

# ccanetwork

quarterly newsletter of the children's craniofacial association

Cher — honorary chairperson

winter 2011

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## aiden's story

By Taryn Skees

**W**hen our first child, **Ethan**, was just three months old, my husband and I were surprised to find out that we were expecting again. In fact, at our first appointment the doctor confirmed the baby's due date to be exactly one year and a day different from what had been Ethan's due date. We were nervous about having two children so close in age, but also very excited, as we knew that they would be best friends.

As with my first pregnancy, I experienced pre-term labor contractions and was put on bed rest during my last trimester right around 30 weeks. I was in and out of the hospital for monitoring and just knew that this baby, whom we had since found out was going to be another boy, was going to come early as well.



## message from the executive director

**a**s we begin 2011, I look back and can't believe another year has passed so quickly. Is it because I am now 22 years older than I was when I first came to CCA? Perhaps. But sometimes I think we are so involved with the day-to-day business of getting newsletters out, booklets published, retreats planned, etc.—and, of course, all the time seeking support to raise enough money to pay for it all—that we forget to stop and take note of the many ways these efforts are paying off.



 **Children's Medical Charities of America**

see **aiden**, page 10

see **executive director**, page 8



## meet meaghan palmer

**T**en-year-old **Meaghan Palmer** lives in a small town in north-central Massachusetts. She's in the fourth grade and really loves her science classes. Meaghan is fascinated with electricity in particular. In fact, her brother gave her a potato science kit last Christmas, and she has had a lot of fun making things run by spud power.

Meaghan is also a member of her school's band. She's focusing on percussion this year, specifically drums and bells. She received individual instruction on these instruments last fall, and during the spring she practices with her band mates. There's even a special performance at the

end of the academic year. Good luck, Meaghan!

As for other school subjects, Meaghan likes going to gym class. She plays a variety of games, including battleship, where you use giant pompons to knock down bowling pins. Outside of gym, she plays basketball, and she participates in drills and unofficial, just-for-fun games at her local parks and recreation center.

Meaghan has a lot of hobbies, too. She's into collecting nutcrackers and anything having to do with Rudolph. She has collected Webkinz cards but is now concentrating on American Girl animals. Meaghan also likes to model things with clay. She made a cat and

a monkey, which at the moment reside in her room.

Her favorite movie at the moment is *Rodrick Rules* (*Diary of a Wimpy Kid: #2*). She also watches all kinds of cooking shows, including *Chopped* and *Ace of Cakes*, and is a pretty good cook herself.

Meaghan's pet, Moxie, is a black, long-haired rescue cat that will only play with her. Moxie misses her so much when Meaghan is away. In fact, the poor cat "acts out" all around the house until she gets back.

Meaghan was born with Goldenhar syndrome and last June she attended her

first CCA retreat. She met a lot of people and looks forward to seeing them again and meeting new folks at future retreats. Schedule permitting, she'll be at this year's retreat in Louisville, Kentucky.

Meaghan has some good advice for other CCA kids. When going to the hospital, she said, "Be sure to bring lots of your favorite foods as well as a special stuffed animal." Plus, when they're trying to get an IV in your arm, "always ask for numbing cream." (Good idea.) And, of course, have your mom stay with you.

# ccakid

# ccateen

## meet casey evans

By Christen Evans

**W**hen you meet **Casey** for the first time, you'll look at her and say, "What a great kid! What an athlete!" But then you'll take a second look at her and think to yourself, "There's something different about that kid."

Casey was born on August 13, 1996, weighing 8 pounds and 13.5 ounces and measuring 22 inches long. What was supposed to be a joyous occasion turned into a dark, scary moment.

From her first breath, the conversations started. I was told I would get used to having a daughter with disabilities and limitations. She would never amount to anything, she would always be different. I was shocked, confused and scared. My baby had a birth defect that I had never heard of. Why did this happen? How did this happen and what was I supposed to do?

Casey was born with unilateral craniosynostosis. She has under gone two cranial surgeries (and may possibly have a third). The first was at Children's Hospital in Oakland, CA, at age 6 months. The second, when she was 2 years old, was at Children's Hospital in Boston, MA (where she is still a case study). Both

surgeries lasted an average of 10.5 hours.

After a battery of tests on her father and myself, it was determined that Casey's condition was not inherited—it just happened—caused by a mutant cell.

Because of her extensive surgeries, she has a severe eye impairment. However, we didn't know this until she was in kindergarten. She had a hard time focusing and was classified as ADHD. But I didn't accept that. There was something wrong with her, but it wasn't ADHD. Luckily my aunt attended a workshop on brain trauma and visual issues, and we found our missing piece of the puzzle.

Casey started working with a neuro-ophthalmologist, who determined she needed to wear special glasses to help her see. She has to wear bifocal glasses with prisms to redirect the information to her brain. When she doesn't wear her glasses, she sees double vision at a 90 degree angle. (Imagine you're on a mountain top, looking straight down, while seeing double.) The glasses fix this. No wonder she couldn't focus!

Her learning has been affected as well. She has

severe learning disabilities. She has short-term/long-term memory and cognitive issues; it's an everyday struggle for her. Needless to say it was a grueling first few years of her life. It seemed we were constantly in and out of doctors' offices, scheduling follow-up appointments, getting new glasses and constantly meeting with schools and teachers.

However, one thing never changed: Casey's can-do attitude. Even when children in school would make fun of her and call her names, she always stood her ground.

One day she decided she wanted to play basketball, and it was amazing. When she had the ball in her hand it was like magic. She could maneuver the ball up and down the court and even get it in the basket! It was her second game when her \$1,200 glasses were pushed off her face, stepped on and destroyed. Since then, we had a special pair of sport goggles made.

As Casey grew, so did her athletic ability. I couldn't understand how a child with such learning and visual issues could do what she was doing. She was now not only playing with



her seventh grade middle school basketball team, she was also playing with her AAU basketball team and playing with girls in high school. Casey's nickname on the court was "Goggles." She then told me she wanted to play lacrosse and later added soccer. I still sit and watch in disbelief.

Casey continually overcomes everyday obstacles with her peers making fun of her at school, for looking and being different. They are soon realizing that "Goggles" is an amazing athlete they can't stop.

