

# ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

summer 2009

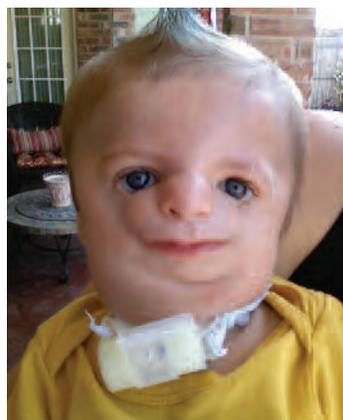
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## samantha and brendan's story

By Teresa Collins



When I was a kid, I could never decide what I wanted to be. I knew I wanted to be a mom, but other than that, I had no idea what else. I always thought that people are here to do something great, even if it is just one thing.

When we found out we were pregnant with **Samantha**, it was at a very stressful time. We already had two boys, **Logan** and **Wyatt**. Logan was two and Wyatt was six months. **Chris** had lost his job, the house was about to go into foreclosure, and we were scrambling for what to do next. But we made the best of it, and things did work out. We managed to rent a house from a friend of ours that wasn't too far from where we were living.

When I was six months pregnant, my doctor noticed that I had extra amniotic fluid, so he sent me to a specialist. After many, many ultrasounds they said that Samantha had a small chin, but otherwise she was healthy.

When he said "small chin," I didn't understand what he meant. For some reason, I thought he meant small, as in pointy. But I was optimistic; I had already had two

see **collins**, page 10



## message from the program director

Can you believe the CCA retreat has already come and gone? Time sure does fly when you are having fun in the sun — and in the giant indoor water park at the Great Wolf Lodge!

This was our largest retreat to date; we had families join us from 30 of the 50 states, Australia, Canada and the UK. Everywhere you looked, there were CCA Retreat T-shirts, which was such a neat experience!

For many, this was their first time to meet another

see **program director**, page 14

# meet brandon moore

**e**leven-year-old **Brandon Moore** is having a fantastic summer. For starters, he went to the CCA retreat in Dallas. He also went on a fishing trip to Lake Charles, which is in his native Louisiana.

Brandon also attended a camp where he spent his days building robots. (How cool is that?!) In addition, he went to a pirate camp, where he learned about the history of pirates and pirate activity in Louisiana. He also attended vacation Bible school.

This summer, Brandon took swimming lessons and has perfected his diving. Most days you can find him in his backyard pool.

He'll be in sixth grade this fall, which for him is middle school. He's looking forward to his math and science classes. They are his favorites.

Brandon is a remarkable student. In fact, he was one of just a few select

students who won the President Rank Award, signed by President Obama, for having straight A's from first through fifth grade and high marks on standardized tests. He also received a Top Dog award in fifth grade, third place in the science fair in fourth grade, and in first and second grades, he won the Terrific Kid award. Recently, Brandon won a Veterans of Foreign Wars essay award. Congratulations, Brandon, on all of these awesome accomplishments!

During the school year, Brandon is one busy guy, with swim lessons, robotics club meetings and church classes.

In between all of his studies and extracurricular activities, Brandon plays baseball and golf on his Wii, plus he likes watching the Disney Channel TV show "Suite Life on Deck." He loves music and listens to Cher, Trace Adkins and

Rodney Atkins. He dances, too (only when you're not looking). He also likes going to the movies. "Cars" is still his favorite film.

Besides CCA retreats, Brandon has taken numerous vacations and has been able to see many places in the U.S. and beyond. His favorite vacations include a Caribbean cruise and a trip to Gatlinburg, TN. Brandon's favorite holiday is Christmas and he enjoys decorating and spending time with his family.

Brandon has been involved with CCA for a number of years and has really enjoyed the experience. In fact, his first plane ride was to the CCA retreat in Nashville, TN, in 2005. He has made a lot of friends and has had the opportunity to meet many other kids in his situation.

Brandon has Crouzon's syndrome and had his first surgery when he was less than four weeks old. He has had his total skull remolded and has a VP Shunt. He wears bilateral hearing aids because of



narrowed ear canals. He also has a fused left elbow that he can not bend, so he is ambidextrous.

Brandon had the RED Distractor system at five years old and had excellent results. He is not up for any further surgeries until he's a teenager, when he will have more facial and jaw work completed.

His craniofacial team is led by **Dr. G.E. Ghali** at Sutton's Children's Hospital in Shreveport, LA. Dr. Ghali is not only his doctor, but also his buddy! Dr. Ghali is amazing and has greatly assisted Brandon and his parents in getting through each of these difficult surgeries.

It's not surprising to know that Brandon wants to be a craniofacial doctor when he grows up. With his drive and incredible aptitude in math and science he will no doubt achieve that goal.



Brandon Moore, left, before his RED distraction, and on the right, after the distraction

# ccakid

# ccagrad

## meet ashley smith



**Ashley Smith** graduated last year from Mustang High School in Mustang, Oklahoma. She now attends computer technology classes at the

local Vo-Tech and is currently enrolled in a vocational rehabilitation program to help prepare her for future job opportunities. Ashley lives at home with her mom and their dog, Nickie.

Ashley participates in many Special Olympics events year-round, including basketball, softball, and track and field. She just recently started practicing for the equestrian event. She looks forward to participating in the Special Olympics State Competition in Stillwater, Oklahoma.

Apart from her classes and sports activities, Ashley's hobbies include watching TV, going to the movies and playing video games. She also enjoys shopping and going out to eat.

Ashley was introduced to CCA from birth. Her first outing was a Christmas Party to see Santa at Medical City in Dallas. She also went to a private party to see Cher at the Planet Hollywood in Dallas. Her first retreat was in 2007 in Salt Lake City, UT. Ashley

made many new friends and is keeping up with them through letters. Through her involvement with CCA, she has gained a better understanding of her own disabilities with Apert syndrome and has gained awareness of others' disabilities.



## firstgiving fundraising proposal to cca families extended! Free retreat hotel stay for future retreats

**O**ur special reward proposal in conjunction with our 2009 20th anniversary year to CCA families who help with fundraising is being extended indefinitely! This means from now on, any family raising more than \$5,000 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 (or the next retreat they attend) for the entire retreat period, including symposium.

As originally stated, this invitation is extended to everyone already holding annual events throughout the year and 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 (800.353.3643) or email [JGorecki@ccakids.com](mailto:JGorecki@ccakids.com) for a form.

### 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](http://firstgiving.com/ccakids) and tell your personal story about why you support CCA or post an event you're having. Then, all you do is email your link to everyone you know and ask them to do the same! This is an especially easy way to "ask" for donations if you're uncomfortable with the face-to-face approach.

# meet logan & wyatt collins



Logan

**m**y name is **Logan Collins**. I am six years old and am in Kindergarten. I have two brothers, **Wyatt** and **Brendan**, and one sister, **Samantha**.

