas. We knew Jaydon had to have the best care we could possibly provide for him, but we were faced with the heavy financial burden of medical expenses and the costs associated with traveling.

At three months, Jaydon had his first surgery to insert tubes and repair his cleft lip. We traveled to Dallas numerous times before and after his surgery. It was a very stressful time for us because we were so concerned about our son's well-being, but we also had financial worries. Soon after his first procedure, we learned from a friend about CCA and their financial assistance program. We contacted Annie Reeves and requested help for the costs associated with travel for Jaydon's care.

CCA has been wonderful from the beginning. The application process for financial assistance was simple during a not-so-simple time, and the staff was very helpful. From the first day we contacted Annie for help she has been incredibly kind to our family. CCA is an amazing organization that has tremendously helped and blessed our family!

—Ashley, Justin, Haley and Jaydon Meyer

donors in the spotlight

This issue we shine the spotlight on **Bobbie** and **Bob Schini**, grandparents of **Sammi Wayne**.

"When Samantha Lynne Wayne was born, none of us had any idea what a large part Children's Craniofacial Association would play in our lives. When Sammi was 15 months old she was diagnosed with Crouzon syndrome. Her team of doctors is at Children's Hospital of Philadelphia (CHOP) and Diana Sweeney, Patient Liaison there, introduced our daughter and son-in-law and us to CCA and urged the family to attend the annual family retreats. Friendships made there have endured ever since!

Bobbie and I contribute what we can to Children's Craniofacial Association because of their wonderful work. CCA's encouragement has helped all of us work through the challenges of Sammi's condition.

We owe an immeasurable debt to the doctors at CHOP and the fine folks at CCA."

Thanks to the Schinis, regular CCA donors and our spring 2011 Donors in the Spotlight!

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.

Click on "Donate" at ccakids.org

cca valentine basket

The winner of our L'oreal Valentine Gift Basket was **Joe Broderick** of Alpharetta, Georgia, who had us deliver it to his good friend, **Tina Seamon**, also of Alpharetta. Congratulations both and thanks to all who participated! The gift basket raffle brought in **$402** for CCA.

cca mugshots

Send us your mugshots!

Alan, Stacy and Kathryn McAllister of St. Paul Park, MN

more fundraising news

In April, **IL CLUB ITALIANO** of Westchester Community College in Valhalla, NY, held a bake sale benefitting the cause nearest and dearest to member **Lindsay Bordonaro's** heart: CCA. Lindsay would like to give a shout out to all her retreat "peeps" and hopes they keep on rockin'!

(Those who attended the Boston retreat may recall the impressive performance by Lindsay's big brother, now-grown-up original "CCA Kid" ***Zach Bordonaro*** *and his ballroom partner,* ***Vicki Gilbert****.)*

The club sent a check to Children's Craniofacial Association for **$350**! Thank you Lindsay and Friends!!!

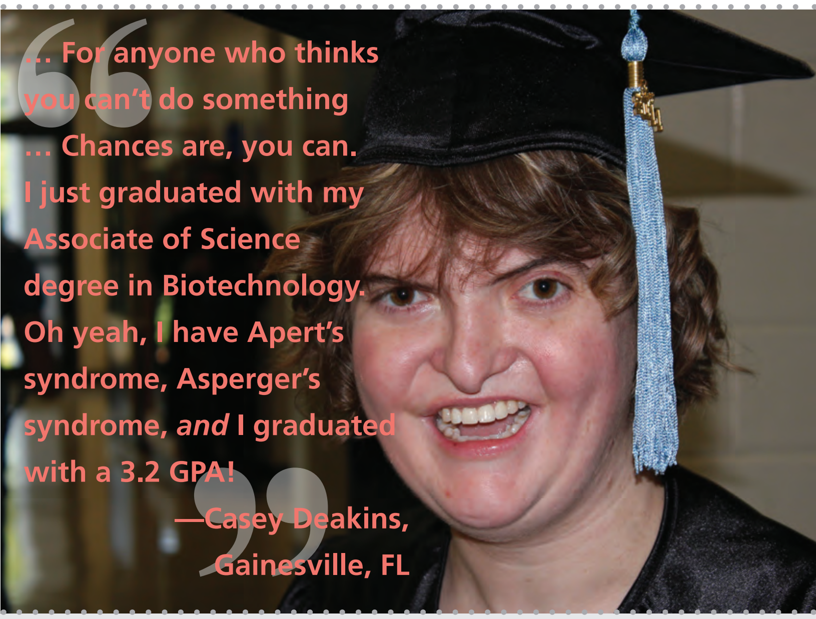
good news

Support Children's Craniofacial Association without having to open your wallet! Our new partnership with Opinions4Good (Op4G) provides you the opportunity to **earn cash for CCA *and* yourself** by participating in research activities such as surveys and focus groups!