Now at age 14, Casey is a beautiful girl with a winning, go-getter attitude with lots of friends. Her goal is to go to college, play basketball and be a gym teacher. Her advice to all of you out there dealing with similar situations is to "never give up — work hard and make your dreams come true."



# cca supersib

## meet kenneth palmer

By Tanya Palmer

favorite things to do on the computer are program in Scratch, play Spore, post on the Sporum where he is QuietSamuri, and video chat with his best friend Matt. He likes to build Mindstorms projects, make creations out of Keva planks, shoot videos with his video camera and play video games.

Kenneth reads just about anything he can get his hands on—from *Harry Potter* to novels by Pseudonymous Bosch, Susan Collins and Douglas Adams, as well as nonfiction books about science. He particularly likes books by Stephen Hawking and about black holes. Sometimes reading can be a bit much, so he indulges his interest in astrophysics by watching documentaries based on Hawking's life and writings.

Kenneth loves to travel. So far he has visited 16 states and six provinces in Canada. His favorite trips have been a cruise to Alaska and almost-annual trips to Prince Edward Island. Some day he hopes to travel to the Galapagos

Islands to follow in the footsteps of Darwin.

Kenneth was just 22 months old when his sister, Meaghan, was born. He was too young to realize just how unusual her needs were. She was, and is, just his annoying little sister. At home they are like any other close-in-age siblings, squabbling over who did what and who's bugging whom and whose turn it is to control the TV or computer or Wii.

However, out and about they've got each other's backs in a special way. He doesn't let anyone treat Meaghan badly, and she watches out for his allergies.

Kenneth went to his first CCA retreat in June 2010 in Boston. He enjoyed staying in a hotel next to MIT, where he hopes to go to school some day. He especially enjoyed being able to eat his fill of nut-free pastries at breakfast and getting to spend all day long in the pool at the pool party. He has to be at a family wedding during the 2011 retreat, but he hopes to meet even more CCA kids and siblings at the 2012 retreat.

**K**enneth lives with his sister **Meaghan**, his mom and dad, and his cats, Harry and Moxie, in a white colonial overlooking a lake in a quintessential New England town. He is 12 years old and in the sixth grade

Kenneth just finished working on this year's winter musical, *You're a Good Man Charlie Brown*. He loves technology and was very happy to be working above the scenes directing the spotlight as part of the tech crew. One could say he made the stars shine.

With the play behind him, he is looking forward to his turn to be on stage. He will be playing the trombone in the sixth grade band in the upcoming winter concert. He's especially excited about a five-night spring trip to Nature's Classroom with his whole grade. He's also thinking of getting involved with a robotics program called BotBall as well as the spring drama production.

Outside of school, Kenneth enjoys nurturing his love of technology. His

# 6th annual friends of jeremy golf tournament

By Kristine Dale



The 6th Annual Friends of Jeremy Golf Tournament was held on Saturday, October 2, at the **Corning Country Club** in Corning, NY. As always, we had an incredible turnout and overwhelming support from the community, our coworkers, friends and family. It was another record year for the tournament with

135 golfers and over 50 sponsors!

The tournament included a raffle, silent auction, closest-to-the-pin, 50/50, closest-to-the-line prize and a skins game. There was a special raffle for a 40" LCD TV and an iPad. The silent auction included exciting items such as an autographed Jorge Posada

baseball and autographed Derek Jeter photo!

Our very supportive local car dealership, **Simmons-Rockwell**, was not only one of our major sponsors but also provided a new car prize for a hole-in-one contest. Unfortunately no one won the car, but everyone had fun trying! The event was a huge success, which raised over **\$31,000** for CCA!

Jeremy was again joined this year by a few of his CCA friends and their families. **Andrew Perry** from Massachusetts and **Ryan Gulich** from Big Flats, NY were back again to golf in the tournament.

We had a new CCA friend join us this year from New Jersey, **Trevor Larys** and his family. It is so wonderful to have CCA friends join us for the tournament each year. The golfers really



enjoy meeting new kids and catching up with kids they've met in the past.

We are so grateful to everyone who supported this event and the kids from CCA. For more information and to see photos from the tournament visit [www.friendsofjeremy.com](http://www.friendsofjeremy.com).



"Miles for CCA Kids" Poker Run organizers, **Frank Leach** (L) and **Lewis Boykin** (R), draw raffle tickets at Bullwinkle's Bistro in Plano, Texas.

## poker run for cca kids

On Saturday, November 13th, the inaugural "Miles for CCA Kids" Charity Poker Run was held. The ride was organized by CCA friends and volunteers, **Frank Leach** and **Lewis Boykin**. It took bikers across the Texas state line to Oklahoma and back to sponsor, **Bullwinkle's Bistro**, Plano, TX, where they finished with refreshments, supper and raffle prize drawings. Other sponsors included **Twin Peaks Restaurant**, **DWMC**, and **2nd Sunday Biker Church** all of Plano, TX; **Loose Wheels Roadhouse**, Denison, TX; **Choctaw Casino**, Durant, OK; **Texoma Harley-Davidson**, Sherman, TX; and **The Cowboy Club**, Van Alstyne, TX. CCA is most grateful to these sponsors and especially to Frank and Lewis and everyone who participated. See you all at the next run!

