

# ccanetwork

newsletter of the children's craniofacial association

Cher — honorary chairperson



fall 2009

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## daniel's story

By Debby Lloyd

**O**ur journey with **Daniel** began when my 20-week ultrasound revealed a large, solid, cystic-looking structure attached to the right side of his cheek/jaw. After two ultrasounds and a MRI were inconclusive, we sought a second opinion. That was also inconclusive as to whether we were seeing a teratoma or a cystic hygroma.

During the rest of my pregnancy, I had sonograms about every two weeks. A genetic counselor asked numerous times if we wanted to abort the pregnancy. Of course we declined. This baby is a gift from God, and we will love him no matter what challenges come with him.



In the womb, Daniel's cystic hygroma was measuring 1 cm. larger than his head. Daniel was given an 80% chance of dying before birth. He had fluid around his heart and at this point, we still

see **daniel**, page 10



## message from the development director

**I** remember a fundraiser we did when I was a youngster. Each of us went door to door around our neighborhoods, asking one household to donate a single egg and the next to purchase the egg for a quarter, alternating until we met our goal or ran out of neighbors. The idea had varying success, depending on how outgoing we kids were and how well neighbors knew and trusted us. But, any success at all was crucial to that first contribution of an egg, even if you had to get it from

see **development  
director**, page 14



**Children's Medical Charities  
of America**

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



# meet ashley bock

**f**ive-year-old **Ashley Bock** is making the big leap to Kindergarten. She's transitioning to a Kindergarten class in the mornings and loves it, especially because she can buy her own lunch.

Outside of school, Ashley enjoys riding horses. She's started a horseback-riding therapy program last January and looks forward to riding Buddy, her favorite horse in the stable. She also likes to dance to all types of music and is a huge Hannah Montana fan. And when it comes to playtime, playing with her dollhouse is her favorite way to pass the time.

Ashley has a twin sister, **Jessica**, and an older brother **Christopher**

(Topher), who is eight years old. Her family has two dogs, Codi, an Alaskan malamute who was rescued from a shelter, and a sheltie named Sadie. Her brother has two dwarf hamsters, Daisy and Minnie. "I love to talk to them and watch them run on their wheel," she said.

She had a busy summer. Ashley went on a trip to San Antonio and then attended a "bunch of therapy camps" at the same place where she rides Buddy.

This last summer, Ashley and her family also went to the CCA retreat at Great

Wolf Lodge. "I had so much fun," she said. "I loved seeing and playing with other kids like me." Ashley met up with her friend Olivia Sanborn and Olivia's sister, Amelia. Plus she saw so many other CCA friends, including Kieran, Seth, Brody, Ashley, Antonio and Alexis, just to name a few. She also met plenty of new friends, too.

Ashley has been to four retreats so far—Grapevine, TX; Nashville, TN; Hershey, PA; and Salt Lake City, UT—and she looks forward to going to more.

Ashley has Apert Syndrome and has had 17 surgeries so far. "Sometimes after surgery your tummy won't feel good," she said.



"And they put stickers all over your chest and tummy and a pulse ox and IV." Her next procedure will be the mid-face.

Always the optimist, Ashley takes everything in stride: "You get to eat popsicles and ice cream and play doctor with your bear. And they have a playroom."

When she grows up, Ashley wants to be a doctor, so she can take care of "surgery kids."

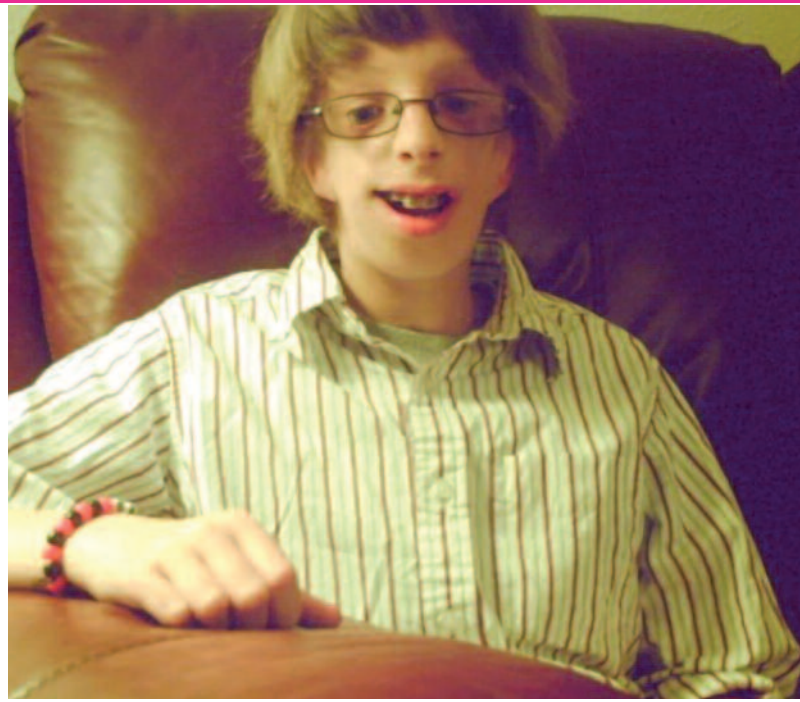


# ccakid



# ccateen

## meet connor bolton



**m**y name is **Connor Ray Bolton**. I was born September 12, 1993, in Albuquerque, New Mexico. I was born at 32 weeks. Right away, I was diagnosed with Treacher Collins Syndrome. I spent the next two and half months in the NICU with many complications. My airway was the main issue that had to be dealt with.



The doctors put a trach in when I was just a month old. They put a G-tube in, since I had a severe cleft palate and wasn't able to suck a bottle.

I finally came home just before Thanksgiving. My parents were ecstatic to bring me home. I was sick a lot when I was little, and I didn't want to learn how to eat.

My parents moved us to Plano, Texas, when I was three years old, where I had many surgeries in my young life. My parents found my doctor in Dallas, Texas, Dr. Salyer. Since his retirement, I now see Dr. David Genecov. I had jaw distraction surgeries, so I could get the trach out. I finally got the trach out just before I started kindergarten.

At that time, I was blessed with a little sister named Molly. Later in first grade, I got the G-tube out. I still struggled with eating for sometime after that. I am currently 16 years old, and I have had as many surgeries as my age now.