My favorite show is "Ben 10" and I love to play with my Legos. I also like to play on our Wii, especially any of the Mario games!

When I grow up I want to be an archeologist, geologist, or a paleontologist. I can't decide! One of my favorite things to do is dance. My dad plays music really loud on the computer and Samantha and I dance around like crazy! Brendan

is too little to dance, but I get to hold him a lot. When I hold him, he likes to touch my face.

Sometimes when we go out, people stare and say things about my sister. I don't like it; it is really mean. I sometimes try to tell people about her. After I do, they are nice to her. But I love her and Brendan no matter what.

We went to the retreat last summer in Myrtle Beach. I had so much fun and met so many people! I got to go to a beach for the first time and collect seashells. We went this year too! I loved the waterpark!



Wyatt

**m**y name is **Wyatt Collins**. I am four years old. My favorite things to do are play outside, wear my knight costume and play video games.

I love Star Wars movies and everything Star Wars. I also like playing with my Bionicles Legos and playing on the Wii. When I grow up I want to be a real knight in shining armor with a real shield and sword!

I like to play with Samantha a lot. We play tackle, color, play with Playdough, and play hide-and-seek. I also show

Samantha how to put together Bionicle Legos.

I also like to play with Brendan. I like to sit on the couch beside him and hold him. We play peek-a-boo.

My daddy is really smart. I like to ask him lots of questions. I have been helping him build a grill in our backyard. And he said when it is done, he is going to build me a robot.

We went to the retreat again this summer. I had a blast at Great Wolf Lodge!

When I see people staring at Samantha and Brendan, I want to tell them to stop. I don't like Samantha and Brendan's trachs. I can't wait until I can throw them away!

# ccasupersibs

# calendar of events

date	event	contact
Sep 5, 2009	<b>3rd Annual Seth's Stride for CCA</b> Canton, OH	mythreekids@neo.rr.com Stacy Swihart www.firstgiving.com/sethsstride
Sep 10, 2009	<b>Heroes4Hope Gala</b> Jorge Posada Foundation New York, NY	JGorecki@ccakids.com www.ccakids.org 800.535.3643
Sep 12, 2009	<b>Alexa's Appeal</b> Dinner/Auction, 5-10 PM Modesto, CA	deniserast@sbcglobal.net
Sep 19, 2009	<b>2nd Annual National Picnic Day in observance of Craniofacial Acceptance Month</b> Sandy Lake Amusement Park, 10 AM-1 PM Carrollton, TX	AReesves@ccakids.com www.ccakids.org 800.535.3643
Sep 19, 2009	<b>2nd Annual Ryan's Road</b> Big Flats, NY	ngulich@yahoo.com
Sep 26, 2009	<b>Lily's 1st Annual Craniofacial Awareness Benefit Dinner</b> Lindon, UT	NurseTosha@gmail.com
Sep 27, 2009	<b>Strike Out Differences</b> in Memory of Wendy for CCA Kids 3pm-6pm Crosley Bowling Lanes Vancouver, WA	tiger32094@yahoo.com Tamara Mantlo
Sep 28, 2009	<b>Jylian's Links of Love</b> Golf Tournament Whitestone Golf Club Benbrook, TX	JGorecki@ccakids.com jylianslinksoflove.com 800.535.3643
Oct 3, 2009	<b>5th Annual Friends of Jeremy Golf Tournament</b> Corning Country Club Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com
Oct 18, 2009	<b>2nd Annual Chocolate Festival for CCA</b> Aventura Mall Aventura, FL	ChefRick2@aol.com

# good news



**m**eeka Rowat (pictured on the right in the above photo) has an ear for music and she loves to share her talent for singing. What's special is that she was born with no ears and can hear only through vibrations conducted by a hearing aid implant and a microphone on her hearing aid.

Her external ears have been constructed from her own cartilage in a series of operations.

Meeka was thrilled to be a contestant in the recent **Our Kids Have Talent** competition, and while she was not one of the top 10 finalists, she did receive the **Rarearth Giving Foundation Award**.

The \$250 will be used to help with medical expenses.

"I was just so impressed with her. She sang a cappella with perfect pitch which is hard for anyone to do," said **Kath Raeber**, organizer of Our Kids Have Talent, which was sponsored by **the Rarearth Jazz and Blues Fest** and **107.5 Kiss FM**.

"She's a very worthy recipient of the first award and we hope she'll keep on singing."

Meeka is a seventh grade Kidston Elementary School student who also has Goldenhar syndrome, Turner Syndrome, Microtia/atresia, severe allergies, asthma and a heart defect.

Meeka does well at school, and she enjoys her computer, swimming, drawing and dancing and playing with her little sister, **Ceanna**.

"It was exciting to be in the competition and win the award," said Meeka. Congratulations, Meeka!

# the retreat: a mom's perspective

By Marilyn Hogan



They gave so many parents hope.

Other things I saw were the siblings getting out there and having a great time with everyone.

I enjoyed visiting with parents as they shared the hurdles they've overcome and the struggles they've endured, all for the love of their children. It was great to share stories with other parents—what worked and what didn't. Plus it was wonderful to see all the moms and dads relaxing and having a good time.

The retreat was a real eye-opener for Emily and me. We saw how far we've come and have more hope in our opportunities for the future. Emily and I are thankful to God for being able to be part of this wonderful adventure.

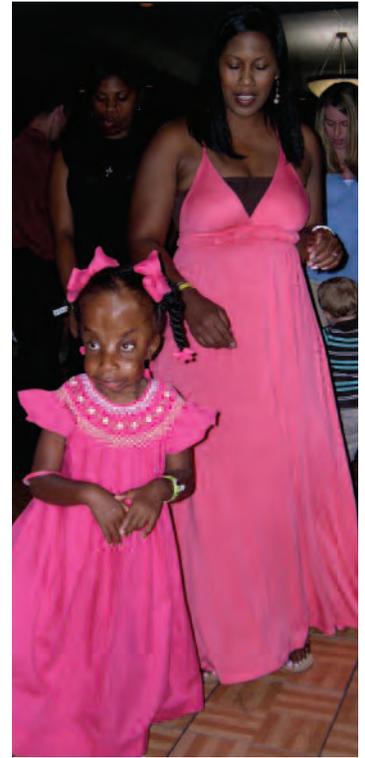
And then, of course, there was the screening of "Torey's Distraction," the phenomenal documentary that truly captures what happens in the homes and lives of parents of children



with craniofacial anomalies.