# calendar of events

date	event	contact
Mar 6, 2011	<b>4th Annual Henry's March for CCA</b> 5k Fun Run CSU, Stanislaus Turlock, CA	<a href="mailto:laurynhenry@sbcglobal.net">laurynhenry@sbcglobal.net</a> myspace.com/henrysmarch 209.664.0500
Spring 2011	<b>3rd Annual Ryan's Road</b> Big Flats, NY	<a href="mailto:ngulich@yahoo.com">ngulich@yahoo.com</a>
May 2011	<b>Fore Ava's Friends Golf Tournament</b> Portland, CT	<a href="mailto:malcolm.beeler@aecom.com">malcolm.beeler@aecom.com</a>
June 23-26	<b>21st Annual Cher's Family Retreat</b> Galt House (galthouse.com) Louisville, KY	<a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a> 214.570.9099 800.535.3643
Aug 27	<b>Jaci's Country Dance Bash</b> Morrisville, PA	<a href="mailto:Countrygirl28567@gmail.com">Countrygirl28567@gmail.com</a>
Sep 2011	<b>7th Annual Craniofacial Acceptance Month</b>	<a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a> 214.570.9099 800.535.3643
Sep 2011	<b>Lily's 2nd Annual Craniofacial Awareness Benefit Dinner</b> Lindon, UT	<a href="mailto:NurseTosha@gmail.com">NurseTosha@gmail.com</a>
Sep 10	<b>4th Annual Craniofacial Acceptance National Picnic Day</b> Sandy Lake Amusement Park Carrollton, TX	<a href="mailto:ARees@ccakids.com">ARees@ccakids.com</a> 214.570.9099 800.535.3643
Sep 24	<b>7th Annual Friends of Jeremy Golf Tournament</b> Corning Golf Club Corning, NY	<a href="mailto:gdale@stny.rr.com">gdale@stny.rr.com</a> <a href="http://www.friendsofjeremy.com">www.friendsofjeremy.com</a>
Sep 30	<b>Links of Love for CCA Golf Tournament</b> Woodbridge Golf Club Wylie, TX	<a href="mailto:JPatterson@ccakids.com">JPatterson@ccakids.com</a>
Nov 7	<b>6th Annual Wendelyn's Course of Dreams Golf Tournament</b> Pleasant Valley Country Club Little Rock, AR	<a href="mailto:wendelynosborne@gmail.com">wendelynosborne@gmail.com</a>

## kappa theta

**J**udy Kemler, grandmother to CCA kid, **Luke Bowen**, is an active "volunteer-at-large" for CCA.

She made a presentation at her local chapter of **Delta Kappa Gamma**, during their **Kappa Theta** meeting in November. The receptive group listened to testimony from Luke's mom, **Heather**, about their experiences with CCA. **Jill Patterson** explained further what the organization does and also shared the creative video of another CCA mom. The evening became a wonderful outpouring of caring and love from the women. They sent along gift boxes for Luke to distribute among other families with kids having surgeries as well as a contribution to CCA of **\$173** in cash from the generous group. Thanks so much to Judy for her tireless efforts, to Luke's family and to Kappa Theta!

# free 2012 hotel stay!

## Fundraising reward extended indefinitely!

**F**or our 2009 20th anniversary year we had a special reward proposal to CCA families who helped with fundraising – any family raising \$5,000 or more for Children's Craniofacial Association through December 31st of that year would be awarded one free hotel room for their stay at the following year's retreat (i.e. 2010 fundraising counted toward the 2011 retreat). This reward has been extended indefinitely!

This invitation is extended to all CCA families, including those already holding annual events throughout the year and it includes any type of effort. So all fundraising efforts for 2011 will go toward the 2012 retreat.

All families who wish to participate are asked to

sign a confirmation form in order that we may track your success and budget for your room. Please contact the CCA office at 214.570.9099, toll-free at 800.353.3643 or email Jill at [JPatterson@ccakids.com](mailto:JPatterson@ccakids.com) for more information.

## Try creating your own firstgiving page

A free CCA-customized "firstgiving" site is available for anyone who wants to help raise funds for CCA. Log onto [firstgiving.com/ccakids](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.



**C**CA Grad, **Nick Wiese**, spoke about Children's Craniofacial Association at a holiday gathering of business folks, **T.A. Robinson Asphalt Paving, Inc.** and **Nick Pasquini Construction**, who also designated our cause as the beneficiary of their raffle proceeds. Nick's efforts provided CCA a gift of almost **\$6,000**. Thanks Nick!

**FREE SHIPPING WITH AN ORDER OF \$100 OR MORE!**

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\$15 each plus shipping

Millefiori glass heart  
No two alike!  
Leather w/CCA logo tag



Stainless steel w/ braided leather; round, heart or dog tag style;  
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Apricot "Orange"



Chrysolite "Lime"



Gold Beryl "Teal"



Light Sapphire  
"Royal"



Multi "Limited Edition" for  
September  
(still available)



**great for easter baskets  
or pesach hampers!**

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

The great response to our CCA bracelets has prompted us  
to sell them throughout the year!

**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  
[JPatterson@ccakids.com](mailto:JPatterson@ccakids.com) • 800.535.3643

**financial assistance**

**d**o 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.

# basebowl charitybuzz auction winner

At the Jorge Posada Foundation's Charitybuzz auction for their Basebowl event, a pair of tickets and a backstage meet/greet opportunity with our national spokesperson and honorary chair, Cher, went to **John Wren**, of Anderson, Texas. A huge Cher fan, John, is also a Grimes County Deputy Sheriff who baked his way to the winning bid. He split the cost with fellow Cher fan, **Roni Heinze**, for a wonderful contribution to the event in the amount of **\$10,500!**

"I've been going to see Cher since 2002. I've seen her more than forty times, in about a dozen different states... Saturday night (1/15/2011), I finally had the opportunity to realize my dream of meeting Cher. It was an incredible

experience to talk with her... I never saw any sign of entitlement or diva-like behavior. She came across as a genuinely gracious and kind person. The highlight of the experience was standing face-to-face with Cher and having the opportunity to thank her for what she's meant to my life. For my friends and family who bought cakes and pies to help me raise money for the Jorge Posada Foundation and CCA and for those of you who sent words of encouragement, I thank you again for helping make this opportunity possible. I couldn't have done it without you."



## executive director, from page 1

It seems when we are most involved in meeting deadlines, or are worried the most about whether or not we'll be able to raise those funds to continue to move forward with our program goals and objectives to effectively serve our families, we will get a phone call, a letter or an email that reminds us our efforts are changing lives.

I remember 15 years ago when CCA was in its most difficult period. It was just me and the board trying to hold it all together. There were days when I would think, "This is too big, and I really need to let it go and move on." Then that phone call or letter would come from a mom or dad who said, "I don't know what we would have done if CCA hadn't been there for us."

The thought of that family being out there alone without anyone to

help guide and support them would always put things back into perspective for me. It wasn't about me, or the board, or how difficult our journey was. It was about the people taking the "real" journey — the people for whom we worked so hard to begin with.

We recently received such a phone call from a family in California. Jill, CCA's Development Director, recognizing the name on the caller ID of a long-time, regular donor, answered the call. The woman was calling to make sure her gifts were being matched and went on to tell how CCA had impacted her family's lives 18 years ago.