Don't wait another minute! We need your help today!

How to Register:

- Visit op4g.com/membership/join/ccakids1234
- Click "Become a Member"
- It will say "Children's Craniofacial Association invited you"; click "continue."
- Complete the short demographic questionnaire *(your information will always be kept private and secure by Op4G)*



> **"… For anyone who thinks you can't do something … Chances are, you can. I just graduated with my Associate of Science degree in Biotechnology. Oh yeah, I have Apert's syndrome, Asperger's syndrome, *and* I graduated with a 3.2 GPA!"**
>
> **—Casey Deakins, Gainesville, FL**

save the date

Links of Love

Friday, September 30, 2011
Woodbridge Golf Club, Wylie, TX

On Friday, September 30, 2011, CCA will hold its fourth annual benefit golf tournament this year at Woodbridge Golf Club in Wylie, Texas.

This year the tournament, "Links of Love," will include many more CCA kids featured on each tee, along with Jylian, our regular CCA kid representative. The event is a scramble that will begin with lunch at registration, and will end with dinner, awards and auctions.

Go to www.linksofloveforcca.com for registration and sponsorship details.

dramatically increasing the quality of life with prosthetic devices

Robert R. Barron specializes in facial prosthetic devices. His purpose in life is to make a difference in the lives of others. He believes his ability to change people's lives is a gift from God. " He is going thru me to improve a person's quality of life."

A prosthetic device restores a malformed or absent part of the human body through artificial means. Disfiguring diseases put people in hiding, and Mr. Barron strives to bring them out of hiding. His priority is always the patient's expectation. The patient's main objective is to be able to interact with the public and to no longer be embarrassed by the stares and unwanted attention produced by their differences. Each prosthetic device is unique and demands inspiration and creativity. They serve as great psychological benefits in restoring the faith and quality of life.

On average, the process requires two to three office visits and is completed within a two- to three-month period. The procedure is painless and is conducted in a relaxed office environment. Prosthetic devices are made of a soft, durable silicone designed for prolonged use under normal conditions. The cost of a prosthetic varies according to the complexity of the product. While the patient is responsible for payment, medical insurance often helps cover cost because prosthetic devices are considered medical necessities in various ways.

Mr. Barron has been working with prosthetics for three decades. His cumulative experience includes some 24 years of altering identities as Senior Disguise Specialist with The Central Intelligence Agency. Blending this unique background with extensive education and research in the private sector, his design, development and creation of state-of-the-art prosthetic devices consistently challenge the status quo.

His career has centered on sophisticated laboratory procedures together with improvement and implementation of reconstructive design. Working closely with physicians and their patients while focusing on the patient's hopes and expectations, his goal is to provide an exquisitely personalized, realistic and functional prosthesis. The basis for his reputation for creative reality can clearly be seen in his finished products.

Mr. Barron was awarded The Career Intelligence Medal in recognition of his exceptional achievements with The Central Intelligence Agency for more than 24 years. The last 15 years were devoted to the disguise branch. In July 1993, former CIA Director, James Woolsey, stated:

> *"Mr. Barron is an extraordinary artist and master of the highly specialized craft of personal disguise. Mr. Barron's competency and artistic skills were unmatched. He was the impetus of the advanced disguise system and the ideal by which all other disguise officers were judged in the area of advanced disguise fabrication. His creativity and initiative were extremely instrumental in the research and development of what the silicone mask is today."*

After retiring from the CIA in 1993, he started his second career by creating his own prosthetic business and named it Custom Prosthetic Designs, Inc. He has combined his talents to help people in need of facial prosthetics whose conditions result from trauma, disease and congenital defects. He also specializes in digital prosthesis resulting from amputation.

Auricular (Ear) Prosthesis

An ear prosthesis artificially restores the ear which has been lost because of radical cancer surgery, amputation, burns and/or congenital defects. The delicate structures remaining after surgery are covered by thin, highly sensitive skin. This soft tissue, being very fragile, must be kept free from irritation and debris from the environment. The protective position of the helix helps to cleanse the air of small particles, which might injure and damage the delicate auricular structure.

The function of the prosthetic ear shape is to direct sound waves into the auditory canal and to maintain a proper environment for the inner ear membranes. It normally improves hearing by about 20 percent. The prosthetic ear will retain eyeglasses and retain a hearing aid if needed. It also serves as a great psychological benefit in the rehabilitation of the patient.