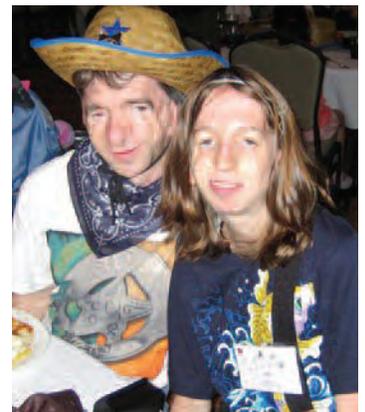
For me, the film was a chance to see the strength of all parents. I looked around the room and saw that they could relate, having faced a lot of the same challenges. I saw hope replacing the fear in parents beginning their long journey with their children. The film showed us that the sky is the limit for our children.

Emily cried for about an hour after saying goodbye to Torey and her family. She cried because she knew she had to go back to her "regular" life. However, it was truly beautiful to see Emily blossom, to see her laugh and have fun with other



girls — without stares, without judgment.

CCA, we thank you! You are truly a network of friends. God bless you in all you do for each and every one of us. Emily and I can't thank you enough for this wonderful, life-changing experience.





# september sales for cca



## Attention All CCA Families and Friends:

Get on board to sell our special rubber bracelets to commemorate Craniofacial Acceptance Month! 2009 marks the 5th year since CCA declared the month of September as National Craniofacial Acceptance Month spreading awareness that "beyond the face is a heart," which fosters our goal of "widening the circle of acceptance," and brings us closer to our vision:

**A world where all people are accepted  
for who they are, not how they look.**

**Bracelets are \$1 each**

Available in the 5 colors of CCA's logo faces:  
royal, orange, teal, purple, lime  
Sizes: 8" (universal/adult) and 7" (small/child)

**To purchase and/or sell, email or call Jill  
JGorecki@ccakids.com • 800.535.3643**

become cca's "friend"  
on facebook!



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



JPM PRO STREET

## Win this Johnny Pag Original!

### Raffle to Benefit Children's Craniofacial Association

- Full-sized motorcycle
- Steel fenders and gas tank
- Dual-disk front brakes
- Two-piston front and rear calipers
- DOT approved
- EPA approved
- Street legal (Highway too!!)
- Inverted front forks
- Cruises at highway speeds
- Liquid cooled engine (No overheating!!)
- Accessories available

Your color choice and delivery included  
just in time for the holidays!

Tickets \$5 each / 5 Tickets for \$20  
Drawing to be held December 1, 2009.  
Need not be present to win.

**CCA Families and Friends, we need your help!  
Contact Jill at CCA if you'd like to help sell tickets.**



[www.johnnypag.com](http://www.johnnypag.com)

# cca holds a craniofacial symposium

On June 23, 2009, Children's Craniofacial Association held its first craniofacial symposium in 15 years. According to **Char Smith, CCA's Executive Director**, holding such an educational meeting has been in CCA's strategic plan for some six years.

In 2005, 2006 and 2007, CCA met that goal by sponsoring the **North American Craniofacial Conference** in Las Vegas. "This year with the Annual Family Retreat being held in our own area, the conditions were perfect for conducting our own educational symposium," Smith said. The symposium started Wednesday afternoon, allowing families to arrive for the retreat Wednesday morning, and it concluded mid-day Thursday before the afternoon retreat registration.

Dallas-area healthcare professionals presented on topics geared to educate and inform children and adults affected by facial

differences as well as their family members. Topics included:

- Family dynamics and teasing by clinical psychologist **Dr. Susan Porter-Levy**
- Syndromic craniosynostosis by craniofacial reconstructive surgeon, **Dr. Jeffrey Fearon**
- Etiology of and association of hydrocephalus and chiari malformations with complex craniosynostosis by pediatric neurosurgeon, **Dr. David Sacco**
- Implications of a compromised airway and options for diagnosis and treatment by craniofacial reconstructive surgeon, **Dr. Carlos Barcelo**
- The use of traditional anthropometric measurements for evaluating the growth of and development of the heads and faces of children with craniofacial anomalies before and after surgery by anthropologist **Dr. John Kolar**
- Self esteem and coping with a difference in today's society—a series of sessions for 6 to 9 year olds, 9 to 12 year olds, teenagers and siblings held by **Amy Dodge, Jennifer Gilblom, Amy Browning** and **Brittany**

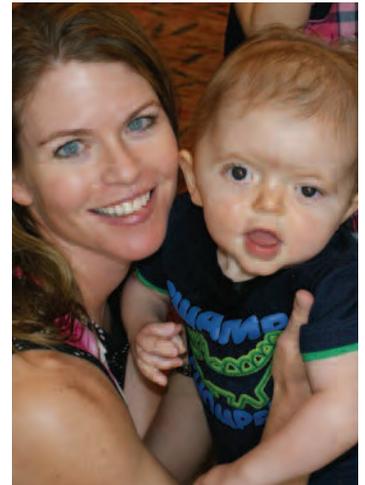


**Blake** from the **Child Life Department** at **Medical City Children's Hospital**.

Discussions are already underway regarding a 2010 Craniofacial Symposium. Stay tuned for details.

In the words of one attendee, "The topics were current and very informative. I learned so much and my kids got to interact with others during their sessions for affected children and their siblings. I hope CCA continues to hold the symposium."

The entire symposium program was filmed and will be available soon.



**collins**, from page 1

beautiful boys. There was no reason to think I wouldn't have a beautiful daughter! But for the rest of my pregnancy, I went every week for an ultrasound.

Delivery day came and we were so excited! We were going to have the first girl in the family! My labor progressed quickly, and we had it planned that Chris would cut the cord, and the doctor would hand her to me right away.

When she was born, the doctor cut the cord, and Samantha disappeared. I could see people in the corner, standing over the bassinet. I kept asking for her because I had not heard her cry. So many people kept rushing in and out of the room, and after a few minutes I was told she had to go to the NICU. About half an hour later, they came to get Chris to give consent for her to have surgery. So that was her first surgery, on her birthday to get her trach.

The neonatologist came in and told us that Samantha had Treacher Collins syndrome. Now, our last name is Collins. So in all of

my confusion, I kept wondering why they put our name on this!

When we finally got to see her, I couldn't understand what had happened. I cried for days waiting to wake up from the dream. Samantha meanwhile was still in the NICU, on a vent. But she was strong and feisty and very quickly moved off of it. She did not tolerate her feeding very well, so when she was eleven days old she had surgery again for her G-Button.

The next step was to tell our boys about their sister. We said there were some problems when she was born, and needed to stay in the hospital for awhile. When we showed Logan the pictures, I was waiting for a million questions. But all he said was "She's beautiful!"

Wyatt was too young; he was barely eighteen months old. But he has never questioned Samantha. Those two are very close!

After all was said and done, Samantha stayed in the hospital seven weeks.

Samantha is a typical three year old. She is independent, happy, loving and full of energy! To date, she has had 10 surgeries. We have tried very

hard to combine multiple procedures into one surgery.

