

ccanetwork



quarterly newsletter of the children's craniofacial association

Cher — honorary chairperson

fall 2010

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brody's story

By Jennifer Lucás

My husband **Eric** and I live in Brighton, Colorado, with our four children **Hunter, Haley, Dillon** and **Brody**. They are 14, 12, 9 and 7 years old. **Brody** is the youngest, and he has Apert syndrome.

On July 11, 2003, we were blessed with our darling, Brody. It was a rough pregnancy. My body kept wanting to go into premature labor. We knew ahead of time there might be some problems. My stomach was measuring larger than it should. So, we were sent to a genetic specialist to have an ultrasound done. The doctor showed us the odd shape of his head and told us the fluid was not flowing through the fingers and toes. They could not tell us absolutely, but thought he probably had Apert syndrome.

Brody was a quick delivery. My water broke and I made the phone calls to the doctor, my husband and my mom



message from the development director

Let's all take a collective deep breath! This year, while it seems to have flown by quickly, has also been a trying one for many. No doubt CCA's was not the only appeal letter you received, tugging at your heartstrings. Now, as we breathe out, let's all smile, because we know for many CCA kids, your help is working! When it seems everything is going wrong in the world around us, it's nice to know you're doing something good for others and your positive actions are truly transforming lives and making a difference.

see **brody**, page 10

see **development director**, page 8





meet connor carlisle

he likes to play *Wall-E* on his Wii.

He and his brother like to go to the park, where they're usually seen climbing up (and swinging from) banyan trees. Connor likes going on all the rides at Magic Kingdom, Epcot and Busch Gardens, too.

One thing's for certain: He absolutely loves being a Cub Scout, even above his love of sports, and is very excited about becoming a Bear Scout this year. His dad is a Cubmaster, and he and his troop enjoy going camping. When they go camping, they take all of Connor's medical equipment into the tent and run extension cords for power — where there's a will, there's a way!

Connor was born with clover leaf skull, Crouzon's syndrome and a Chiari malformation. Needless to say, he's had some very challenging early years. At the moment, he still relies on a ventilator to help him sleep, and he continues with 100 percent g-tube feeding. He has difficulty with gait and balance and tires when walking long distances. Connor got

his first hearing aid this summer and has adapted well to it.

Throughout all of this, Connor has remained a delightful boy, an awesome brother and a good friend to his classmates and fellow Scouts. He's very determined and always ready to go on outings and have adventures — baseball, bike riding, climbing trees and camping, anyone?

Connor and his family went to their first CCA retreat this summer in Boston and had a terrific time. He got to meet other kids going through similar circumstances. Until now, he was the only one he knew who had a g-tube. Hopefully, they'll be at the retreat next year. We look forward to seeing them again!

Connor Carlisle just had a birthday in October. The second grader from St. Petersburg, Florida, turned nine years old. To celebrate, he and 20 friends and family members gathered at a bowling alley for an afternoon of fun. As a special request, Connor asked that everyone sing "Happy Birthday" quietly, which they did. Those 20 voices must have sounded so beautiful together.

In lieu of birthday gifts, Connor asked that people make a donation to CCA. They collected **\$325** total. Thank you so much, Connor, for your generosity!

Connor enjoys school, except for math. P.E. is his favorite "subject." He loves it when his class gets to play baseball, and he particularly likes hitting the ball. He likes playing basketball during P.E.,

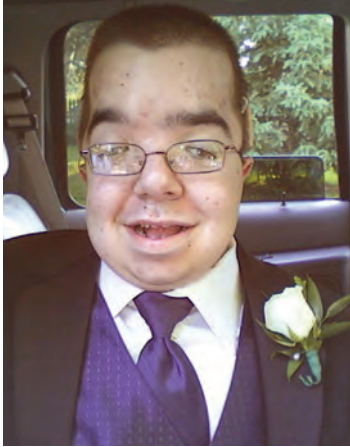
too. Every spring, Connor plays baseball in a Special Challenger League, and when he can, he goes to see the Tampa Bay Devil Rays play.

He also likes to swim and has a special flotation device that keeps him partway above water, enabling him to use his legs only to swim across this pool. What's more, Connor is able to go bike riding with his friends. He has an adaptive trike with a basket in the back that holds all his medical equipment.