Ear Reconstructive Surgery

Ear Reconstructive Surgery does not give you a normal, realistic-looking ear. The final composition will fall short of giving you a pleasing, convincing and reasonable appearance of a normal ear. It is advised that you carefully look at your options before making a final decision.

Orbital with Ocular Prostheses (Eye)

An orbital with ocular prostheses artificially restores the eye, eyelids and the adjacent hard and soft tissues which have been lost as a result of radical cancer surgery. They protect the exposed orbital, nasal and sinus tissues from the elements and restores normal speech patterns when the nasal and sinus areas are involved. The orbital prosthesis device maintains normal humidity and moisture for the maxillary sinus, oral and nasal cavities. It also houses the ocular piece (artificial eye) and restores the normal appearance of the face. It also serves as a great psychological benefit in the rehabilitation of the patient.

Nasal Prosthesis (Nose)

A nose prosthesis artificially restores all or part of the nose which has been lost because of radical cancer surgery, traumatic amputation and serious burns. The delicate remaining structures and mucous membranes lining the nasal passages must be kept moist and free from irritation. The prosthesis duplicates the function of the nose by directing air flow to the nasopharynx. It also helps to maintain proper humidity for the sinuses and respiratory mucosa. Normal speech resonance is also restored. It provides support for eyeglasses. It also serves as a great psychological benefit in the rehabilitation of the patient.

Digital Prosthesis (Finger)

A custom-designed finger prosthesis replaces a portion or all of an absent finger. If the patient has movement in the remaining portion of the finger, the prosthesis will restore the function of the finger. This type of prosthesis is attached by suction or adhesive. The prosthesis will protect the sensitive tip of the finger from trauma and extreme temperatures. It will allow the patient to type or use a computer keyboard correctly and without discomfort. It also serves as a great psychological benefit in the rehabilitation of the patient.

For further information visit his website at prosthesis.com *or email the office at* cpdrbarron@prosthesis.com


BEFORE AFTER

Top to bottom: Freddie Seitz, Poland, OH; Jeremy Dale, Corning, NY; Meaghan Palmer, Littleton, MA

cca sweatshirt blanket

High quality, jersey blend material is screen printed with eco-friendly, high color ink. These blankets are great for snuggling up on the couch, taking on road trips, and for showing your CCA pride at chilly football games. The blankets make great gifts and shipping is free

First Run is the Classic Sweatshirt Gray with a Red CCA Logo and sells for $35

Order via our secure checkout for you and for all of your family members. Go to **www.promotes.me/cca** to order!

donors, january 1 – march 31, 2011*

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up to $1,000

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$5,000-$10,000

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Up to $1,000
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Chocolate Festival / Chef Rick Chiavari
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$1,000-$5,000
Rick's Raffle / Raffle Ticket Sales / Established by Ann & Doug Burgin
Wendelyn's Course of Dreams, 2011

$5,000 or more
Nick Wiese fundraising effort

$10,000 or more

$20,000 or more
Henry's March for CCA / Johnson Family; Rachel, TJ, Lauren, Henry

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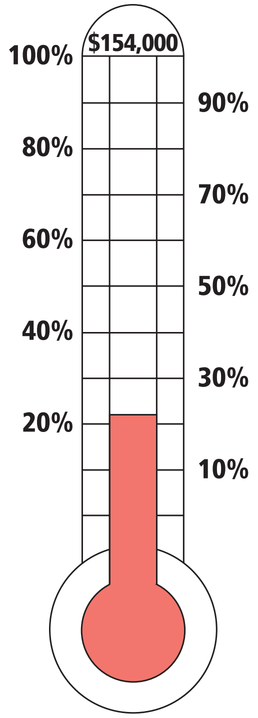

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We do our best to accurately recognize donors. If you notice an error, please let us know.