I found out on Valentine's Day that I was pregnant with

**Brendan**. We had been told that Samantha was a one-time occurrence, so I was pretty confident that nothing was out of the ordinary. When my doctor sent me to see the specialist again, I thought that it was just as a precaution.

When we did the first ultrasound, the doctor said that he didn't see very much bone in the lower jaw. I told him he wasn't looking hard enough! There was no way it was happening again. Months went by, ultrasounds went by, and I just knew. Brendan had Treacher Collins syndrome as well.

With Samantha's pregnancy and delivery, I was a wreck. I couldn't understand it all and everything had an almost surreal feeling. And there are things and days I don't even remember. I was determined not to be that way again. I had the benefit of knowing this time. So I called all of Samantha's doctors, the nursing agency, the medical supply company, and anyone else I knew and told them about Brendan. We set up his



Newborn photos of Samantha (left) and Brendan (right)

room to accommodate what medical supplies would be coming and bought other little things we knew we would need for his care.

Early one morning, my water started to break. I was worried because I had excessive amniotic fluid again. Right away, Chris and I drove to the hospital. We got checked in, put in a room, and I got my epidural. I labored for a few hours, or so I thought. My doctor came in to check my progress and said that I had not progressed at all! By now, my kidneys were not functioning properly. They were being compressed by the weight of the amniotic fluid. So I was taken straight into the OR for a C-Section. Just a few minutes later, Brendan arrived!

He was taken over to the NICU for observation. His lower jaw was so small; you could see his top gums. They managed to intubate him, but not for long. Early the next day he had surgery for his trach. My doctor said that Brendan looked healthy, and by the way, you had



Samantha (left) and Brendan (right), trachs in place

continued next page →

almost nine liters of amniotic fluid!

Brendan stayed in the hospital for three weeks, just long enough for us to get supplies and nursing set up. He is growing so fast, and getting so big. All of his siblings just love him!

Having four children is not easy, especially when two of them have medical issues. We have done the best we can, and still do everyday. We have a goal to raise all of our children without any differences. When we go out, people stare and look. Sometimes they will do a double take, and sometimes some kid will say something mean. I try not to let it bother me because if my kids see that it does, then it will bother them.



Parents Teresa and Chris Collins, with Brendan after a surgery.

After Samantha and Brendan were born, there was a definite period of adjustment for us and the rest of our family. I think we were trying to find our balance; a new kind of normal. It took some time, but we finally did.

There were friends and family that just didn't know how to deal with Samantha, and they haven't come around

much. But we also now have people that are genuine, wonderful friends and family. We have a great support system and all of the kids have people who love them. I like to call our life imperfect perfect. It's not the perfect family I imagined we would have, but it is the perfect family we needed.

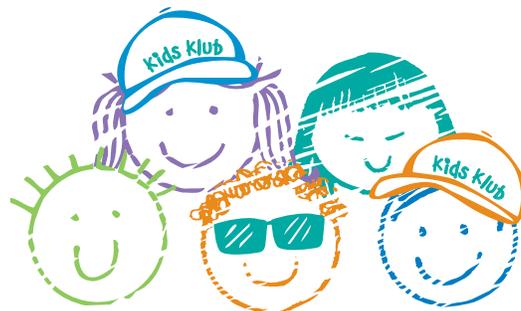
## united way campaigns underway soon!

You may notice a number of United Way contributions listed in CCA's donor lists. Although Children's Craniofacial Association is not a United Way "agency" (organizations receiving direct support from United Way), as an IRS-designated 501(c)(3) nonprofit, we may receive your **directed donations** when you give to your local United Way Campaign. Most local United Way groups allow donors to designate a specific organization as long as you indicate our number (**75-2265649**) when you agree to participate in the campaign. If you lose track of our number, we're just a phone call away at 800.535.3643. When you direct your donations to CCA, you are able to help your favorite cause while also helping your employer and local United Way campaign folks to reach their goal. Thanks for joining in on this win-win giving!

## Kids Klubs

Want to stay in touch with your CCA friends throughout the year? Join one of CCA's Kids Klubs. You'll talk with other kids your age, make new friends, play games, and take part in discussions. Sign up for one of four age groups: Kindergarten through third grade, fourth and fifth grades, sixth through eighth grades, and ninth through twelfth. Each level has age-appropriate activities that will keep you connected. So join your CCA friends now and let the fun begin!

Contact Annie Reeves for a Kids Klub application today!



children's craniofacial association

## fundraising news

# raffle for cca: family fun stimulus package

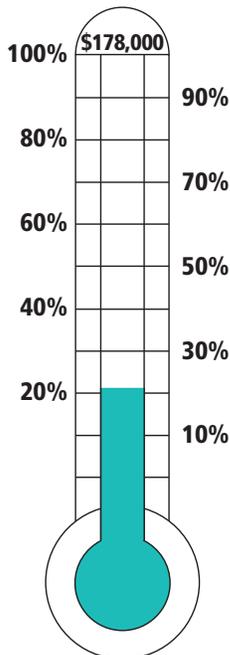


Matthew Abernathy and Wes Rowe of the Simoniz Wash Depot

CCA's **Jana Peace** teamed up with regular CCA volunteer and young philanthropist, **Matthew Abernathy**, (see "Three Cheers for Volunteers," page 20) to raise funds for Children's Craniofacial Association. They held a raffle for "The Family Fun Stimulus Package" of dining, pampering, and entertainment for the whole family to enjoy. Special thanks to all our sponsors!

The raffle raised almost **\$2,000** and the winning ticket was drawn by Matthew at the **Simoniz Wash Depot**, where the winner will enjoy over a year's worth of car washes. Congratulations to **Christine Buckley** of Dallas, the big winner of the Family Fun!

2009 FAMILY FUNDRAISER  
GOAL THERMOMETER



Kim Rogers, CCA kid, Katherine Rogers and grandmother, Diane Dietz

## business casual day for cca!

**The Village Hall** offices of the Village of Orland Park, IL held a Business Casual Day for CCA in honor of CCA kid, **Katherine Marie Rogers**, granddaughter of **Diane Dietz** who works for the Orland Park Police Department.

Together the generous group raised **\$565** and presented Katherine and mom, CCA local volunteer, **Kim Rogers**, with a letter for CCA from the Village, proclaiming the day and their special effort to help all CCA kids in Katherine's name. Sincere thanks to everyone who participated!



## annual chance raffle at cca's family retreat

**F**amilies attending CCA's Annual Family Retreat participate in our chance raffle by contributing filled baskets or other items from their hometowns/states and then purchasing raffle tickets to win the ones they want. This year's raffle was our most successful yet bringing in a little **over \$1,500** in cash from tickets sold.