He's also really into Legos®. Recently, he and his dad built a vulture droid with the *Star Wars* Legos. (By the way, Connor and his brother, **Reid**, are huge *Star Wars* fans!) Connor has a set of *Toy Story* Legos he likes to build with as well. Connor is a big Xbox® fan and plays *Clone Wars* and *Republic Heroes*, and



cca kid



hi. My name is **James Ryan Foley**, otherwise known as **J.R.** I was born May 26, 1990, with a number of medical issues. The one most responsible for most of my medical problems is called craniosynostosis.

When I was born, I was transported immediately to the New England Medical Center in Boston. During my first few years of life, we realized I had many complicated medical problems.

First, I had a lot of fluid in my head. To prevent things from getting worse, the doctors decided to place a shunt in my head to help remove the fluid. A shunt is a device like a small pump that moves fluid from the brain area to the stomach. I had to overcome many obstacles with my shunt. It malfunctioned six or seven times, plus I had a couple of infections. I had to go to

the OR many times for just my shunt. I also had some big craniofacial surgeries, but I was too young to remember them.

Another issue was the fact that I couldn't eat by mouth. The doctors placed a tube in my stomach called a g-tube, which helped me get food and nourishment. Another problem was that I had trouble breathing. The doctors performed a tracheotomy to help with that.

In May 2000, I had a big mid-face surgery and had to wear the RED device. This surgery was very tough to go through, but it had a lot of advantages. The biggest one was getting rid of my trach, because I could now breathe on my own.

In 2003, I had heel chord surgeries on both of my feet. I also had a hip surgery in 2006, which didn't go too well. Then we were struggling with the fact that I couldn't walk.

During this time, my parents noticed that I started to lose the use of my left hand. We went to see a bunch of doctors to try and figure out what was going on. Then I had an MRI, and the doctors noticed a lot of pressure on my brain stem. I had to

have spinal fusion surgery in 2008. Since then, I haven't been able to turn my head very well. I have to turn my body if I want to look at something out of my direct field of vision.

Then in February of last year, I had a second hip surgery, which was successful. All the pain has gone away, but we still don't see a huge change in my walking. I can't walk without a walker because there is still pressure on my brain stem, but I can really get around on my power chair.

Over the years, I could not have managed to get through all the surgeries without the help of my parents, **Karen** and **Jimmy Foley**. My grandparents, **Jane** and **Paul Scarborough**, and my other grandmother, **Betty Foley**, have also been there to support me.

Recently, I attended CCA's 20th Annual Cher's Family Retreat in Cambridge, MA. I had the time of my life and met many new friends. My favorite part of the weekend was the teen night, a time for young adults 13 and over to gather for an evening of fun, dancing and laughter.

Right now I attend Cotting School in Lexington, MA, and can

go there until I'm 22. That means I have just two more years to learn new things and try to become more independent. It's a great school, and I have lots of friends who will be my friends forever.

I love going to see my favorite team, the Boston Red Sox, play. I also love to travel, and my favorite places to go are New York City, where I can see Broadway shows, and Disney World. As much as I love traveling with my family, it's always fun to go away without them to try out my independence skills. I've been on ski trips and weekends away with friends from school, and it feels great when I can do things on my own.

This is going to be a very exciting year for me because I will be going on my senior trip to Disney World. Also, I'm hoping to be elected class President — I'll keep you posted. And I'm excited that we're getting an adaptable vehicle, so I can use my power chair more. Most of all, I'm healthy and very blessed to have such a wonderful family and lots of friends.



cca supersib

meet reid carlisle



my name is **Reid Carlisle**. I'm 11 years old and just started sixth grade at Thurgood Marshall Middle School in St. Petersburg, FL. My favorite subjects are World History and Science. I love drawing science fiction characters, and I enjoy gymnastics — my favorite events are the bars and tumbling.

Earlier this year, I advanced from Cub Scouts to Boy Scouts. I'm excited to have just completed my requirements for my Tenderfoot rank, and I had a blast at my first Scout adventure camp last July.

This summer, my family and I attended our first CCA retreat. My brother **Connor** and I had a great time in Boston! We also explored the city, plus we took a trip to Maine.

We made lots of new friends at the retreat, including **Scott, Logan, Lee, Peri, Rachel** and so many more.