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

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Amy Abernathy, in honor of Char's birthday
Mario Adamo, in honor of Scott Guzzo's birthday
Mario Adamo, in honor of Erica Mossholder's birthday
Mario Adamo, in honor of Jill Patterson's birthday
Mario Adamo, in honor of Jana Peace's birthday
Mario Adamo, in honor of Annie Reeves' birthday
Mario Adamo, in honor of Jaci Samhammer's birthday
Mario Adamo, in honor of Rose Seitz' birthday
Mario Adamo, in honor of Becky White's birthday
Mike & Susan Akin, in honor of Wendelyn Osborne
Jennifer Allen, in honor of Sam Greer
Anonymous, in honor of the Clay family
Anonymous, in memory of Rick Dornier
Anonymous, in honor of John Gorman
Anonymous, in memory of Betsy Moore
Anonymous, in honor of Bob & Julie Sanchez
Anonymous, in honor of Logan Traeger
Monica Arcement, in memory of Rick Dornier
Dana Archambeau, in memory of Rick Dornier
Melissa Asevedo, in memory of Rick Dornier
Jill Autiello, in honor of Megan Cronin
Erin Basden, in honor of John Gorman
Agnes Beckett, in honor of Casey Deakins' Birthday
Constance Betts, in memory of Rick Dornier
Judith Black, in honor of Max's recovery
Charles Bluman, in honor of Seth Swihart
Lisa & Michael Bock, in memory of Rick Dornier
Randy & Carol Bonnecaze, in memory of Rick Dornier
Julia & Robert Boyce, in memory of Rick Dornier
Janna Brewer, in honor of Char Smith's birthday
Richard Buchholz & Keiko Teranishi, in memory of Rick Dornier
Richard & Mary Buchholz, in memory of Rick Dornier
Heather Bull, in memory of Rick Dornier
Forrest Burke, in memory of Betsy Moore
Laurinda Calongne, in memory of Rick Dornier
Larry Carpenter, in honor of Cher's birthday
Melissa Caruso, in honor of Christian
Jeffrey Castor, in honor of Jeremy Dale
Eunice Caswell, in honor of Trevor Larys
Sheila Circello, in memory of Rick Dornier
Gregory & Lucille Clark, in memory of Betsy Florita Moore
Beverly Cook, in memory of Betsy Moore
Dadami Family Trust, in memory of Rosaleen Egan
Felicia Damato, in honor of Trevor Larys
Ruth & Jerry Dankelson, in memory of Donna Hirt
Martha Dartt, "in memory of little Rick Dornier with love"
Joseph Davino, in honor of Trevor Larys
Casey Deakins, to commemorate her birthday
Lisa & Richard Deeming, in honor of Brody Lucas
Henry & Marlene Deily, in honor of Jeremy Dale and in memory of Donald Constantine
David Diaz and friends, in honor of Juliana Wetmore
Joan Dornier, in memory of Rick Dornier
Melisse Dornier, in memory of Rick Dornier
Rene Dornier, in memory of Rick Dornier
Rene Dornier, in memory of Rick Dornier, from the Dornier's in Klein, TX
Maxine Douglas, in memory of Betsy Moore
James & Betty Doyle, in memory of Shelly Doyle
Sue Dunn, in memory of Rick Dornier
Walter & Mary Elff, in honor of Trevor Larys
English Family Trust, in memory of Rosaleen Egan
Regina Farrell, in memory of Rick Dornier
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Jeffrey Fearon, MD, in honor of his colleagues
Scott Fligel, in honor of Sophia Weaver
Burke Forrest, in memory of Betsy Moore
Dolores & Patrick Fox, in honor of the wedding of Erica Chambers & Bob Willson
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May Klein, in memory of Rick Dornier
Jo Koelz, in memory of Rick Dornier
Adam Lamar, on behalf of the employees of Delray Lighting, in memory of Jerry Feig
Adam Lamar, in memory of his "beloved father, Roy Nickola Lamar & blessed Patti Welch who went to the Lord at the age of 9"
Cheryl Landry, in memory of Rick Dornier
Mary Lazin, in memory of Betsy Moore
Chuck & Sue Leader, in memory of Betsy Moore
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Ellen Lomonoco, on behalf of K.C. & John Haycraft
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Mr. & Mrs. Lawson Lott, Jr., in memory of Rick Dornier
Mary Lazin, in memory of Betsy Moore
Ann & Don Lucas, to honor their 45th wedding anniversary
Ann Lucas, in honor of Don's birthday
Ann & Don Lucas, in honor of Brody's birthday
Jon Lukowski, in honor of Sam Greer
Marcia Mackay, in memory of Rick Dornier
Ronald Magee, in memory of Rick Dornier
Kristen Manning, in memory of Rick Dornier
Kimberly Martin, in memory of Ellery Walker
Jeffrey Matthews, in memory of Betsy Moore
Douglas Maxine, in memory of Betsy Moore
John & Cecilia Mazzocca, in honor of Jaci Samhammer
Lisa McBride, in memory of Betsy Moore
Darryl & Kathleen McCauley, in memory of Dorothy Nester
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Leanne Monroe, in memory of Rick Dornier
Tina Moore, in memory of Rick Dornier
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Alison Morrissey, in honor of Char Smith's birthday
Erica Mossholder, in honor of Char Smith's birthday
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Greg & Jill Patterson, in honor of Annie Reeves' birthday
Greg & Jill Patterson, in honor of Jaci Samhammer's birthday
Greg & Jill Patterson, in honor of Char Smith's birthday
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Jana Peace, in honor of her own birthday
Jana Peace, in honor of Annie Reeves' birthday
Jana Peace, in honor of Char Smith's birthday
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Ray Poindexter, in loving memory of Ann Poindexter
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Randall Riddick, in memory of Rick Dornier
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Jere Robertson, in honor of Jane Monell's Birthday
Leslie Robidoux, in memory of Rick Dornier
Marie Rourke, in memory of Rick Dornier
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Robert Rutemiller, in honor of wife, Maura's birthday
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Patricia Sharpe, in memory of Rick Dornier
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Charlene Smith, in honor of Casey Deakins' birthday
Charlene Smith, in honor of Kathy Hubbard's birthday
Charlene Smith, in honor of Jill Patterson's birthday
Charlene Smith, in honor of Jana Peace's birthday
Charlene Smith, in honor of Annie Reeves' birthday
Charlene Smith, in honor of Jaci Samhammer's birthday
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up to $1,000