I enjoy eating all the same food my family eats. Through the years, I got ears through reconstructive surgery and a bone-anchored hearing aid (BAHA), and I am now in the middle of braces.

By the time you read this, I will have started high school. I am studying for my driving permit and enjoy all my classes especially, history and science. My goal is to go to college and study history and eventually get my Ph.D. in history. I'd like

to one day work in a museum.

When I am not doing homework, I enjoy playing with my Wii and reading all the WWI and WWII books that I can get my hands on. I enjoy drawing all kinds of animals in my spare time. I also enjoy spending time with my sister.

When I think back on my life, I feel blessed to have my family with me every step of the way. I know my future will be bright because I learned to work hard and never stopped believing in myself. But most of all, I just keep remembering that God made me who I am.

# meet christopher and jessica bock

By Lisa Bock



## Christopher

**C**hristopher is eight years old and will be in second grade this fall. He was two weeks away from turning three years old when his twin sisters were born.

Ashley came home from the hospital first, and Christopher immediately bonded with her. He would just lie on the couch and hold her while she slept. A few days later, Jessica came home and Christopher wanted to know why Jessica's head looked the way it did. He had gotten so use to the way Ashley looked he actually thought something was wrong with Jessica.

They still have a very special bond. Sometimes I bring him to Dallas with Ashley and me so he can see what takes place when we are there for appointments. He also does a great job of helping me with her and keeping her entertained.

Christopher loves race cars and trucks. Since he was two years old his Dad has taken him to NHRA drag races every year as well as monster truck shows. He has a small-engine go-cart at his grandfather's farm that he loves to drive on the weekends. In the past, he has played soccer and baseball, but he really loves football. He has played flag

football for two years and will start tackle football this fall. On the weekends, he lets his parents sleep in by feeding his sisters breakfast (cereal and milk) and watching cartoons with them.



## Jessica

**J**essica is Ashley's twin sister. She is super sweet and gives the best hugs to everyone she knows. She and Christopher have like personalities and

therefore do most of the fighting in our house.

She loves her sister Ashley. They play really well together with only the occasional disagreement. Jessica and Ashley both know their ABCs, can count to 20, know their address and telephone number, and can spell their names.

Jessica is five years old and will be doing a "learn a lot" kindergarten program this fall. This will be her third year at the preschool, and she loves it there. She will also be in her third year of tap and ballet classes. She loves to dance, play dress up, play with her dollhouse and watch the movie "Cinderella." Jessica also plans to play soccer at the YMCA this fall.

She will be going to school until 1 p.m. every day while her sister and brother will be at school until almost 4. So this year Jessica gets to make up all the time she missed out on with Mommy when she was in Dallas for Ashley's surgeries and doctor appointments. They are really looking forward to some quality time.

# ccasupersibs

## calendar of events

date	event	contact
Dec 5, 2009	<b>CCA Holiday Party–Midwest</b> Brat Stop/Parkway Château Kenosha, WI	JPatterson@ccakids.com 214.570.9099 800.535.3643
Dec 12, 2009 10 AM-Noon	<b>CCA Holiday Party–Dallas</b> Southfork Ranch Parker, TX	ARees@ccakids.com 214.570.9099 800.535.3643
Mar 7, 2010	<b>3rd Annual Henry's March for CCA 5k Fun Run</b> CSU, Stanislaus Turlock, CA	laurnhenry@sbcglobal.net myspace.com/henrysmarch 209.664.0500
Jun 24, 2010	<b>Craniofacial Symposium</b> Hyatt Regency Cambridge Cambridge, MA (overlooking Boston)	ARees@ccakids.com 214.570.9099 800.535.3643
Jun 24, 2010	<b>20th Annual Cher's Family Retreat</b> Hyatt Regency Cambridge Cambridge, MA (overlooking Boston)	ARees@ccakids.com 214.570.9099 800.535.3643
Aug 28, 2010	<b>5th Annual Wendelyn's Course of Dreams Golf Tournament</b> Country Club of Arkansas Maumelle, AR	wendelynyvonne@hotmail.com
Sep 2010	<b>Jylian's Links of Love</b> Golf Tournament Location TBA (Texas)	JPatterson@ccakids.com www.ccakids.org 800.535.3643
Sep 19, 2010	<b>Smiling Thru the Mask – A dinner to benefit CCA</b> Restaurant 1620 Little Rock, AR	wendelynyvonne@hotmail.com
Sep 25, 2010	<b>Little Fire, Big Heart Dinner/Auction</b> Melwood Art Center Louisville, KY	TarynSkees@gmail.com www.littlefirebigheart.com

## cca mugshots



▲ CCA supporters, Richie Cook and Adam Golden got their "girls" Presley and Paisley to "mug" for CCA.

## h&r block

If you're not already a customer of the H&R Block folks for your taxes, having your return done for 2009 with their help will also help CCA!

H&R Block will donate \$25 to Children's Craniofacial Association if you designate CCA as your charity when you have your taxes done there! Call Jill at CCA for a form.

## bracelet sales continue!



### "Beyond the Face is a Heart" wristbands

The response to our CCA bracelets is so enormous, we'll continue selling them throughout the year!

**Bracelets are \$1 each**

They'll make a great stocking stuffer!  
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  
JPatterson@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!



# happy 20 years!

So many changes have taken place over the past 20 years. In 1989, it was as difficult for CCA to find families affected by facial differences as it was for them to find CCA. Later, articles in *Redbook*, *People* and *Parade* magazines helped tremendously, but CCA still mostly relied on word of mouth to lead families to our toll-free hotline.

Another important issue for families was finding quality medical care for their children. At that time there were few qualified craniofacial centers, and, unless the family contacted CCA, the odds of finding those centers were slim.

Another major issue was knowledge about the conditions. In order to educate themselves about craniofacial disorders and treatments, families had to resort to complicated medical publications. Without CCA, families were “out there” on their own. The only time they could talk to another family going through similar experiences was in the confines of a hospital setting, where most of their time was spent concentrating on their own child, leaving little time for commiserating.

CCA was founded in February 1989 and began serving families affected by craniofacial differences,

offering a toll-free hotline and a financial assistance program as well as publishing a newsletter. By fall 1992, a new logo was created, and the first syndrome booklet, “A Guide to Understanding Craniosynostosis,” was published in an easy-to-read format. A parent support program was in the planning stages, and CCA held the second annual family retreat.