Connor and I like to play Wii games together, build with Legos, go camping, have nerf gun battles and sleep over in each others' rooms. It's fun to be in Scouts together too! Connor is the best little boy I know, and I love him.

apert feet

By John C. Kolar, PhD/Clinical Anthropologist
Medical City Children's Hospital

apert syndrome includes a wide range of physical anomalies involving the head, face, hands and feet. While a lot of attention has been directed at treating the craniofacial problems and syndactyly (fusion of the fingers) of these children, very little has been written or done about the anomalies of their lower limbs, especially their feet.

The most obvious problem in the feet of children with Apert syndrome is fusion of their toes. This is similar to what is seen in their fingers, with three types of feet identified. In Type I, the second through fourth toes are fused, with the big and little toes separate; in Type II, toes two through five are fused; while in Type III, all five toes are

joined. There also are a few studies of x-rays and three-dimensional CT studies which show abnormalities of the other bones of the foot as well.

Children with Apert syndrome have small feet, which are reduced more in length than width. As they grow, growth of their feet is below average in both length and width.

In addition to their small size, Apert feet are misshaped. Some children have flat feet, with or without a prominent bunion at the base of the big toe. These bunions are due to an abnormal angle between the toe, which is turned toward the outside of the foot, and the first metatarsal, one of the long bones of the arch of the foot. Other children may have a similar projection on the outside of the foot,

between the little toe and the fifth metatarsal.

The most common deformity of the foot is found in the ball of the foot, at the base of the toes. When you look at a normal footprint, you can see a large area of the sole which is in contact with the ground, from the large heel, along the side of the arch and across the ball of the foot. In a normal foot, all five bones of the arch touch the ground at the ball. This gives you a solid base to stand and walk on. In most Apert children, one of these bones, usually at the base of the second toe, projects downward more than the others. This produces a visible, heavy callus at the end of the bone. Instead of a broad base of support along the ball of the foot, all of the weight of the body is shifted to this single point. This makes balance much more difficult whether

standing or walking and is part of the problem many Apert children have with walking or running.

This change in the foot means that the entire body has to adjust itself to maintain its balance. One of the results of these changes is an increase in the curvature of the lower back. This is known as lumbar lordosis or "swayback."

All of these changes to the foot and the lower body contribute to one of the common problems in Apert syndrome children – finding comfortable footwear that fits. Right now, there is no solution to this problem. Because Apert syndrome is so rare, there is not enough data right now to aid in designing orthopedic shoes to adjust for the deformities. Each child's feet are different and need different solutions.



calendar of events

date	event	contact
Dec 4, 2010	CCA Holiday Party—Midwest Brat Stop/Parkway Chateau Kenosha, WI	JPatterson@ccakids.com 214.570.9099 800.535.3643
Dec 11, 2010	CCA Holiday Party—Dallas Southfork Ranch Parker, TX 10 AM – Noon	areeves@ccakid.com 214.570.9099 800.535.3643
Mar 6, 2011	4th Annual Henry's March for CCA 5k Fun Run CSU, Stanislaus Turlock, CA	lauryhenry@sbcglobal.net myspace.com/henrysmarch 209.664.0500
May 2011	Fore Ava's Friends Golf Tournament Portland, CT	mbeeler@trcsolutions.com
June 23-26	21st Annual Cher's Family Retreat Galt House (galthouse.com) Louisville, KY	areeves@ccakid.com 214.570.9099 800.535.3643
Nov 7, 2011	6th Annual Wendelyn's Course of Dreams Golf Tournament Pleasant Valley Country Club Little Rock, AR	wendelynyvonne@hotmail.com
Spring, 2011	3rd Annual Ryan's Road Big Flats, NY	ngulich@yahoo.com

donors in the spotlight

This issue we honor **Jim and MaryJo Montalbano**, who have been donors to CCA for years now and have reluctantly consented to take an *almost* anonymous bow. No smiling photo to share with you, just these kind words, *"Mary and I feel honored that you would think of us. I can only say that we are glad to give the children something that can bring some hope and joy into their lives. We know the heartache and worry that parents endure, but most of all the courage of the children to live with their burden—sometimes their whole lives—but of course, you know this.*

We have first-hand knowledge of this because of our own daughter. She is 35 now, married, with two beautiful daughters. Our oldest granddaughter was born with a different condition. We ended up contacting a doctor on your medical advisory board. I wish we had more to give—even when things are a little tight that does not mean we are going to stop supporting the association. We believe in what you are doing for the children. We are always thinking of your staff and the kids. Thank you for the honor, take care and be good. Regards, Jim & MaryJo"

We asked permission to highlight their giving because, like so many of you, they give year after year, no matter what. We have such wonderful donors. Thank you again and again, Jim and MaryJo Montalbano, for your support!

free 2011 hotel stay!