The caller related how her son needed surgery back then, and money was very tight for them at the time. She said she called CCA one week before the

appointment. Mrs. Smith told her it was too close to the appointment time for us to approve financial assistance, but if she would keep her receipts, and send them in afterward, CCA would try to reimburse their expenses. Much to her surprise, we did. She said it meant so much to them that they will never forget it. Once they were able, they began giving back and have remained steadfast donors since. CCA's help made such a positive impact on their lives, enough that she was moved to make that phone call 18 years later to thank us again.

Things have changed a lot. It's no longer just me and the board. We have a great staff providing many more services to our families. Now even the families we serve have joined forces and are serving others, educating the communities in which

they live and even taking a huge role in helping raise the funds needed to support the programs and services.

So as we begin 2011, let's all take a moment to realize our efforts, however difficult they sometimes seem, are changing lives and making life-changing impacts on families. And, to remember that sometimes when things seem too big, we are not willing to simply "let it go and move on."

We won't leave families like this caller's to take the journey alone. Our CCA family will be there, welcoming them in, providing for their needs and surrounding them with love and support on their journey through life with their precious kids.

Charlene Smith  
CCA Executive Director



## dallas holiday party



CCA, together with **Dr. Jeffrey Fearon**, hosted its 21st annual holiday party at **Southfork Ranch**, in Parker, TX, on Saturday, December 10th. Around 500 attendees joined us for a morning full of fun!

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

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

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

CCA would like to thank **Southfork Ranch** for hosting, as well as their wonderful staff! A huge thank you goes out to **KLS Martin** and our wonderful volunteers from the **Italian Club of Dallas**, CCA Parent, **Heather Bowen** and her friend, **Sara**.



## midwest holiday party

Cookies, candy and crafts in Kenosha were Santa's plans for the day on December 4th in Wisconsin for the CCA Midwest area Christmas party. It was a smaller turnout this year, but no one seemed to mind amidst fun and games to go with the pizza lunch and raffle prizes. After photos and gift requests on Santa's knee, we sang Christmas carols along with the holiday harmonica of **Paul Zasadny**.

Special thanks to mom, **Marla Verdone** for all her help. See you next year!

## h&r block

If you're a new customer to H&R Block having your 2010 tax return done, H&R Block will donate \$25 to Children's Craniofacial Association when you designate CCA as your charity using a special form. You can also make copies of the form and give them to your friends and family! Also available in Spanish!

For a form, contact CCA at 800.535.3643 or email [JPatterson@ccakids.com](mailto:JPatterson@ccakids.com)

**aiden**, from page 1

At 32 weeks I spent a few nights in the antepartum unit at our local hospital because my labor contractions were becoming productive (meaning I had started to dilate). They gave me a shot to develop the baby's lungs should he arrive early and also magnesium sulfate to try to keep the labor from progressing. After 3 days I was sent home, still on bed rest. This was very difficult given the fact that I had a husband who worked full-time and a 10 month old that was not yet walking!

Just a week later I began having more contractions, although they weren't as strong as some I had before. There was a winter weather advisory, and we lived in an area that made it tricky to travel the 35 minutes to the hospital in snow, so to be on the safe side we grabbed our already packed bag and braved the cold. We dropped our son off with family and were on our way.

My husband and I had previously decided on the

name Aiden. Five and a half weeks early, Aiden was ready to make his debut! My water had broken (unbeknownst to me) and it was time. A few hours after getting to the hospital the weather took a turn for the worse. From my hospital bed I could see cars sliding all over the freeway. The airport had closed. Doctors and nurses were unable to leave. We had made it just in time!

Because of the weather, this experience was going to be very different from when we had Ethan. None of our family members were able to be out in the waiting room in anticipation of Aiden's arrival. My parents were actually in Florida for the month of February – they thought it was a good time to go since my sister had a baby in January and I wasn't due until the end of March!

On February 11, 2008, Aiden Joseph Skees came into our lives and changed them forever. Despite being "sunny-side-up", my actual delivery was smooth and pain free. With my husband

Ricky at my side, the doctors laid Aiden on my chest just as they had done with my first son. Looking back, I remember the room being very quiet, but I had

no idea it was because something was wrong.

It wasn't until Ricky asked "Are his hands okay?" that anything even seemed out of the ordinary. Because Aiden was pre-term, a neonatologist was present and gave us the news, Aiden had Apert syndrome. None of the other doctors or nurses in the room had ever delivered a baby with this condition before which is why the room fell silent. They literally didn't know what to say.

A million things raced through our minds as we tried to comprehend the events unfolding around us. Aiden was rushed out of the room to the NICU because he was having trouble breathing. The doctors and nurses exited as well, leaving Ricky and me in an eerily quiet and cold hospital room. My head was spinning.

We waited nearly 30 minutes before anyone came in to give us more information about Aiden. A nurse handed us a paragraph she had printed off the Internet about Apert Syndrome and told us he was stable and we could go to the NICU to see him and discuss his diagnosis in more detail soon.

Our hands shook as we made the very difficult phone calls to family to tell them the news. I remember telling my parents that he

had no hands — because that's what I gathered from seeing his type III syndactyly in the few brief moments I held him.

My parents wanted so badly to be there to comfort us that they said they were booking the next flight into town. Unfortunately, they were unable to since the airports were all closed. Later, we realized it might have been a blessing in disguise that the horrible weather kept everyone away that day. We had a hard enough time processing the news on our own without having to then go out to a waiting room of excited people and watch their faces turn to heartbreak before our eyes.

We spent the next two weeks staying at the Ronald McDonald Family Room at the hospital where Aiden was in the NICU. It was so very difficult to have our 11-month old at home with family while we weren't there but we knew we couldn't leave Aiden. When he was finally ready to go home, we left with an apnea monitor and a laundry list of scheduled doctors' appointments. It was overwhelming.

Ricky and I got right to work researching everything to get a better understanding of what Apert Syndrome was, what treatment he would need and where the best place was for him to receive





we spent four more days at our local children's hospital.