Many thanks to all who participated and congratulations to all the families who won the fabulous raffle items.

# helpful tips

READ ME!

Information for Families as reported in the Chronicle of Philanthropy

## Applications for grants from the United Healthcare Children's Foundation

**g**rants of up to \$5,000 each will help parents and caregivers pay for health-care services for sick children that are only partially covered by insurance plans. Services must aim to improve the children's quality of life, including dental treatments, eyeglasses, hearing aids, physical therapy, and speech therapy. Additional information is available on the foundation's website.

**Who may apply:** parents and caregivers for children age 16 and younger. Applicants must live in the United States and be covered by a commercial health insurance plan. Grants will not support families whose adjusted gross income per individual exceeds \$20,000. Grants will also not pay for past medical costs.

Contact: UHCF P.O. Box 41, MN012-S286, Minneapolis, Minn. 55440; (800) 328-5979, ext. 24459

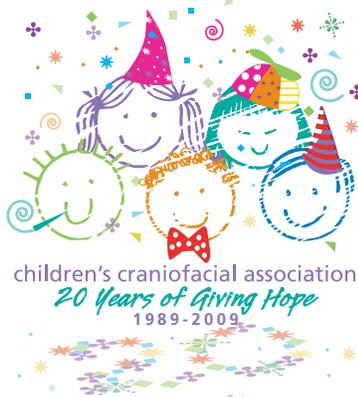
<http://www.uhccf.org/apply.html>

## cca 20th anniversary t-shirts

**O**ur limited edition 20th Anniversary Logo T-shirts are available for purchase at \$20 each plus \$5 priority shipping (more than one shirt, actual shipping-weight charges will be quoted).

Or one T-shirt is free, upon request, with a single donation of \$100 or more.

Initial production of the special celebrative shirts comes in Adult sizes, S, M, L, XL, 2XL, and 3XL. **And we're happy to announce youth sizes are now available:** XS (2-4), S (6-8), M (10-12), (L youth, order S adult).



## cca mugshots



◀ Daniel Lloyd, 3 years old, Elk Grove, CA



▲ Char Smith, CCA Executive Director, Dallas, TX



◀ Avery Lytle, 8 years old, Pennington, NJ



▲ Rae Gene Munglioli, Italian Club of Dallas volunteer



◀ Emily Tipton, Starbucks Manager and Dedicated CCA Supporter

## program director,

from page 1

family who has a child with a craniofacial difference. Families who belong to our online support groups were finally able to meet each other.

This year, we added an educational symposium to the schedule, which started on Wednesday afternoon and resumed Thursday morning. We had several professionals from the Dallas/Fort Worth area lead the sessions. There was something for everyone. (See page 9.)

The retreat itself started on Thursday evening with the traditional ice cream social. As an icebreaker, the families were all given an animal they had to imitate. Their goal was to find other families making the same animal sound. Once they located everyone in their group, they had to draw their animal. This was a great way for the families to instantly connect and meet families dealing with the same syndrome. A hotel employee judged the drawings and the winner was announced. Everyone did a fantastic job!

On Friday following breakfast, there was a screening of a film called "Torey's Distraction." A local Dallas director filmed a

documentary about three girls born with Apert syndrome. Two of the girls were at the retreat and they held a Q&A session after the film.

We celebrated CCA's 20th Anniversary with a huge birthday celebration. **Radio Disney** came out and helped us celebrate this incredible milestone. Everyone played games, including hula-hoop contests, and we ate lots of yummy cake. The mascots from the **Dallas Cowboys, Texas Rangers, Fort Worth Cats** and **Great Wolf Lodge** also joined in the fun!

We had a "Texas Hoedown" Friday night, complete with a BBQ dinner and square dancers. The kids learned how to square dance and did such a great job! Meanwhile, the teens enjoyed some time away from their parents at Teen Night at GR-8 Space (a special area in the lodge just for them), where they listened to music, played games and surfed the web.

For the fourth consecutive year, we held a chance raffle. Families brought baskets with goodies from their hometown cities and states. It was a huge hit!

We met for breakfast again Saturday morning and then headed to the indoor/outdoor water park

for some fun in the sun! All enjoyed a full day of swimming, racing down waterslides, floating in the lazy river, riding waves in the wave pool and enjoying some good ole' Texas sun.

After cooling off in the pool, everyone got dressed up for our most popular event—the dinner dance. While the adults were filling their plates with food, the kids were already out on the dance floor. Families danced the night away!

Saturday also marked another special milestone for CCA. **Executive Director Charlene Smith celebrated her 20th anniversary with the charity.** To honor her years of dedication, the CCA board and staff presented her with a plaque, flowers and a charm bracelet. The bracelet was inscribed with "CCA 2009," and each charm represented every retreat, all of which she planned and has attended.

Afterward, her daughter and four grandkids took the stage. Char's oldest granddaughter spoke very sweetly about her "Grammie" and presented Char with a special framed photo. Then a group of CCA teens and adults who have known Char for years came up to say what she means to them. Many families brought gifts and cards for her as well.

It was a very touching night and the tears were flowing. After everyone congratulated Char, the dancing continued well into the night! The retreat ended with a farewell breakfast Sunday morning, and more tears followed when everyone had to say goodbye.

We are truly one big, happy family. This retreat is amazing. You may read about our retreats in the newsletter, but **until you experience one in person, it is hard to understand the benefits.** Please join us for our 20th Annual Family Retreat next June, in Boston, MA. Registration is officially open!

I would like to end by applauding Char Smith once again for her 20 years of dedication to CCA. We are indebted to her for the organization's very existence, as she kept it going on her own from home and without pay during some dire years about a decade ago. Her commitment to our CCA kids and their families inspires us all. Many thanks, Char!

Annie Reeves  
CCA Program Director

# Eighth Annual heroes4hope gala

Children's Craniofacial Association is proud to announce we have again been invited to join the **Beneficiaries Circle** of the **Jorge Posada Foundation's Eighth Annual Heroes4Hope Gala**. The Gala will take place on **Thursday, September 10, 2009**, at the Sheraton New York Hotel and Towers in New York City.

Joining other organizations such as Montefiore Medical Center and the National Foundation for Facial Reconstruction, CCA will raise funds and awareness for programs and services. As a member of the Beneficiary Circle, the Jorge Posada Foundation grants CCA 100% of the proceeds from our efforts.

The Jorge Posada Foundation is a nonprofit organization founded by New York Yankees' All-Star Catcher, **Jorge Posada** and his wife, **Laura**. Their son, **Jorge, Jr.** was diagnosed with Craniosynostosis when he was just 10 days old and had to undergo seven major surgeries to correct the condition.