Fast forward 20 years and you’ll find families easily finding CCA via the Internet and getting education and support through our comprehensive website [CCAKids.org](http://CCAKids.org). CCA has published 13 syndrome booklets and translated them to Spanish and now publishes a much more comprehensive quarterly newsletter.

CCA continues to offer a financial assistance program for food, travel and lodging, maintains a list of the International Society of Craniomaxillofacial surgeons to ensure families find comprehensive quality surgical care. In 2008, Kids Klubs were formed to educate and support kids of all school ages, and Webinars were added to the stable of programs and services, providing yet another source of education and support.

In September, 2009 CCA observed the Fifth Annual



Craniofacial Acceptance Month that included governors’ proclamations in 19 states, distributing hundreds of packets to media outlets and holding observance picnics across the country. And in June, CCA held its 19th Annual Family Retreat (the most attended ever) and, in conjunction with the retreat, re-established our educational symposium.

For 20 years CCA has served families affected by facial differences and has helped raise a whole generation of “kids.” In 1990 ten families met in Washington, DC, to testify in front of the House Budget Committee. Of that group Rob Gorecki, Erin Williams and Zach Bordonaro, were just toddlers, Jennifer Johnson was around 10 and Dan Sweeney and Stephen Wright were in their teens.

Today all of these individuals and/or their families are still involved with CCA in one way or another. In fact, Stephen Wright serves on CCA’s Board of Directors. Erin Williams was awarded a very generous grant for

CCA last year. Rob Gorecki has been involved in motorcycle-related fundraising activities over the past seven years and has represented CCA at many events, and his mom, Jill Patterson, is CCA’s Development Director. Jennifer and her mom, Carolyn have volunteered for CCA over the years. Dan’s mom, Diana, is a former board member and currently serves on the financial assistance committee.

So for 20 years, CCA has been there for families navigating this unfamiliar territory. We have listened to our families, addressed their needs, and defined and refined the programs and services we offer.

As our 20th anniversary year comes to an end, Children’s Craniofacial Association is proud to be recognized as the premier craniofacial family support organization based on offering the most comprehensive programs and services, addressing the broad range of medical, financial, emotional, psychosocial and educational issues related to facial differences. And we will continue to be a source of empowerment and hope for our families for as long as our services are needed.

## cca 20th anniversary t-shirts

**O**ur limited edition 20th Anniversary Logo T-shirts are still 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).



## goodsearch & goodshop

**E**very time you shop online at your favorite stores you could be saving money and earning a donation for Children's Craniofacial Association.

Our new toolbar, developed by **GoodSearch & GoodShop** takes just a few seconds to download. More than 1,300 top stores including **Apple, Best Buy, Gap, PetSmart, and Staples** are pitching in and will donate a percentage of each sale to our organization. There's no extra cost to you and you may even save money as the merchants are providing us thousands of money-saving coupons!

The GoodSearch toolbar also includes a search box which is powered by Yahoo! Each time you search the web, about a penny is donated to us!

There's no easier way to help CCA. Please spread the word! Here's a link to the toolbar for more information: <http://www.goodsearch.com/toolbar/childrens-craniofacial-association-cca>

## donor in the spotlight

**J**ohnny "JR" Pagnini, known as **Johnny Pag, Johnny Pag Motorcycles** and the **Pagnini family** have been long time supporters of Children's Craniofacial Association. They have known CCA kid (now grown) **Robbie Gorecki** for years and Rob's first motorcycle was a Johnny Pag original.

Most recently, Johnny donated the bike on CCA's behalf for the 7th Annual Heroes4Hope Gala hosted by the Jorge Posada Foundation. The bike was autographed by Jorge and his fellow Yankees and auctioned last year for around \$30,000! For the 8th Annual Gala in



September this year, JR customized his Barhog model into a one-of-a-kind Yankee's edition with a ball signed by Jorge Posada embedded in the gas tank, the foundation logo emblazoned into the leather seat and again, autographed in person by Yankees players current

and past at the event to bring \$29,000 during the live auction.

Johnny Pag Motorcycles is dedicated to helping many charities raise funds and has a goal to reach \$500,000 for his stable of causes. To that end, Johnny has also donated another bike to

JR Pag with Rob Gorecki



CCA Kid Jeremy Dale sits on the NY Yankee bike donated by JR Pag for the 2009 gala.

CCA for raffle, the winner of which will be drawn December 1st. Children's Craniofacial Association is proud and extremely grateful to be among the beneficiaries of JPM generosity.

Sincere thanks to JR Pagnini "Johnny Pag," our Fall 2009 "Donor in the Spotlight."





DFWBid founder, Sanj, presents a check to CCA

## "gives back" program

**d**FWBid.com has gained national exposure for its revolutionary approach to auctioning off **gift cards for pennies on the dollar**.

Now, DFWBid.com "Gives Back" and you can help.

**Friday – Sunday, December 18th – 20th,** DFWBid.com will give a portion of every auction entry and final auction price to **CCA**.

Grab a bargain and know you are also contributing to your favorite cause!



CCA's own Annie Reeves gave birth to her second son, Caden Cole, on October 26th.

**t**he **National Inclusion Project** grew out of the relationship between **Clay Aiken** and **Diane Bubel** and Diane's then 13-year-old son, **Mike** who had been diagnosed with autism. The bond between them grew strong as they shared a vision of a world where children like Mike could be fully immersed in society. They had both witnessed children with disabilities repeatedly turned away from activities open to typical children. Both Diane and Clay realized that an organized effort could encourage and facilitate community inclusion and empowerment of individuals with disabilities.

While many people dream of an opportunity to assist children with disabilities, very few have the opportunity to do so. As Clay Aiken became a household name through American Idol, he and Diane knew that he had been blessed with an unprecedented opportunity to turn their shared goal into reality. Clay announced the formation and purpose of his foundation on national television and his fans responded with over \$1 million of support. Since that time, the National Inclusion Project has established itself as a leading voice for inclusion

working with a "Who's who" list of youth organizations – YMCAs, Best Buddies International, Boys & Girls Clubs, CampFire USA, 4H, the ARC – as well as many other local parks and recreation departments, community centers, and privately-run programs. They have also formed partnerships with Johns Hopkins University's National Center for Summer Learning, the University of Massachusetts-Boston's Center for Social Development and Education, the University of New Hampshire's Institute on Disability, the University of Minnesota's Institute on Community Integration, and the University of North Carolina-Chapel Hill's Frank Porter Graham Child Development Center.