When we prepared for his second

surgery three months later, we hoped it would be without the complications of the first and luckily it was. Everything went smoothly and we were surprised (and, quite frankly, bummed) at how comfortable our time in hospitals had become.

Another three months went by and we flew back to Dallas for Aiden's cranial vault in May, when Aiden was 15 months old. After making another difficult decision on whether to proceed with the surgery because of a nasty respiratory virus that was plaguing Aiden, we found out post-op that we had made the right choice. The neurosurgeon confirmed that things were "getting pretty tight" in his head. The timing was perfect — had we waited any longer there could have been damage to his brain from intracranial pressure.

When things settled down and months went by surgery-free, we began to fully understand the gift we had been given with a child like Aiden. He has opened our eyes and hearts to a new kind of compassion.

He fills every day with extreme joy. He has helped us to appreciate the work that medical professionals put in to making the lives of others better.

At just 3 years old, Aiden has enriched my life in ways I never would have imagined possible when I was scared and worried at the beginning of this journey. And countless others have told me that Aiden has touched their lives similarly.

With the support of friends and family, I decided I wanted to do something to "give back" to an organization that provides such important resources and information to parents looking for someplace to turn. I was able to meet the staff at CCA during one of Aiden's surgeries in Dallas, and I knew that I wanted to raise money to help their efforts.

Last September I organized a silent auction and dinner event in Louisville, which raised

more than \$30,000 for CCA! I hope to continue to spread awareness about craniofacial conditions in the future as I believe it is vital to our children's future success.

Aiden is thriving despite having Apert Syndrome. Nothing seems to hold him back, and he continually amazes us with his resilience and his ability to adapt to complete everyday tasks with his very special hands.

Like most kids with craniofacial conditions, he will need several more surgeries in the coming years. Each one will be difficult, I'm sure, but Aiden's strong will and lovable personality will get us all through. Amidst all of the worrying and uncertainty that the first two years of Aiden's life brought our family, one thing turned out as we had expected — Ethan and Aiden are truly best buds and hopefully always will be!



# “testimonial

**m**y son **Reece** was born June 5, 2003, in New Orleans, LA, with a cloverleaf skull, Pfeiffer syndrome and a chiari malformation. Reece had numerous surgeries in New Orleans until Hurricane Katrina. After the hurricane, his surgeon left the area. It was my decision to move Reece’s medical care to Dallas, TX. Since then, he has endured six more surgeries and numerous doctor visits.

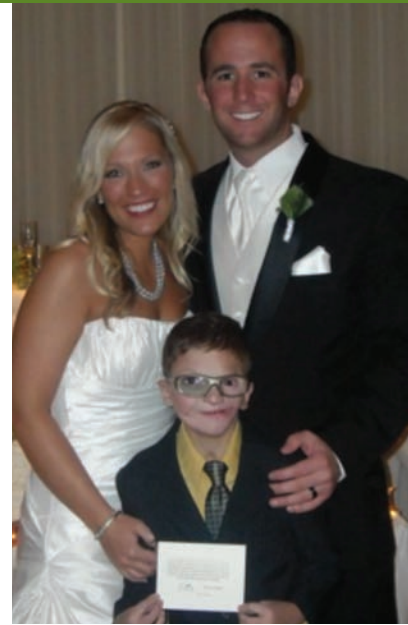
Without the help of CCA’s Financial Assistance program, Reece’s medical care could have been in jeopardy—we couldn’t afford the travel expenses and hotel accommodations to continue his ongoing medical care. I feel like CCA is our “guardian angel.” Thank you so much for your continued help and support.

—Michele and Reece Williams



## caring cousins

**n**ewlyweds, **Brianne (Strongy)** and **Michael Morgan** of Jessup, PA, surprised cousin, **Kristine Dale** by making a donation to Children’s Craniofacial Association to honor her son, CCA kid, **Jeremy Dale**, in lieu of wedding favors at their reception. Kristine didn’t know until she saw the special tent cards announcing the gift which were placed on each table. What a thoughtful and caring thing to do for Jeremy and all CCA kids! Best Wishes and a big thank you!



## donors in the spotlight

**C**CA Kid, **Avery Lytle**, is the inspiration for the generous giving by this issue’s “Donors in the Spotlight,” her grandparents, **Mary Lytle** and **Mike & Marty Willson**.

Mary has been a long time donor both personally and through her business, **Jefferson Lumber**.

The Willsons give monthly through automatic credit card donations as well as when our direct mail appeal letters arrive. All are ardent supporters of our annual family retreat. Avery is a lucky girl to have such wonderful grandparents and family support. Children’s Craniofacial Association is the proud beneficiary! Thank you, thank you thank you to our Winter, 2011 Donors in the Spotlight!



**j**onathan Siebert got in the spirit of Craniofacial Acceptance Month and collected funds for CCA during the family garage sale last September. Thanks Jon!

**The 2010 year-end donor list will be published in our Spring 2011 issue.**

## rick's raffle



Since Thomas the Train was one of Rick's favorites, the Burgins will be donating a "Thomas" train table every spring around Rick's birthday. Children's Craniofacial Association will raffle off the train table in Rick's memory. Funds from the raffle will be used for patient financial assistance. "It would have been very helpful to our



CCA supporters, **Ann** and **Doug Burgin**, are establishing an annual raffle in memory of their beloved grandson, **Rick Dornier**. Rick died from meningitis on Christmas Eve, 2009 at the age of 3 ½ years. Their hope is to honor Rick's memory while helping other CCA kids.

family if there had been some assistance available to help with the cost of the conformers that Rick needed for his eye. We hope to raise enough money with this annual raffle to give some relief to other families with similar expenses" said Ann Burgin.

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

The drawing will be held each year on (or around) Rick's birthday, April 25th. CALL NOW to purchase your tickets!

Contact Jill at [JPatterson@ccakids.com](mailto:JPatterson@ccakids.com) or 800.535.3643 or 214.570.9099

## cca mugshots



CCA Spokesperson, **CHER**, shows off her CCA mug after one of her shows at Caesar's Palace.