Fundraising reward extended indefinitely!

For 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. 2009 fundraising counted toward the 2010 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 2010 will go toward the 2011 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 for more information.

Try creating your own firstgiving page

A free CCA-customized "firstgiving" site is available for anyone who wants to help raise funds for CCA. Log onto firstgiving.com/ccakids and tell your personal story about why you support CCA or post an event you're having. Then, 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.

good news



Torey's Distraction won **Best Documentary Feature** and the **Audience Award** at the New Orleans Film Festival! That's TWO awards!

Patti Casey and **American Southwest Insurance** made a generous donation of cases of brand new folders to CCA. Many Thanks!

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

cca
web store

\$15 each plus shipping

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



Stainless steel w/ braided leather; round, heart or dogtag style;
"Beyond the Face Is a Heart" on reverse



"Swarovski-type" genuine Austrian crystal
stretch bracelets with stainless steel CCA logo tag



Alexandrite
"Purple"



Apricot "Orange"



Chrysolite "Lime"



Gold Beryl "Teal"



Light Sapphire
"Royal"



Multi "Limited Edition" for
September
(still available)

wristband sales continue!

"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 • 800.535.3643

financial assistance

do you travel to receive quality medical care?

If you do, and need financial help, CCA has a financial assistance program that will help with food, travel and/or lodging. Call CCA for an application at

800.535.3643. All we ask is that you **apply at least**

four to six weeks prior to your next appointment.

development director, from page 1

Now, while you're all in a great mood, let me get in a shameless plug for our CCA Legacy Society. In the past, and even now, we are often surprised by folks who leave us the gift of a bequest upon their passing. But, unfortunately, this way, we're unable to say a proper, "Thank you." We established our Legacy Society so that people can let us know their estate plans ahead of time if CCA is included in their wishes.

To be perfectly honest, to date, our Legacy Society consists of only those of us closest to the organization; staff and board members who have remembered Children's Craniofacial Association in their wills. This commitment reflects our strong belief in CCA's purpose.

The ideal situation would be for no more births of facial difference to occur, no more accidents, no more disfiguring disease. However, we must plan to be prepared for the need, nonetheless. We do believe our vision will one day be realized, that all people will be accepted for who they are, not how they look. But, until then, resources will continue to

be needed for awareness and education to foster understanding and acceptance.

Nobody likes to talk about death and dying and it's a very personal thing to share one's final decisions with anyone. We will respect each individual's preference as to how one would like to be acknowledged for membership in the Legacy Society.

A charitable bequest through planned giving is the type of gift that works well for folks who believe in our cause but can't part with their funds at the present time. Please think seriously about joining me in the Legacy Society.

While most of us won't have a hospital wing or a building at our Alma mater named for us, we can still make an impact by leaving a legacy that will ensure and shape the future for CCA kids.

I wish you and yours a blessed holiday season and all the best in the New Year!

Jill Patterson
CCA Development Director



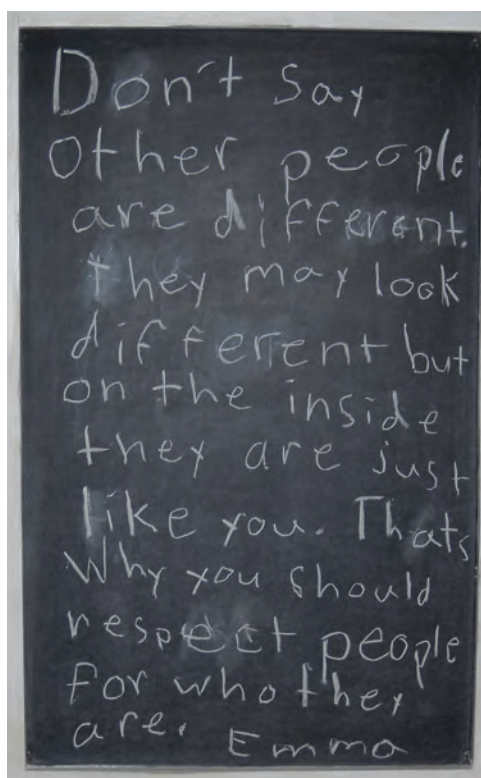
craniofacial acceptance month

This year marked the sixth observance across the nation of Craniofacial Acceptance Month in September. 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.