In 2008, both of the Project's cutting edge inclusion models – Let's ALL Play and the K-12 Inclusive Service Learning Program – were closely evaluated with overwhelmingly positive results. Children with and without disabilities in these programs saw growth in motor skills, social skills, and self-esteem, and the impact of the friendships they made will last long into the future. The National Inclusion Project provides the training for



these programs, and it provides funding so the youth organizations can offer scholarships for children to participate.

The National Inclusion Project has worked with hundreds of programs, trained numerous staff members and leaders, and provided inclusive opportunities for over 20,000 children. CCA's hope is that our parents will reach out to their local youth organizations to explore a partnership with The National Inclusion Project to provide programming that not only welcomes children with craniofacial differences, but all children who need to be embraced by their peers and the community.

The National Inclusion Project is poised to continue to make an impact with thousands of children nationwide as well as raise the national consciousness about the need for and benefits of inclusion. To learn more about The National Inclusion Project or ways to get involved visit their web site at

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



# 4th annual wendelyn's course of dreams

As a lead-in event to September's "National Craniofacial Acceptance Month," the 4th Annual Wendelyn's Course of Dreams was held Saturday, August 22nd at **Country Club of Arkansas** in Maumelle, located just outside Little Rock. On an absolutely gorgeous day, 60 players were greeted with an assortment of pastries, compliments of **Maumelle's Super Center** and an assortment of drinks provided by **Coca-Cola Bottling of Arkansas**.

After **Tim Jenkins**, owner of the club, gave the rules for the competition, Wendelyn gave a brief overview about CCA and the role they play in the lives of individuals with craniofacial conditions. Then, she told her own story of living with craniometaphyseal dysplasia.

Throughout the tournament, golfers and volunteers enjoyed snacks



provided by **Ben E. Keith Distributors**, and water provided by **Rainwater, Holt & Sexton Law Firm**. At the turn-a-round, they had the opportunity to view a slideshow of CCA Annual Family Retreats while enjoying ice cream novelties by **Blue Bell Creameries**.

After completing 18 holes, players enjoyed lunch catered by **Evette**



**Brady and Tim Morton of Restaurant 1620** and participated in a live auction while waiting to find out who won the competitions.

Wendelyn would like to thank her volunteers whose help made it a wonderful event: **Roberta Long, Cindy Ford, Linda Dicus, Pamela Barker, Oginga Carr, and Payton Berklite**.

Thanks also to the support of many other businesses and individuals as well as **Tammy Taskey** with **Academy Sports**, **Lindy Blackstone** and her crew at **103.7FM the BUZZ** all-sports radio station and local **ABC affiliate, KATV, Channel 7** for all they did to promote this event and our cause. (Channel 7 had a foursome and their own, **Steve Sullivan**, aka "Sully" helped promote the competitions and raffles at the beginning of

the event!) Everyone participating, directly or indirectly, has helped to heighten awareness and foster acceptance for individuals living with facial differences!

Mark your calendars now for the **5th Annual Wendelyn's Course of Dreams** to be held **Saturday, August 28, 2010** at Country Club of Arkansas in Maumelle which will be followed by the **2nd Annual Smiling Through the Mask**, black-tie dinner at **Restaurant 1620** on **Sunday, September 19th**, to commemorate "National Craniofacial Acceptance Month." Both events promise to be very enlightening and loads of fun!



**daniel**, from page 1

did not know what was actually wrong.

On January 11, 2006, Daniel Lloyd was delivered three-and-a-half weeks early, weighing a healthy 7 pounds, 14 ounces! Once his airway was secured he was taken for a CT where it was confirmed he had a cystic hygroma. He was placed on a breathing tube in the NICU. By the second day the tube was removed.

We were told he would more than likely have to be in the NICU for two months, but he came home in six days! We were not prepared for him to come home so soon. Two very sweet ladies from church showed up on our doorstep with a new crib, diapers, wipes and clothes. A few days later our church family threw a baby shower for Daniel. Blessings surrounded us!

His first couple of months were, "wait and see" times. On April 4, 2006, Daniel went in for his first MRI. During the scan, Daniel's right lung collapsed. When we went to see him in

recovery our "Little Man" was on a ventilator. A three-month-old baby should not be on a ventilator! He was moved to ICU, and the next day his surgeon said he was going to remove the breathing tube and see how Daniel did. He said he wanted to do this in the OR just in case Daniel's airway was too compromised and surgery would need to be done. Seven hours later, we saw the surgeon. Daniel's "chubby cheek" had been resected and sclerotherapy (a treatment used with a chemotherapy agent to treat vascular malformations) had been done. His surgery was successful.

Daniel only slept on the right side for the first three months because his cystic hygroma was too heavy for him to turn his head. He wore a corrective helmet for plagiocephaly, and we had to drive two hours each way every other Friday to have his helmet adjusted. We did this for almost a year.

Daniel has had five sclerotherapy treatments. During the next year we found out Daniel had mild hemi paresis on the left side (Cerebral Palsy). He wears an ankle foot orthotic (AFO) and a hand splint. He has a chest wall deformity (Pectus



**Daniel after a surgery**

Carinatum) and mild scoliosis.

In January 2008, Daniel's airway was obstructed. During a bronchoscopy, the doctor's found Daniel's airway would completely close when his head was turned to the left side.

During the next surgery, doctor's removed his tonsils, adenoids, redundant tissue and did more sclerotherapy. He was in ICU this time for seven days, mostly on a ventilator.

In April 2008, Daniel had major dental surgery because of bacteria getting trapped on the hygroma side of his mouth. In August, I heard the same horrible breathing sounds I had heard when Daniel had airway issues the first time. This time an obstruction was growing at the back of his tongue near where his tonsils had been. The obstruction could be seen when he opened his mouth. Daniel had another surgery.