## rock n' bowl for cca with kayla smith



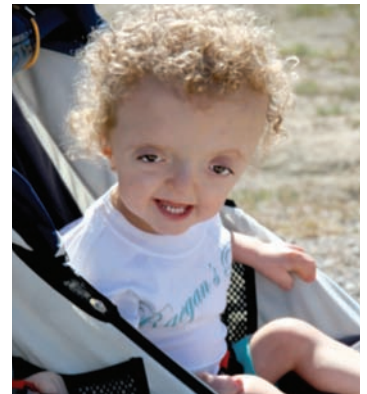
In preparation for her graduation this spring from Warren Area High School in Pennsylvania, **Kayla Smith** put together a fund-raiser titled "Rock N' Bowl for CCA with Kayla Smith" to benefit Children's Craniofacial Association. The bowling event was held on September 25, 2010 in observance of National Craniofacial Acceptance Month. Kayla herself, has Apert syndrome and has had to overcome a number of obstacles, one of them, to be accepted. Her hope is that everyone will accept individuals with facial differences. In addition to the bowling fun, there were raffles and auctions for great prizes donated by area merchants, corporations and friends.

Kayla's mom, **Michelle**, was a big help as well as were her co-workers at **Northwest Savings Bank**. Everyone had a great time, especially Kayla, who raised almost **\$2,000** for CCA. Thanks!

## mrs. santa?

Special thanks to CCA mom, **Janice**

**Strange**, who surprises us each year at our holiday party with gifts from her "Strange Tinkering" line of handmade jewelry pieces. She always brings enough for us to give to other CCA moms whose kids are in the hospital, to cheer them as they wait. This year she was kind enough to treat all of our CCA volunteers at the party too. Thanks so much Janice!



## jeans day and bake sale

The **BASICS Community Service Club** in the Cambridge, Ohio area held a "Jeans Day and Bake Sale" to benefit Children's Craniofacial Association last November, in honor of CCA kid, **Reagan Daugherty**. Thanks for helping us spread awareness for CCA while raising a couple hundred in cash for CCA kids!

# 3rd annual chocolate festival for cca kids

The Chocolate Festival event was conceived 4 years ago during another CCA fund-raiser, Ohio's "Seth's Stride," when **Seth Swihart's uncle, Chef Rick Chiavari** held a simultaneous stride in Florida. He vowed to involve his culinary pals in an effort to help CCA Kids in Seth's honor. Sure enough, the following year, the **Aventura Mall's Laura Nichols** teamed with Chef

Rick, his associates and friends to create the most delightful & delicious funder yet!

Aventura Mall's 3rd Annual Chocolate Festival for CCA Kids was held on Sunday, October 10, 2010. Their Center Court became a thoroughfare of "sweet shoppes," one after another, displaying delicious chocolate morsels prepared by some of South Florida's most popular restaurants including **Chef Allen's, the Grand Lux Café, Schokolad, Chocolate Factory, Grateful Palate, Nordstrom, Turnberry Ocean Colony, Godiva, We Take the Cake, Ocean Prime, Porto Vita, Starbucks, FIU-Florida Int'l School of Hospitality & Tourism Mgmt,** and **Fairmont Turnberry Isle** and of course, **Chef Rick and Turnberry Ocean Colony.** Rick was joined by his General Manager, **Rachel Forte, Carolina Restrepo** and **Nicole Veil** from **Turnberry Ocean Colony,** as well as **Bruno Macazaga, Nick Katusa, Tania Marzouka** and the **Porto Vita gang.**

Chocoholics were treated to entertainment along



with a choice of raffles and silent auction items like **Hobo Luxury Bags** upon which to bid. The "icing" to top it off was a chocolate carving exhibition by **Danny Malone** of **Fairmont Turnberry Resort** and **Eric Potzinger** of **Porto Vita** and a runway show featuring chocolate-inspired fashions designed by students at **Miami International University of Art & Design.**

Chef Rick's able assistant, **Marina Guimaraes,** enlisted a host of returning and new sponsors for the event such as **Gym Kidz, Norwegian Cruise Line, Dorchester-South Beach, Hampton Sun, Aquafina, Atlas Pary Rental, Cupcakes-Changing the World, Townhouse Hotel South Beach Miami, Over the Top, Shape-Students Changing the World, New York Bakeries, ONE Bal Harbour Resort &**



**Spa and Turnberry Ocean Colony.**

CCA is grateful to everyone involved, especially Chef Rick and his family and all of the returning volunteers along with the new friends who came out this year to help. Thank you **Laurie, Kelsey, Brett, Janet, Jamie, Leo, Eliane, Amy, Mishelle, Eileen, Robin, Harley, Dylan, and Renée** and all! The 3rd Annual Chocolate Festival contributed almost **\$16,000** to CCA... SWEET!





# jorge posada foundation + baseball event 2010

CCA Attendees, (L-R) Rob Gorecki, Justin, Prince, Liz Prince, Jorge Posada, Lee Scimeca, Jill Patterson, Anthony Scimeca

Bill Mecklenburg, Morgan Mecklenburg, Jorge Posada, Christine Condino Mecklenburg

On Sunday, November 7th, the **Jorge Posada Foundation** held their annual Celebrity Baseball Tournament benefiting Craniosynostosis at Chelsea Pier in New York City. Once again, the Foundation created a magical experience for everyone involved. Children's Craniofacial Association was invited to participate and CCA families and donors came out to support the event through an enjoyable afternoon of bowling, bidding and imbibing!

Seven bowling lanes were filled by the following groups providing \$7,500 sponsorships toward the Baseball event to benefit CCA: **Lexington Insurance, The Redwoods Group Foundation, Ironshore Insurance, Aran Insurance Services Group** and **Bill Mecklenburg & Christine Condino-Mecklenburg**.

CCA was also fortunate to be the beneficiary of contributions and participation from **Joe & Julie Davies, Partner Reinsurance Company, Guy Carpenter & Company, Kent Penwell, Deutsche Bank, David Brown, Rob & Nicole Bentley, Ralph Caravello, Jim & Mary Pouliot, Katy Reynolds, John Walbrink, Elizabeth Prince, Andrew & Andrea Potash, Mike Amatrudo, Jim & Mitsuko Condino**, and the **King, Mahoney** and **Greer-Dremann** families.