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Permission, Inc.
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Truist (Employee Giving Management Fund)
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Up to $1,000

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Jean Day & Bake Sale for CCA / BASICS Community Service Club, Cambridge, OH
Justin Graham's Fundraising / Firstgiving Page & Bracelet Sales / Graham Family
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Larys Family Fundraising / Kim Trzanowski, CCA Volunteer
Miles for Kids Poker Run / Frank Leach, Lewis Boykin, CCA Volunteers
PSA Denim Day for CCA / Yandy Green & friends
Rocky River High School Homecoming Fundraiser / Emerald Demor & RRHS Student Council
Tamale Sale for CCA /Booz Allen Hamilton CRT & Aldine Church Ladies Group, Houston area
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$1,000-$5,000

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Jammin' Jeans Week in honor of Luke Bowen for CCA / Judith Kemler, CCA Volunteer
Nitro for Charity / Terry Stewart, CCA Volunteer
Rock n'Bowl for CCA with Kayla Smith / Michelle & Kayla Smith, CCA Volunteers
Smiling Through The Mask Unevent / Wendelyn Osborne, CCA Volunteer

$5,000 or more

Annual Lily's Dinner for CCA / Firstgiving Page /Tosha Walker, CCA Volunteer
Annual Seth's Stride for CCA / Stacy Swihart, CCA Volunteer
Raegan's Rally / Ashley Daugherty, CCA Volunteer
Annual Wendelyn's Course of Dreams Golf Tournament / Wendelyn Osborne, CCA Volunteer

$10,000 or more

Chocolate Festival for CCA Kids / Chef Rick Chiavari, CCA Volunteer
Jylian's Links of Love Golf Tournament for CCA / CCA & Bilbow Family, John, Kendall, Jylian, Mikey, Ivy, Patrick

$20,000 or more

Henry's March for CCA / Johnson Family; Rachel, TJ, Lauren, Henry

$30,000 or more

Annual Friends of Jeremy Golf Tournament / Dale Family: Kris, George, Jeremy, Tommy, Cody
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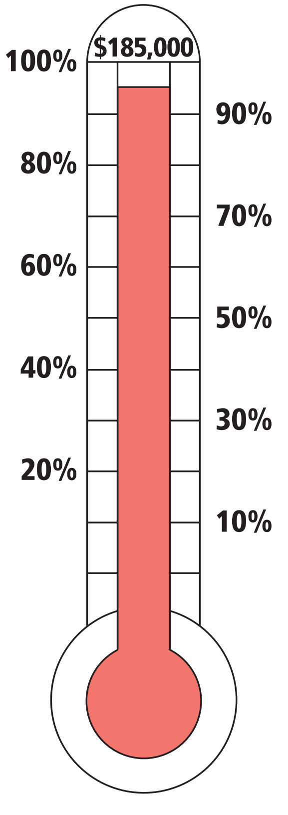
2010 FAMILY FUNDRAISER GOAL THERMOMETER



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3cheers for volunteers!

CCA is so fortunate to have **Lou Anderson** as one of our volunteers. Over the years, Lou has made quilts, blankets, pillows and much more for our families. Her latest way of helping families is by sending Build-A-Bears® to us. These are given to our kids in hospitals nationwide, and provide much comfort to them during their stay.

Lou's warm, giving spirit has touched so many lives. She's our angel! Thank you for all you do for CCA and our families!

(Above) Ashley Bock of Houston, TX, snuggling up with her Build-A-Bear®, before surgery

(Left) Lou Anderson of New London, WI, CCA Volunteer

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