Daniel is also treated at our local Shriner's Hospital for his scoliosis. During his

last six-month check up, the Orthopedist thought Daniel's thymus gland was too large. We contacted Daniel's pediatrician at Kaiser and another MRI showed Daniel's thymus gland to be full of and surrounded by lymphatic tissue (macro and micro cystic). His cystic hygroma actually runs down to his liver. Daniel had a short break from doctors' appointments while we attended the CCA Retreat in Grapevine, TX. But immediately following in July, Daniel was scheduled to have a right-side hemi-thymectomy and more sclerotherapy done.

Daniel loves his doctors, which is a huge blessing. He has nicknames for most of them. His doctor's are so good about listening to me and very good at educating me. Daniel has been in physical, occupational and music therapy for the last two years. He enjoys his therapy time and the therapists.

Daniel has a big huge smile. He laughs a lot and loves to play, especially outside. He has mastered his first scooter and continues to amaze us. We encourage him to try most typical activities. I am so happy he is my third child or I may have coddled him too much.

He watches baseball with his brothers and his



**Daniel at 3 months old.**

continued next page ➡





Daniel at 2 years old.

favorite player is David Ortiz. He recently went to his first AAA baseball game and had a blast. He likes playing soccer and was so happy to receive a soccer pattern on his last AFO.

Daniel will start preschool in August and is more than ready! He is an avid Star

Wars action figure fan and also loves Dora!

Daniel is such a blessing, not just to our family, but to everyone he meets. He is a gift from God. We are so thankful for our family, church family and our friends who have supported us over the past three years. We know Daniel has more bridges to cross and valleys to walk through, but we will continue to hold his hand through his journey.



Sammi (right) and her friend Kayleigh

## lemonade sale for cca

CA kid, **Samantha Wayne** of Coatesville, PA, got together with her friend, **Kayleigh** and put up a lemonade stand during her mom, Jennifer's, rummage sale and brought in **\$335** for CCA! Wow Sammi, THANKS!

## Kids Klubs



children's craniofacial association

**W**ant 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!

## 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)

**For a complete list of our programs and services, visit:**  
**[www.ccakids.org/prg.asp](http://www.ccakids.org/prg.asp)**

**LOOK FOR THE COMPLETE  
2009 DONOR LIST IN OUR NEXT ISSUE**



## fundraising news

# third annual seth's stride for cca

by Stacy Swihart



Gabe (4), Mitch, Stacy (standing), Sydney (3) and CCA Kid Seth (6)

It was another great year for the 3rd Annual Seth's Stride for CCA. We couldn't have had more beautiful weather! There were many new faces this year, which is always exciting! New faces = more awareness of CCA and our awesome kids. We were honored to meet two new families. **Julie and Pat Foley** from Columbus, Ohio came with their eight beautiful children. Their son, **Kevin**, has Apert syndrome and is such a sweetheart. We also got to meet **Melissa Hunter** and her boys, **Braden** and **Colton**.



Seth and baby Kevin

It was so nice to see them all hanging out and enjoying the day. Thanks for coming you guys!

I want to thank our sponsors: **Marathon Petroleum, JMW Trucking, E&M Liberty, Yoho Photography** and **Jim and Barb Maraccinni** for their continued support, and my committee of volunteers for making this event

possible! We are already looking forward to next year!



Jaci Samhammer and Country Dance Bash goers, Brittany Stevens and Suzanne Ronczka

## jaci's country dance bash

Jaci's Country Dance Bash was held on Saturday, July 18, 2009 at the **Elks Lodge** in Fairless Hills, PA.

This was an afternoon of dancing, food, and fun. We **raised over \$2000** for CCA by ticket sales, donations, 50/50 raffle, and an auction. Some of our generous sponsors were: **Knights of Columbus, Sons of the American Legion, Philadelphia Flyers, Philadelphia Phillies, Sesame Place, Curves, LA Fitness, WAWA, Country Music Fever, Olive Garden, Yardley Flower Company, Lower Bucks YMCA, Cold Springs Beverages, Cramer's Bakery, American Legion Knowles Doyle Post 317, and Congressman Patrick Murphy**, as well as many other individuals and businesses.

Brochures, information, and a PowerPoint presentation were available to familiarize everyone with CCA.

Special thanks to **Mickey McAllister** for tremendous help in soliciting donations and assisting in more ways than we can list; **Elizabeth Xibos** and **Trish Hallam** for helping to sell tickets, decorating, and promoting this event; **Ken Kotnarowski**, our bartender, decorator, setup person; **Harry Beerhalter**, our DJ who volunteered his services, and **Lydia Devlin** and staff at the Elks Lodge, who helped make this event a success.



Jaci Samhammer and Mickey McAllister

## fundraising news

# second annual alexa's appeal for craniofacial awareness



Comedian, Cash Levy, CCA Kid Alexa and her mom, Denise Rast

The Second Annual Alexa's Appeal was an amazing night filled with tears, hugs and laughs. The evening included a delicious dinner, an emotional video of CCA families and friends, and a comedy show that left everyone in stitches.

Denise Rast started this event last year after finding out her daughter, Alexa, had Coronal Craniosynotosis. She found CCA and reached out to them. After

helping her with the hotel costs for Alexa's surgery and selecting their family for one of the sponsorships

for the 2009 Retreat, she knew they wanted to give back to help others as well.

Denise's main goal is to spread awareness and acceptance for those living with craniofacial conditions. In her small town she tries to reach as many people as possible. This year's event had a heart-wrenching presentation showing what these children must endure during surgeries and recovery. Then a **Comedy Central** comedian named **Cash Levy**, who just returned from Afghanistan where he was performing for our troops, put on a show that had everyone laughing.

With help from the community and local businesses, Denise was able to reach out and help spread awareness and acceptance for people living with craniofacial conditions. You can see more pictures and what people are saying about this event at

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



## jewelry sale for cca

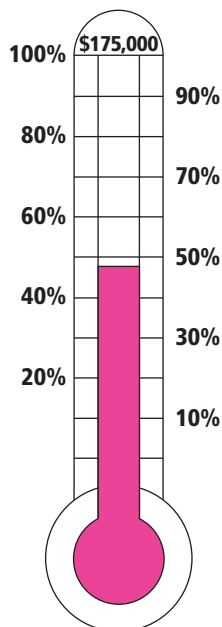
ever since reading a newsletter story about **Jeremy Dale** in our Spring, 2004 issue, **Peggy McDannel**, a Cher fan and Cher Convention enthusiast became permanently attached by the heartstrings to CCA and our cause. She is

an avid fundraiser for Children's Craniofacial Association, caring for CCA kids like Jeremy by raising funds with email appeal letters and most recently, by selling her hand-crafted earring creations and bookmarks at local gatherings in her Limon, Colorado hometown. She donates 50% of all sales to CCA. We applaud Peggy for her years of dedication. Many thanks Peggy!