The gala is attended by many of Jorge's friends from the **New York**

**Yankees** team, both past and present, including **Derek Jeter, Bernie Williams, Jason Giambi, Alex Rodriguez, Tino Martinez, Mariano Rivera, Robinson Cano, Bobby Abreu, Willie Randolph** and **Joe Torre** as well as many other celebrities and close friends. Last year's emcees were **Kelly Ripa** and **Mark Consuelos**. This year, actor **Paul Rudd** will help host the festivities and the event will honor the 20 greatest New York Yankees catchers!

Tickets are on sale for \$750 per ticket or a table of 10 for \$7,500.

Families are encouraged to spread the word to businesses or others who may wish to attend or sponsor a table for the cause. **The table sponsorships do count toward our 20th anniversary promotion for CCA families to get their next retreat hotel stay free!** (See "Firstgiving" on page 3.)

For more information on tickets and corporate sponsorships, please call CCA Development Director, **Jill Gorecki** at 1.800.535.3643, or email her at [jgorecki@ccakids.com](mailto:jgorecki@ccakids.com).

# ccaprograms

and services in the spotlight

Families of craniofacial patients often call CCA to seek emotional support, discuss problems and identify resources. Through our database, we are able to network families with support groups and/or others who have similar conditions and experiences. We also keep a list of helpful resources and are always willing to listen and offer emotional support to family members who need a shoulder to lean on. For further assistance or information call Annie Reeves at 800.535.3643 or email [AReves@ccakids.com](mailto:AReves@ccakids.com)

## programs we offer

- Toll-free hotline
- List of qualified physicians
- Information and support
- Educational booklets
- Financial assistance
- CCA Network, a quarterly newsletter
- [www.ccakids.org](http://www.ccakids.org) website
- Annual Cher's Family Retreats
- Public awareness
- Family networking
- Advocacy
- Kids Klub
- Yahoo support groups
- Webinars

## 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/](http://health.groups.yahoo.com/group/ccateens_middleschool/)

High School Age:

[http://health.groups.yahoo.com/group/ccateens\\_highschool/](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](mailto:areeves@ccakids.com)

# regional volunteers

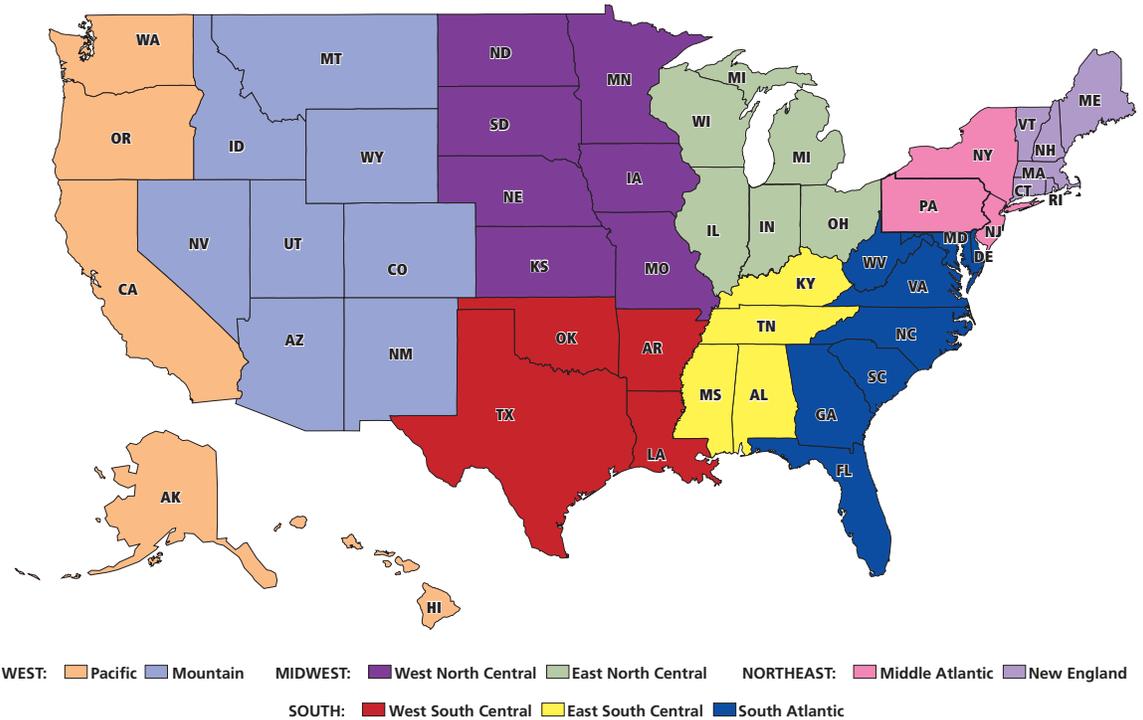
Public awareness about craniofacial conditions is important on several levels.

It's important that families find quality medical care, that healthcare professionals are aware of the special medical and emotional needs of children and adults with facial differences, that the public understands and accepts facial differences and that individuals with facial differences feel accepted.

The regional volunteers and CCA will now turn to local areas to recruit volunteers who will distribute educational materials throughout their communities.

If you would like to help educate your community and take part in this national awareness effort, call or email CCA Program Director, Annie Reeves at 800.535.3643 or [AReves@CCAKids.com](mailto:AReves@CCAKids.com).

## CCA Regional Map



# join us for golf!

Monday, September 28, 2009  
**Jylian's Links of Love**  
Whitestone Golf Club  
Benbrook, TX



On Monday, September 28, 2009, the headquarters of Dallas-based Children's Craniofacial Association will hold its second annual "Jylian's Links of Love" benefit golf tournament at Whitestone Golf Club in Benbrook, Texas. The tournament will begin with a shotgun start at 1:00, (registration begins at 11:00 a.m. with lunch) and will end with dinner, awards, raffles and auctions. Visit [www.jylianslinksoflove.com](http://www.jylianslinksoflove.com) for registration and sponsorship details. See Calendar of Events on page 5 for family-held fundraisers around the country.

# Craniofacial Acceptance Month

This year marks the fifth 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 that **"beyond the face is a heart."**

As part of the observance of Craniofacial Acceptance



Month, CCA will hold its 2nd Annual National Picnic Day on September 19th (or date of your choice in September). 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 spreading 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 Gorecki for materials about this year's fundraising events.

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

## donor in the spotlight

Frederick Seitz has been active throughout the year helping CCA with funds raised from the volunteer efforts of his youth group. He also has a FirstGiving page which is currently the leader of the pack in donation dollars.