In addition, the Jorge Posada Foundation held their 9th annual auction online through Charitybuzz auctions. Children's Craniofacial Association partnered with them, adding to the parcels with vacation packages from **The Royal Palms Resort and Spa in Phoenix, AZ, The Surf and Sand in Laguna Beach, CA, The Four Season Resort and**

**Spa of Scottsdale, AZ, the Marriott Laguna Cliffs Resort and Spa-Dana Point, CA**, and tickets to **Disneyland Resorts** and the **Los Angeles Angels vs the New York Yankees**, all through the direct efforts of **Coast-to-Coast Destinations**. CCA's national spokesperson, **Cher**, donated tickets and a meet/greet to a show during her final run in

Vegas at Caesar's Palace as well.

We are "bowled over" by the personal regards the Posadas extended to everyone at the event and it turned out a wonderful success for all involved. Thanks again to all who participated, we encourage others to join in the 2011 event and we hope to see everyone next year!

## our emerald is a real gem

CCA Teen **Emerald Demor** and the **Rocky River High School Student Council** in Ohio held a Hollywood-themed homecoming and sold "stars" to fellow students to raise funds for Children's Craniofacial Association. The students wrote their names on the stars they purchased and the stars were placed on the floor to line the entrance into the homecoming event so they could be read like the Hollywood Walk of Fame. The effort raised **\$500** for CCA! Thanks to Emerald and all of the kids who helped! Wow!





**Fresh Start Surgical Gifts is an amazing charitable organization that provides reconstructive dental and plastic surgery for kids free-of-charge.**

Every 6-7 weeks throughout the year Fresh Start Surgical Gifts holds a Surgery Weekend and 80-100 highly talented individuals provide reconstructive plastic surgery and reconstructive dental surgery for infants, children and young adults with physical deformities free-of-charge. Surgery Weekends are held at the Fresh Start Clinic at Rady Children's Hospital in San Diego, CA. All medical and support personnel generously volunteer their time, talents and expertise.

Fresh Start Surgical Gifts serves US-based children as a priority and reaches out internationally as they believe that no child should suffer with a physical deformity due to birth defect, disease, accident or abuse. With insurance deeming more and more deformities as "cosmetic," they are determined to make certain that all children get the medical attention they need regardless of the family's ability to pay.

Fresh Start accepts children and young people under the age of 18 from:

- financially disadvantaged families with no health care insurance;
- families whose health care insurance won't pay for the procedures because they are deemed "cosmetic";
- families who do not qualify for state-funded programs;
- families who would suffer significant financial hardship if they were to have to pay for the necessary and costly medical treatment.

For additional information, please visit [www.freshstart.org](http://www.freshstart.org) or call **760.944.7774**.

## charitable IRA rollover extended for 2010 and 2011

It's official—the president signed the charitable IRA rollover extension into law, and it will be in effect for 2010 and 2011. There are several important points donors interested in this provision must be aware of:

- Donors aged 70½ or older are once again eligible to make direct transfer of funds from their IRAs to qualified public charities without having to pay income taxes on the gifted money.\*
- The funds must be directly transferred from IRA accounts to the charities (donors should ask their IRA custodians for special forms to make these requests).
- Each individual is entitled to make a total of \$100,000 in gifts to charities each year under this provision.
- 2010 IRA rollover gifts can be made through January 31, 2011.
- These contributions do not qualify donors for an additional charitable income tax deduction as not being taxed on the withdrawal is worth even

more than a standard charitable deduction.

- Only standard IRAs and Roth IRA accounts qualify under this law; other retirement accounts such as 401(k), 403(b), SEP, KEOGH, and SIMPLE IRA plans cannot be used to make an IRA rollover gift.

The provision is a **significant opportunity for donors** who hold assets in their IRAs that they do not need or for those who would like to make a large one-time gift. It also serves well for those who do not itemize or who are subject to the 2% rule that reduces itemized deductions. This can be utilized by those who plan to leave part or all of their IRA to the organization upon their passing.

Contact your financial planner for assistance.

**Consider a gift to Children's Craniofacial Association!**

\*Sources: *The Stelter Company* and [ChangingOurWorld.com](http://ChangingOurWorld.com)

## philanthropic paisanos

Children's Craniofacial Association has long been assisted by kind volunteers from the **Italian Club of Dallas**. This year, while helping at the Dallas holiday party, **Ben Parlapiano and crew** presented CCA Executive Director, Charlene Smith with a check for **\$1,000!** CCA is extremely grateful to ICD for their faithful support with helping hands and with this boost to our budget. You're all so kind and generous too! Thank You!





**GO PAPERLESS** and view the newsletter online in FULL COLOR! Email [AReesves@ccakids.com](mailto:AReesves@ccakids.com) and let her know you want to save the environment and save money for CCA.



**PERMISSION™**  
Skincare for Men

### giving back

CCA is proud of our cause-related marketing alliance with Permission products, a line of skin care. "Permission formulas help you face the world with new confidence, and you'll be helping others do the same. A portion of proceeds from each product go to benefit Children's Craniofacial Association..."

**Our friends at Permission offer a 25% discount on all products if you mention CCAKIDS with your order!**  
[www.permissionskincare.com](http://www.permissionskincare.com)

### family retreat— play a bigger role!

CCA families who wish to do more to help support Children's Craniofacial Association in our effort to put on the Annual Family Retreat may take part in sponsoring or finding sponsorship for any of the following:

- Ice Cream/Dessert Social \$7,500
- Retreat T-Shirts \$3,000
- Teen Night \$ 500

**Click on "Donate" at [ccakids.org](http://ccakids.org)**

## become cca's "friend" on facebook and twitter!

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

Follow us on twitter at [twitter.com/ccakids](https://twitter.com/ccakids) or [twitter.com/ccateens](https://twitter.com/ccateens).



**Make your birthday wish for CCA on facebook!**

## cca's yahoo support groups

**CCA is now offering support groups for 3 ages!**

Middle School Age:

[http://health.groups.yahoo.com/group/ccateens\\_middleschool/](http://health.groups.yahoo.com/group/ccateens_middleschool/)

High School Age:

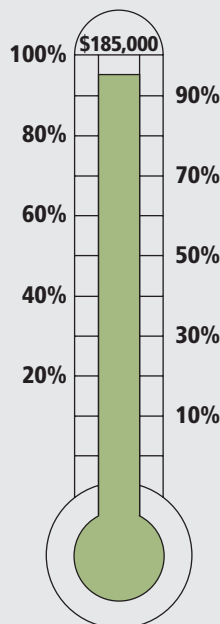
[http://health.groups.yahoo.com/group/ccateens\\_highschool/](http://health.groups.yahoo.com/group/ccateens_highschool/)

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, [AReesves@ccakids.com](mailto:AReesves@ccakids.com).