## cca wish list

- Regular Bond Copy Paper
- Card Stock (Cover Weight) Paper
- Boxes of Crayons
- Used cell phones, empty ink & laser cartridges for recycle rebates
- Cases of bottled water
- Candy canes for holiday party
- Golf-related items for charity tournaments
- Hand-cart dolly that folds down like a flatbed for hauling newsletters
- Easel flipchart pads of paper
- Portable headset microphone/amplifier
- 8 or more gig flash drives
- Postcard stamps / postage
- Badge / Button maker
- Large quantity break-away lanyards for retreat name tags
- Screen and projector for powerpoint presentations
- 2-pocket folders
- Report binders
- Manilla letter-size file folders
- 11x14 'craft' envelopes
- 9x12 white mailing envelopes
- Avery Labels #5962
- Airline Miles
- Big quantity of large tote bags for retreat
- Colored Pen Sets (gel/roller ball)
- Regular and Fine Tip Sharpie markers-all colors
- White rectangle flag map pins

2009 FAMILY FUNDRAISER GOAL THERMOMETER





your own family. This memory illustrates the importance of the in-kind donation (goods, not funds) to a fundraising effort.

While nonprofits are advised to look to in-kind giving during our current economic woes, this has been the practice at CCA since our beginning. We now have a cache of in-kind supporters giving time, talent and in-kind treasure to help sustain funds when cash donations are down. This enables us to use an impressive percentage of our resources directly toward forwarding our mission.

Non-monetary gifts have always been an important part of everything we do, from raising funds for programs and services to subsidizing general office operations. Our organization utilizes significant volunteerism with a board of directors, regional and local volunteers, and families holding fundraising events around the country to extend the reach and proficiency of only 3.5 paid employees for the entire nation.

CCA's list of in-kind donors is extensive and includes numerous gifts for our family fundraisers and special events for auction, raffle and door prizes as well as contributions of

expertise for day-to-day functions.

Beginning in 2010, we will add some degree of "in-kind" acknowledgements to our list of donors published in our *CCA Network* newsletter and posted online (as always, unless anonymity is requested). Until then, I'd like to recognize some of the in-kind giving that has helped our organization grow:

**Cathy Evans**, a former board member from our Dallas headquarters area, garnered the donation of our furniture, and **Dana Heter** of **Direct Strategies** in Richardson, Texas, contributed another desk as we grew. Neighboring suites in our building have given us file cabinets, office supplies, and they also regularly relinquish their empty computer ink cartridges for CCA to rebate for cash instead of turning them in for themselves.

**Robin** and **Bruce Williamson** of **Williamson Creative Services** provide graphics and marketing expertise; **Lisa Vernon** of **Vernon Creative** has donated all graphics work for our fund appeal

packages and collaborates on other projects such as Craniofacial Acceptance Month; **Fred** and **Rose Seitz** of **Directed Technologies, Inc.** in Youngstown, Ohio, have been hosting our website for more than a dozen years; **Kurt Allen, JD, CPA, CFP, WMA** in Canton, Ohio, helps with legal concerns, documentation and accounting advice; **Bill** and **Christine Mecklenburg** of Coto de Caza, California, donate our custom-printed T-shirts for CCA's annual family retreats; and **Linda Vala** and other **Cher fans**, who plan and participate at the bi-annual **Cher Conventions** to benefit CCA, donate entertainment at the event, collectibles for auction and merchandise for sale.

We currently have a motorcycle raffle for a bike donated by **Johnny Pag Motorcycles**, a long-time supporter of CCA (see this issue's "Donor in the Spotlight" on page 7); **C.R. Conant** and colleagues at **Liquid Logixx** and **Mark Menza** in Dallas produced a remarkable PSA for CCA at no charge; **M3 Films** taped our 20th Anniversary

festivities at our annual family retreat and are gifting footage to assist with cause awareness and marketing of Children's Craniofacial Association. And the list goes on.

We constantly reach out to our CCA "family" for that first egg and you haven't let us down for 20 years. Whether you're donating the egg or buying it, you're helping CCA kids! Thanks to all of you who are helping, giving—whether "in-kind" or in cash.

Just as we are feeling the pinch and shortfall from the current economic climate, we understand it is affecting everyone and we are extremely grateful for each and every donation. No gift is too small or insignificant, all are helping make a difference for CCA kids!

Best wishes for all the blessings of the season and a prosperous 2010!

Jill Gorecki Patterson  
CCA Development Director

P.S. In the spirit of in-kind giving, we've included a CCA "Wish List" on page 13.

**JackTheDonkey.com**



**THE COMMUNITY WHERE YOUR TIME ONLINE  
SUPPORTS THE CHARITY OF YOUR CHOICE**

*Jack is free & easy. Jack makes cents for your favorite charities.*

Recently launched, is a social network called [www.JackTheDonkey.com](http://www.JackTheDonkey.com)  
Please register and name Children's Craniofacial Association to benefit! Thanks!



# the jorge posada foundation's eighth annual heroes4hope gala

CCA is proud to have been invited back as a member of the Circle of Beneficiaries for the Heroes4Hope Gala on Thursday, September 10th in New York City. The gala was hosted by **Jorge** and **Laura Posada** and their children **Jorge Jr.** and



Kristine Dale and CCA board chairman, George Dale (right) enjoy the cocktail reception with fellow CCA board member, Bill Mecklenburg

**Paulina**. The couple gave a heartfelt accounting of what they had gone through with Jorge Luis and how they decided to create this wonderful organization to help other families coping with similar craniofacial challenges.

This year the gala honored the 20 Greatest Yankees catchers and was



Christine Condino-Mecklenburg and Bill Mecklenburg

emceed by **Harold Reynolds**, Major League Baseball's on-air personality. Harold also moderated a Q&A session with the famous catchers, including notables like **Jorge Posada, Yogi Berra, Rick Cerone, Don Slaught, Ralph Houk, and Jose Molina**.