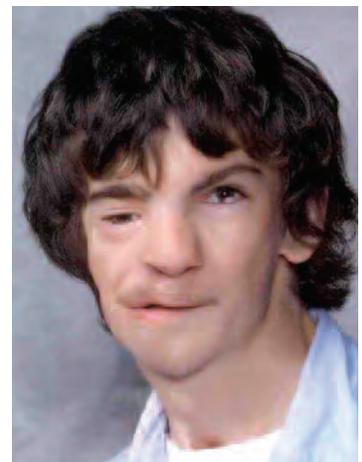
But most impressive is his notoriety with the **Youngstown Hearing and Speech Center**. On June 2nd Frederick and his family received the **May Vetterle Award**. This award is given by the Center to an individual or family who has overcome obstacles related to deafness. This year the award was given to Frederick and the **Seitz family** for advocating for

the deaf and raising awareness for individuals with facial differences. The award was presented at a dinner attended by 700 people, with **Ray "Boom Boom" Mancini** as the guest speaker. During the Youngstown event, **The Deaf Youth and Recreation Club** also presented Frederick with **\$500** for Children's Craniofacial Association. His own speech inspired many of the Firstgiving contributions which put his page ahead of the rest!

Following those achievements, sixteen-year-old Frederick got his coveted driver's license! Good thing too, because Frederick also started a job

with the Youngstown Hearing and Speech Center.

We are extremely proud of and grateful to Freddie, who has grown up with CCA and become Frederick, our summer, 2009 Donor in the Spotlight.



## 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.

# donors, january 1 – june 30, 2009\*

## Gifts from Individuals

### CCA Friends

(\$100 +)

Anonymous  
Lemmu & Sallie Austin  
Polly & Mark Barton  
Phyllis & Jerame Breeden  
Debra Breslow  
William & Ann Burgin  
Lily Burton  
Beverly & Jim Butera  
Roger S. Chin DDS, PS  
Louise Corrigan Jordan  
Arlene Coudare  
Angela Cronin  
Steve Daignault  
David & Patricia DeLong  
Mike & Maria Estrada  
Francis Fisher  
Phil & Lynn Gadd  
Erick Gorecki  
Jill Gorecki  
Ingrid Haaijer  
Sarah Hall  
John J. & Arleen Heirty  
Jesse & Elizabeth Hernandez  
Daniel & Angela Herstine  
Carolyn & Douglas Hopkinson  
Hugh & Joanne Jarvis  
Carol & Russell Jenna  
Elizabeth W. Jones  
Shelly & David Katz  
Richard Kinas  
Esther Krieger  
Roger & Carolyn Lamb  
Sylvia & C.K. Lawson  
Dr. Vincent & Susan Longobardo  
Robert Nordness

Jimmie & Gina Pavlu  
Jana & Hugh Peace  
Preston & Martha Peak  
Paul Pokladnik  
Mary Reif  
Andrea Richard, D.O.  
Jere Robertson  
John & Catherine Romero  
Eric Ronczka  
Joanne M. Roosevelt  
Randolph Schaefer  
Paul Schmidt  
Barry Scurren  
Rose & Fred Seitz  
Jeffrey & Patricia Sharpe  
Mark & Diana Shea  
Charlene Smith  
Chase Stehr  
Christopher Stokes  
William & Nancy Suwalski  
Stacy & Mitch Swihart  
Arlon Tietz  
Kenneth Wilson

### CCA Extended Family

(\$500 +)

Mario Adamo  
Martha & James Brown  
Diana Critchlaw  
George & Kristine Dale  
Fred & Judi Freeman  
Courtney Vincent

### CCA Sponsor

(\$1,000 +)

John & Sheryl Paul

### CCA Benefactor

(\$5,000 +)

Bill Mecklenburg & Christine  
Condino Mecklenburg

### CCA Guardian

(\$10,000 +)

Marie Florence Desrosiers Trust  
Bequest  
John & Patricia Dyer

## Memorials / In-Honor Gifts

Anonymous, in memory of Ellery  
Everett Walker  
Lemmu & Sallie Austin, in memory  
of Ellery Walker  
Yolanda Baker, Austin, TX, in honor  
of Henry Johnson  
Deborah Breslow, in honor of Mrs.  
Alice Kintisch, Edith Katzourin,  
Rabbi Elyse Frishman, Cantor  
Leon Sher, thanks for helping  
with Robbie's Bar Mitzvah  
preparation  
Brookwood Hall Dept of Parks &  
Rec Staff / Sunshine Club in name  
of Janice Stegmann  
Edward Brooks, in memory of Ellery  
Walker  
Christian Callens, in memory of  
Sidney Goldman  
Larry Carpenter, in honor of Cher's  
birthday  
Steve Daignault, in memory of Ellery  
Walker  
Gary & Grace Deily, in honor of  
Jeremy Dale  
Judy Donaldson, in memory of Talin  
Robert Shaw  
Erick Forseter, in memory of Ellery  
Everett Walker  
Fred & Judi Freeman, in honor of  
Michael Esser's college  
graduation  
Phil & Lynn Gadd, in memory of  
Ellery Walker  
Linda Gaida, in memory of Ellery  
Walker  
Jeremy Gaige, in memory of Ellery  
Walker  
L. Goodwin, in memory of Ellery  
Walker  
Sylvia Gonzales, in memory of Ellery  
Walker  
Jill Gorecki, in honor of Mike Esser  
Jim & Arleen Heirty, in memory of  
Bill Hayes  
Jim & Arleen Heirty, in memory of  
Rosalee Grant  
Jim & Arleen Heirty, in memory of  
Robert Korn  
Jim & Arleen Heirty, in memory of  
Dorthea Saether  
Jim & Arleen Heirty, in memory of  
Bob Watier  
Amparo G. Hernandez, in memory  
of Ellery Everett Walker  
Jesse & Elizabeth Hernandez, in  
memory of Ellery Walker  
Carolyn & Doug Hopkinson, in  
honor of Duncan Hopkinson's  
birthday  
Margaret Jenna, in memory of  
Maxine Reed  
David & Shelly Katz, in memory of  
Ellery Walker  
Linda & Rudy Kessman, in honor of  
Natasha Urban  
Susanne Laird, in memory of Ellery  
Walker  
W. David & Rhonda Leonard, in  
honor of Casey Deakins  
Sylvia & John Loving, in honor of  
Ryan Holliday  
Ann Lucas, in honor of Brody Lucas  
from grandparents  
Jim & Maryjo Montalbano, in honor  
of their daughter, Jennifer's 34rd  
birthday  
Kelly Mourer, in honor of Reese  
Mourer  
Eldora & Howard Niedermiller, in  
memory of Ida Schneider  
Jean Oleary, in memory of Sidney  
Goldman  
Johnny Pag, in honor of Robbie  
Gorecki  
Jimmie & Gina Pavlu, in memory of  
Ellery Walker