2010 FAMILY FUNDRAISER GOAL THERMOMETER



**My advice to parents** faced with a child of any kind of disability is to teach your child they can do anything they put their mind too. Let them know they can talk to you about anything—be their "BFF." In school, be their advocate; question everything and accept only the best. At home, support them, help them find their natural talents and most of all, love your child unconditionally. Truly, the sky is the limit.

—Christen Evans

## leave a legacy

**W**e wish we could thank those who thought ahead, arranging planned giving according to their wishes, and who made the decision to champion CCA posthumously.

To that end, we have initiated the CCA Legacy Society, for those who wish to name Children's Craniofacial Association as a beneficiary. Through this effort, we will chronicle information about those who endow our future and the future wellbeing of our CCA kids.

If you wish to fill out a declaration form and legacy history for our society archive, please contact us. If you have already set up a bequest in CCA's name, please allow us to include your intentions in our records, describing your gift of security, for the future of Children's Craniofacial Association.



## cca logo sweatshirt blanket

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

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

Order via our secure checkout for you and for all of your family members

Go to [www.promotes.me/cca](http://www.promotes.me/cca) to order!

## good news about dental and health insurance

**K**im Trzanowski, mom of CCA Kid **Trevor Larys**, is a National Benefit Specialist for **Ameriplan**, and is offering to donate her commission back to the CCA for every enrollment! Please visit [www.givingushope.weebly.com/our-programs.html](http://www.givingushope.weebly.com/our-programs.html) for more information on dental and family health insurance, or call her at 888.842.7136! Be sure to mention you saw it in the CCA Newsletter!



## cca gift basket raffle

**m**ike Wiese of Baden, Pennsylvania or more accurately, his daughter **Liz**, was the lucky recipient a huge assortment of products from Lancôme, L'Oréal, Maybelline and Matrix. **Fred Smith**, our building engineer, drew the winning ticket on December 15th. The raffle raised over **\$1,000** for CCA! Congratulations, Liz!



# wendelyn's course of dreams

The 5th Annual Wendelyn's Course of Dreams was a fun-filled day. Golfers were greeted at registration by wonderful volunteers: **Cindy Ford, Roberta Long, Payton Berklite, Pamela Barker, Lana Brooks, Jennifer** and **Shelly Mollette**.

As the golfers made the turn-a-round, they were treated to Blue Bell Cookie Cones, snack crackers, water, Gatorade and Coca-Cola products as well as a chance to view and bid on silent auction items. Once scorecards were turned in, all were treated to a lunch and dessert buffet catered by **1620 Restaurant**. The scores were posted on the scoreboard, which was surrounded by 18 different pictures of CCA kids, all friends of Wendelyn's and examples of the many forms of craniofacial conditions.

This year was made even more special with player **Kyndall West**, who also has a facial difference. Wendelyn really enjoyed getting to know this delightful and very talented young man. Kyndall happened to have an 8 handicap!

Congratulations to **Rance Bryant's** team for reclaiming their overall winning title. Rance says his team will be returning

next year to defend their title—and they welcome all challengers!

Wendelyn would like to thank everyone who had a hand in making this event a success.

Supporters include:

- Rainwater
- Holt & Sexton, LLC
- Ben E. Keith
- Blue Bell Creameries
- Arkansas Coca-Cola Bottling Co.
- Golden Eagle of Arkansas
- Senior Respiratory Solutions Inc.
- G.C. Brown Associates Inc.
- Domtar of Ashdown
- Landers Auto Sales of Saline County
- Superior Dodge Chrysler Jeep
- Roberson's Fine Jewelry
- Mr. & Mrs. John Long
- Parker Cadillac
- FedEx Freight East
- Coulson Oil Company Inc.
- Arvest Bank
- Arkadelphia Medical Clinic
- Academy Sports
- 103.7 The Buzz all-sports radio station and the "Show With No Name" crew
- KATV channel 7 producer Katrina Dupins and sports director Steve Sullivan
- Fast Signs
- Sir Speedy on Shackleford Road
- Wal-Mart, Maumelle

- And all the businesses and individuals who donated silent auction items and monetary donations.

This event could not have happened without your generous support!

Wendelyn can't wait to see everyone at next year's tournament which will take place at a new location, **Pleasant Valley Country Club** in Little Rock. Mark your calendars for Monday, November 7, 2011.



This move promises to bring increased awareness to facial differences by garnering more support from local and state businesses than in previous years. Because "Daylight Savings Time" leaves less daylight for play, teams will be limited to the first 25 "paid" foursomes.

There are various sponsorship levels available for purchase. If you want to participate in 2011, please contact Wendelyn at [wendelynosborne@gmail.com](mailto:wendelynosborne@gmail.com). For more information about Pleasant Valley Country Club, contact Gary Proud at 501.225.5622.

## save the date

June 23-26, 2011

**CCA's 21st Annual Family Retreat**  
Louisville, Kentucky

The 21st Annual Family Retreat will be in Louisville, KY, June 23-26, 2011. **CCA will also hold a craniofacial symposium on Thursday, June 23rd.** We will be staying at the Galt House Hotel & Suites. For more information about the hotel, please visit [galthouse.com](http://galthouse.com). For a full list of attractions and restaurants, please visit [louisvilleexplorermap.com](http://louisvilleexplorermap.com).

If you are planning on attending, please e-mail [ARees@ccakids.com](mailto:ARees@ccakids.com) and we'll send you the retreat registration form. The deadline to register is May 20th.

We hope to see you there!

# children's craniofacial association

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it be removed from the mailing list.

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



**3** Cheers  
for volunteers!



CCA wishes to thank the **Italian Club of Dallas** for volunteering their time to help with our newsletter mailings, campaign mailings and for helping at our annual Holiday party. They are such a fun and generous group and CCA is so grateful for each and every one of them! Grazie!