An online auction began 2 weeks before the Gala and ended a week afterward with a few items auctioned live during the evening including autographed catcher's mitts on each table. A motorcycle donated through CCA by **Johnny Pag Motorcycles** and signed by Jorge and the famous guests was auctioned to a winning bidder for \$29,000. (See "Donor In The Spotlight," page 7.) Two tickets donated by **Cher** to see her Vegas show in Caesar's Palace and meet her backstage for a photo op were also auctioned. A highlight of the night was singer **Jon Secada** who, at one point, was accompanied on guitar by NY outfielder, **Bernie Williams**. That, along with more fine entertainment, a complimentary cocktail reception, a 3-course meal served with wine and gift



CCA's Development Director, Jill Gorecki and Executive Director, Char Smith meet singer, Jon Secada

bags upon departure made it a memorable evening.

Through our beneficiary circle participation, Children's Craniofacial Association will be granted funds for our programs and services, because of the generous participation of folks like **Bill Mecklenburg** and **Christine-Condino Mecklenburg, George and Kristine Dale, Bob and Molly Lytle** and **The Redwoods Group Foundation, Platinum Reinsurance, Chartis, Ironshore Insurance, Allied World Assurance Company, Partner Reinsurance, Guy Carpenter & Company,**

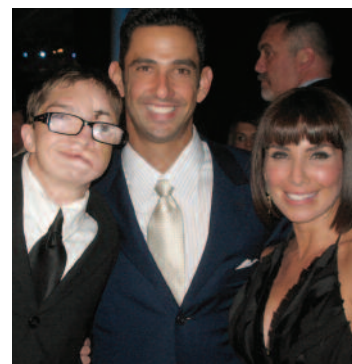


Brennan Lytle (second from left) and his dad, Bob, visit with Jorge and Laura Posada (Bob wore a photo badge of his CCA kid, Avery, on his lapel)



CCA Kid Jeremy Dale meets Yankee shortstop Derek Jeter

**Kent Penwell, Amy Rowland-Smith, Michael Amatrudo, Gary Tiepelman, Eliza Kraft Olander and Brian McHenry**. We are extremely grateful to all of these friends and those at the Jorge Posada Foundation for this wonderful opportunity to help more CCA kids and their families.



Rob Gorecki gets another photo op with the Posadas

# thanks for your help, cca!

By Jennifer Ford

I remember it like it was yesterday. I was 30 weeks' pregnant with **Sydney**, my second child. I just had a 3-D ultrasound, which indicated she would be born with a cleft lip and palate. I had never known anyone with any facial difference and I went through about every emotion possible.

I searched the Internet to learn as much as I could to help my baby and met many other parents going through the same thing. We researched and found several surgeons across the country; we met with the local cleft surgeon in our state twice.

I think choosing the surgeon that would change my precious daughter's face forever was probably the hardest decision my husband and I have ever made. We knew it would probably be easier to stay close to home, but after much prayer and thought,

we felt the best outcome for our daughter would be to go out of state to a doctor in Boston.

We had no clue how to make this financially possible, since our income is very limited. After talking to other parents, I found others who also chose to go out of state for their child's medical care. They told me about CCA and how they could help us. I emailed Annie Reeves, CCA Program Director, and the rest is history!

Our daughter's first surgery was at seven weeks old. Things were so hectic those first few weeks with learning how to feed her, dealing with reflux, hearing issues and trying to plan for an out-of-state surgery. But in a very short time, CCA was there supporting and helping us.

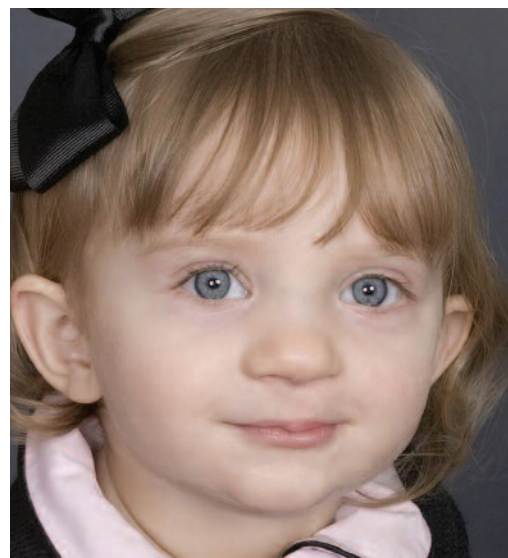
We have had to go to Boston five times in the past two years, and every time Annie and CCA have

been there to meet our traveling needs. We traveled for a two-stage lip/nose repair, palate repair and then to two annual cleft clinics. I know there are more surgeries in my daughter's future, and it's nice to know CCA is there wanting to help families like ours get to qualified medical care. With CCA's help we didn't have to worry so much about the traveling part and we could focus more on taking care of our daughter before and after surgeries.

I continue to be in awe that such an organization even exists! The help CCA has given our family to get our daughter to the doctor of our choice is the most amazing gift we have ever received. I honestly don't know if it would have been possible without CCA, and I thank God for them every night. Sydney is now two years old and is the



Sydney Rose BEFORE surgery, 5 weeks old



Sydney Rose AFTER surgery, 18 months old

happiest, healthiest little girl I know.

It's difficult to put into words how much CCA's help has meant to us, but I look forward to one day meeting these very special CCA angels that are now part of our family and thanking them from the bottom of my heart!

## 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.



# Craniofacial Acceptance Month

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

Many of our CCA families were able to get their local newspapers to feature them



in the paper. Radio stations also ran PSAs throughout the month of September. And this year, the governors of Alabama, Arkansas, Connecticut, Indiana, Kentucky, Louisiana, Maine, Michigan, Minnesota, Nebraska, New Mexico, North Carolina, Oklahoma, Tennessee, Texas, Vermont, Virginia, Washington and Wisconsin each declared

September Craniofacial Acceptance Month in their state! In addition, Congressman Mike Ross of Arkansas and Congressman Eric Cantor of Virginia both submitted congressional records for it on the House floor. They also acknowledged CCA's 20th Anniversary.