Many of our CCA families were able to get their local newspapers to run a feature article on

them. Radio stations also ran PSAs throughout the month of September. And, for the third year, CCA held National Picnic Day in September as part of Craniofacial Acceptance Month. CCA families held picnics in Alabama, Florida, Nebraska, New Hampshire, Ohio (two), Texas and Utah!

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



Written by Emma Cronin, 7, big sister of CCA Kid, Megan Cronin, from Greenwich, NY



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OHIO



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FLORIDA



OHIO



FLORIDA



TEXAS

brody, from page 1

to meet me. I drove myself and my other three children to the hospital. We all got there at about the same time. My mom took the kids and Eric took me inside. They got me on a bed and I had to start pushing. My doctor wasn't there yet, so they grabbed some OB/GYN to "catch" Brody.

It was a lovely 45 minutes from when my water broke to when he was out, but we could not celebrate yet because they whisked him away. I remember hearing there was something wrong. I can't remember how long it was before I saw him. Eric was telling me Brody was having a

hard time breathing and they thought his nasal passages were closed since they couldn't get a tube down his nose.

I was concerned and wanted to see my baby. Eric took me down to the nursery and I saw my Brody. He was in an oxygen tent and didn't look like any of the other babies. Other people would walk by and just stare at him. All I could think was, "my poor baby," and I wanted to cry. He had a bunch of dark, black hair, his fingers and toes were fused, he had a long head, and his color was wrong. They wouldn't let me hold him.

He was soon heading to the Children's Hospital in the Flight for Life Ambulance. Now I had to get myself out of that hospital. No one wanted me to leave, but I said I had to get to my baby. They finally let me out later that evening so I could go be with my child.

Brody then spent the next week in the NICU. I was afraid he would not make it. I kept praying every day they would let me take him home. He was on oxygen and on a lot of monitors. He had pneumonia, and

they were doing all kinds of tests and ultrasounds. He failed his newborn hearing test and had a heart murmur, as well as a lot of fluid in his head.

Every day I cried, not knowing if I would ever bring my baby home, and each day felt like an eternity. When I was in the hospital, I worried about my other children at home. When I went home, I worried about Brody.

After about a week, we were finally able to bring him home. He would have to continue to be on oxygen, and we would need to visit many specialists. I thought to myself, "Sure, no problem. Just let Brody go home." I have three other children at home who need me and we all need to be together. So, we went home.

Brody was a wonderful baby. He hardly cried, and when he did, you really had to listen. He had difficulty with a bottle while trying to breathe. He lost a lot of weight. Nursing him was practically impossible. He needed to breathe through his mouth since his nasal passages were so small. When he tried to eat, he was not getting any air, so I pumped my milk and he drank from a fast-flow bottle. He struggled every day for survival. He needed eye cream in the evening to keep his eyes moist. He was unable to close them

all the way. We had to meet with doctors all the time. He continued to be on oxygen.

We met with the neurosurgeons and plastic surgeons at The Children's Hospital in Denver. We were told Brody would need many surgeries, but because of the way his head was formed, things may be more difficult than usual. He had many bony spikes inside the skull and they were worried about those spikes going into his brain.

In November 2003, Brody had his first surgery, a craniectomy. They removed the occipital bone in the back of the head. This was to relieve pressure on his brain as well as make room for his brain to grow properly.

This was to be a simple procedure, but we almost lost him on the table. The surgeons came out and told us they had finished on the back of his head, but when they turned him over, he was not responding. It could be over for my 4 month old. They said they were going to go back in and keep us posted. After some time, we were told he was in recovery, and we could meet him in the PICU. He was originally supposed to stay just a couple of days, but it turned out to be two weeks. While in the hospital, he had a collapsed





to be going well. He seemed to be more alert and was really learning how to manipulate his tiny pinky finger. His fingers were fused together to look like a rosebud, but he had a tiny portion of his pinky finger which stuck out and he used that pinky for everything such as, maneuvering his pacifier and grabbing toys.

Most nights Brody had to sleep in his car seat in our bedroom. He was constantly oozing mucus out of his nose and fluid from his ears, and his lungs always sounded congested. We had to suction his nose and throat often.