\*Listed are **Monetary Donations of \$100 or more** through 2nd quarter, 2009. We are extremely grateful for these and all other fees, purchases, fundraisers and in-kind donations not recorded here. **Note: For space consideration, 2009 donations under \$100 (CCA Supporters) will only be published in our year-end list. Cumulative \$100+ donations and In honor or In Memory dedications will continue to be published in each quarterly issue**

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

CFC (Combined Federal Campaign, federal-employee giving)

Harold & Elvia Prange, in memory of Carolyn Muse  
 Mary & Megan Reif, in honor of JoAnn Kopshinsky & Robbie Gorecki  
 Jere Robertson, in honor of Jane Monell for her birthday  
 Criss Scruggs, in memory of Ellery Walker  
 Fred & Rose Seitz, in honor of all CCA kids  
 Fred & Rose Seitz, in honor of Freddie Seitz  
 Stephen & Lila Shain, in memory of Talin Robert Shaw  
 Jeffrey & Patricia Sharpe, in honor of Rick Dornier  
 Mark & Diana Shea, in honor of Brielle Shea  
 Taryn Skees, in honor of John Gorman  
 William & Nancy Suwalski, in memory of Victoria Suwalski  
 Lisa Tafolla, in memory of Ellery Everett Walker  
 Doris & Ralph Teneyck, in honor of Tamara Mantlo  
 Timber Ridge Elementary School Collection in honor of Cale Morris  
 Mary Wilcox, in the name of Sarah Wilcox  
 Joseph & Rosalia Wilkes, in memory of Sidney Goldman  
 J.B. & Cynthia Wills, in honor of Reed Wills

## Corporate / Foundation Gifts

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

AT&T (Employee Giving)  
 Aptus Partners, LP (John Romero)  
 Baker Roofing Company  
 Bank of America (United Way Campaign Employee Giving)  
 Charity Motors (CARS; Charitable Auto Resources)  
 Children's Medical Charities (CFC)  
 Creative Growth Counseling & Coaching, Inc.

Dominion Foundation (matched gift of John Charles Larson)  
 Epic Systems, Inc.  
 Frugal Flower  
 Funding Factory  
 Johnny Pag Creations  
 Justgive (donors listed separately)  
 A grant from Kraft Foods Global, Inc.  
 Kroger  
 Neal Oral & Maxillofacial Surgery, PLLC  
 Network for Good (donors listed separately)  
 One Cause  
 Pfizer (United Way Campaign Employee Giving)  
 Prudential Foundation (Employee/Matching Gifts)  
 Prudential Foundation (Matched Gift of Diana Critchlaw)  
 Safeway, Inc. (purchases percentage incentives)  
 Sarah Hall Productions by Sarah Hall  
 Schoolpop (online purchases percentage program)  
 A grant from Tektronix Foundation (Larry Bolton)  
 United Way of California, Capital Region (Donor-Directed Donations)  
 United Way of Central Maryland (Donor-Directed Donations)  
 United Way of Greater Milwaukee (Donor-Directed Donations)  
 United Way Mile High (Donor-Directed Donations)  
 United Way New York (Donor-Directed Donations)  
 United Way of Southeastern Pennsylvania (Donor-Directed Donations)  
 United Way of Tucson and Southern Arizona (Donor-Directed Donations)  
 Wellpoint Foundation Funds Management  
 Wells Fargo (Employee Giving)

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

Association Works by John & Sheryl Paul  
 A grant from the Chatlos Foundation  
 A grant from Lifetime Fitness Foundation  
 A grant from the Perot Foundation  
 The Redwoods Group (Matched Gift of Bill Mecklenburg)  
 Starbucks Corporation  
 Vivo Brothers, Inc.

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

A grant from May & Stanley Smith Charitable Trust  
 Triangle Foundation (Donor-Advised Grants)

### CCA Corporate / Foundation Partners (\$10,000 or more)

Cher Charitable Foundation

## Fundraising Events

### Up to \$1,000

Alexa's Appeal for CCA / Denise Rast, CCA Volunteer  
 Brookwood Hall Dept of Parks & Rec Staff / Sunshine Club Collection in name of Janice Stegmann  
 Carnival of Caring / Avery Lytle, CCA kid  
 Ink / Cell Recycle for CCA / CCA Families & Friends  
 Jewelry Sale / Robyn Johnston  
 Tamara Mantlo's Firstgiving Page  
 Johnny Pag Motorcycle Raffle  
 Jana Peace Email Fund Appeal  
 Orland Park Village Denim Day / in honor of Kate Rogers, CCA kid  
 Permission Men's Skin Care Line  
 Timber Ridge Elementary School Collection in honor of Cale Morris

Hannah Steinagel's Firstgiving Page / Kathie Steinagel, CCA Volunteer  
 Sammi Wayne's Lemonade Sale for CCA / Samantha & Jennifer Wayne

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

Be Brody's Angel / Jennifer Lucas & Family, CCA Volunteers  
 CCA Family Retreat Chance Raffle  
 Cher Convention / Kim Werdman, Judy Didelot, Coordinators  
 Family Fun Stimulus Package Raffle / Matthew Abernathy, CCA Volunteer w/Jana Peace  
 Friends of Freddie Firstgiving Page / Rose Seitz, CCA Volunteer  
 Seth's Stride / Swihart Family, Stacy Swihart, CCA Volunteer Coordinator  
 Smiling Through The Mask Dinner / Wendelyn Osborne, CCA Volunteer  
 Starbucks Community Clean-Up / Emily Tipton, Organizer w/Jana Peace, CCA Volunteer

### \$5,000 or more

### \$10,000 or more

### \$20,000 or more

Henry's March / Johnson Family, Rachel, TJ, Lauren, Henry

# 3 cheers for volunteers!

family and friends top **Matthew Abernathy's** list of what's important to him. Always exuding kindness and selflessness, he is committed to helping others and considers CCA to be part of his community.

Matthew first learned about CCA several years ago when he and his brother decided to form KLUBHOUSEKIDS. Their vision was to support the community by giving their time for causes that needed a helping hand. CCA needed just that, a helping hand with selling raffle tickets for a motorcycle to be raffled at a bike rally. Matthew even spoke at a Rotary breakfast to raise awareness of our kids and their families and let people know there is an organization that offers assistance.

Now a teenager, Matthew is still involved with CCA. He volunteers when Starbucks teams up with CCA to raise funds through



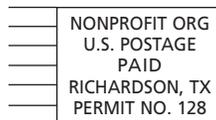
Matthew Abernathy looking spiffy during confirmation at his church.

environmental clean-up programs along local walking trails. Matthew recently held a successful raffle for CCA to raise more funds and awareness.

We want to thank Matthew and say "3 cheers!" for your continued commitment and willingness to support CCA. Your gentle character and smile remind us that we can all make a difference!

## children's craniofacial association

13140 Coit Road, Suite 517 • Dallas, TX 75240



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Cher

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