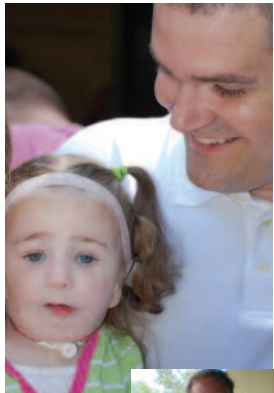
For the second year, CCA held National Picnic Day in September as part of



Craniofacial Acceptance Month. CCA families held picnics in California, Florida, Missouri, Nebraska, New Mexico, Ohio, Texas and Utah!

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

## Photos from picnics across the country







# 2nd annual ryan's road for cca fundraising news

**O**n September 19, 2009 we held our **2nd Annual Ryan's Road for CCA** walk at the **Horseheads Holding Point**. It was a great success. We were blessed with great fall weather and a wonderful turnout from our local community. This year we held a few mini events to add to our fundraising total. Altogether, we **raised over \$7,000!**

We kicked off our events at **Sam's Club**. Our mission was to spread awareness of CCA and Ryan's walk by passing out brochures. We sold raffle tickets for a gas grill that was donated anonymously. We took donations and also sold candy bars.

The last Sunday in August we held a pancake breakfast at **TGI Friday's**. Our family and friends got together and pre-sold tickets for the breakfast

and then worked the event. Even though it was smaller than we hoped, we **raised over \$500 in 2 hours!** It was so much fun. Ryan got to help seat guests and bus tables. He thought that was great. He even got to serve his grandpa pancakes!

The grand finale was, of course, the walk! We had about 100 community members come out for the walk this year. We kicked off the walk with a fun run for the kids. **Ian Aepelbacher** won for the 6-9 yrs. run and **Lauren Gulich** won for the 3-5 yrs. run. After the run, the kids joined their families for a great fall walk. Then we enjoyed a picnic-style lunch donated by **Corning Catering, The Dairy Barn, Frito Lay, Herr's, and Strohman's**. A huge thank you to **Danielle Peters, Debbie French, and Julie Kucko** for

arranging the lunch donations! After lunch we all pulled out our raffle tickets. Over 50 items were raffled off to our lucky winners. The grand prize winner of the gas grill valued at \$600 was **Charlene Tompkins**. In addition, this year we added a silent auction!

A special thanks to **Tanya Mattison** for ALL your hard work helping Ryan Sr. and I put on this event. For the second year Tanya has put in countless hours towards helping us organize and plan the walk. Thank You Tanya!

Thank you to our committee members and Team Leaders; **Tanya Mattison, Dorie Hughson, Jessica Drake, Debbie French, Lauren Schnautz, Vickie Whitaker, Beth Smith, Jeanie and Craig Smith, Tyler Mattison, and Danielle Peters**.

Our top team was **Jessica Drake and Judy Hillman**. These ladies sold raffle tickets for the gas grill, pancake breakfast tickets, and held two bake sales at their county office! Their team was the highest

in team totals **raising over \$750** for CCA! Thank You!

Our top sponsors were **Gas Field Specialists, Schweizer Aircraft, Emery Industrial Supply, Five Star Bank, X-Gen Pharmaceuticals, The Dairy Barn, Dandy Mini Mart, the Gulich Family, the Dale Family, the Steckowski Family, and the Peters Family**.

A special thanks to the **Dairy Barn, Julie and Jim Kucko** and **staff** for selling \$53 worth of CCA hangers to your patrons during the first two weeks of September! Thanks also to **Gerould's Pharmacy** for taking donations!

This year was such a community effort. Interesting to note, with the decrease in donations from our corporate sponsors, individuals dug deep and gave more—even during this tough economy.

We are truly blessed with such a loving and accepting community! Thank you to all who participated! We look forward to seeing you at the 3rd Annual Ryan's Road for CCA!

The Gulich Family





# jylian's links of love golf tournament



**O**n Monday, September 28nd the 2nd Annual Jylian's Links of Love golf tournament was held, raising over \$10,000 for CCA!

CCA kid, **Jylian Bilbow** is the daughter of **John** and **Kendall Bilbow** from Arlington, TX and she was the perfect representative for the event, visiting and posing with golfers.

**Whitestone Golf Club** in Benbrook graciously hosted the event once again with the help of **Susan Grawe**. Golfers were treated to lunch upon arrival, a

complimentary beverage cart throughout the day (provided by local distributors, **Coca-Cola**, and **Coors**), and a barbeque dinner (from **Spring Creek Barbeque**) following golf.

We are extremely grateful for the sponsorship, both in-kind and monetary, of numerous friends of CCA including, **Southwest Airlines**, **Avid Golfer magazine**, area **Marriott** hotels, golf stores, area merchants, **Chamberlain's**, **Mike**

**Janicek** at **Chick-Fil-A** on Bryant Irvin in Ft. Worth, **What-A-Burger**, **Winchester Carlisle Real Estate Partners**, **Direct Strategies**, **Team**

**Margaret**, and many other supporters throughout the DFW Metroplex and beyond.

Thanks to volunteers who came out to help: **Lee Gwatney**, who lent his golf skills for the 'Beat the Pro' competition, **Rene Kamper** and **Clint & Jodie Hall** all of the Ft. Worth Police Dept., **Andrea Daily** and **Dick Smith** from the Ft. Worth Cats, **Jane Monell**, **Rob Gorecki**,



**Jylian, Mikey, Ivy, Kendall** and **John Bilbow**.

And, of course, we could not hold a successful event without our wonderful golfers and all the companies who supported us by sending teams. Thank you so much for participating! We had a great time and hope to see everyone again next year!



# 3 cheers for volunteers!



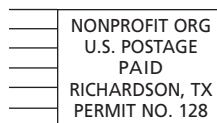
**K**elly Liszt has been editing the CCA Network newsletter for the past seven years. She also interviews and writes the CCA Kid feature within each issue. "I love interviewing the kids," she says. "They're so amazing, and I learn something valuable from each and every one of them."

Although she lives in Miami, Kelly grew up in Texas. In fact, she's a sixth-generation Texan. "I love Florida, but I sure do miss the Texas hospitality—and the great BBQ of course."

Kelly just had a baby girl in May, and right now she is juggling new motherhood with freelance work and her CCA responsibilities. She wonders if there could be more than 24 hours in a day just to catch up on everything, especially sleep. "This is such a magical time for me. I'm enjoying every minute of being a mom; however, I could do without singing B-I-N-G-O in my dreams."

Thanks, Kelly, for all that you do. Three cheers from all of us at CCA!

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



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Cher

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