In March 2004, we noticed that Brody seemed lethargic. One night around one in the morning, he started vomiting and had a very high temperature. I was told to go to the ER at Children's. I woke up Eric and told him what was going on and to take care of the other kids.

I learned Brody had a staph infection from when he had the shunt placement. This meant they would have to remove the shunt, and with a tube, drain the extra fluid out of his head into a bag. This hospital stay was about a month long, and in April they replaced the shunt once his infection cleared.

Once the pressure seemed to be under control, Brody finally

started to show signs of development. He began to sit up and show some personality. Then about six months later he had to have another shunt revision; some blood clogged the shunt, not allowing it to flow properly.

Two months after that, Brody has his first finger separation, the thumb and pinky. He also had his frenulum clipped (the small piece of skin under the tongue to provide more movement) and tubes put in his ears to help drainage and help his hearing. The next month he had a hydrocele repair.

The doctors told us they would not be able to give Brody all his fingers on both hands. One hand would only have three fingers and a thumb. This to me was unacceptable. I researched other doctors and heard about a doctor in Texas who has only had one case where he couldn't provide all the fingers. He also separates the toes.

So, we decided to see Dr. Fearon in Dallas, Texas. By the time he was two years old, he had his second finger and first toe separation. Four months after that, he had his third finger and second toe separation.

During that last trip to Dallas, we learned Brody had a chiari malformation and would need to have it repaired. In September

2006, when he was three and a half, he had a rear cranial vault and the chiari malformation fixed. Two years later, he had his front cranial vault and more ear tubes. It has been pretty quiet the last couple of years with only a third set of ear tubes. We are getting ready for the fourth set of tubes and eye muscle surgery. Brody may continue to have surgeries for awhile, maybe until he stops growing. Time will tell.

In the meantime, Brody receives a great deal of love and a lot of therapy at home and school. He's extremely sociable, and anyone who gets to know him will agree he's adorable and lovable. Brody strives to be independent, but there have been many obstacles in his way. We're just thankful for today and will worry about tomorrow when it comes.

lung and could not be extubated because of his breathing problems. He also had pneumonia again.

Brody had his second surgery that December, a VP shunt placement. Brody was still having pressure problems in his head. He was vomiting and his development seemed delayed. The shunt placement was supposed to be a simple procedure, with Brody able to leave the hospital in 24 hours.

Again they could not extubate him because of his breathing issues. Brody ended up being hospitalized for another two or three weeks. I didn't think he would ever get that tube out of his throat. Every day he would just lie there, drugged and fighting to get better.

After Brody got out of the hospital, things seemed



testimonial

Our daughter, **Kate**, has born with Pfeiffer syndrome and has undergone 3 surgeries in the last year in Dallas, TX.



Without the help of CCA's financial assistance program, we would not have been able to afford these trips. CCA was able to help us shoulder the burden of flying a few thousand miles from home.

We live in Minnesota and the trips have given Kate the best care possible. Thank you CCA and all of their supporters for giving our daughter the best chance at a healthy and normal life. Without CCA, this would have been so much more difficult for our family... if not impossible. Thank you so much for everything you have done to help our family!

Stacy, Alan, Dakota, Leland and Kathryn (Kate) McAllister.



Enjoying their CCA mugs, left to right: John Gorman, Rory Cate Gorman, Molly Bono, Sadie Bono

more fundraising news

CCA Friends at **Merle Norman Marion B. Keegan Studios** on Preston Road in Dallas with the help of **Angela Pitts** held a "Christmas in July" sale. They gave shoppers 15% off storewide with 5% of the profits coming to Children's Craniofacial Association for a donation of **over \$100**. Thanks so much!

Regular CCA Supporters, **Honda Financial Services**, held a cell phone collection and garnered **over \$250** in the process! Thanks again!

The **Gulich Family*** has some great friends! "**Premier Designs**" presenter, **Connie Judd** holds "Charity of Choice" raffles at her home parties and Nicole's friends, **Lauren Schnautz** and **Maria Benckendorf** both chose CCA for a total of **\$175!** Thank you all!

*Ryan and Nicole Gulich put on an annual family fundraiser, a walk called, "Ryan's Road" named for their son, CCA kid, Ryan Gulich....the next one is slated for Spring, 2011

Jaci Samhammer has been out selling and **outselling** everyone! She already has **almost \$1,000** in sales of our new CCA jewelry! Go Jaci!

Thanks to all of the folks who added **Children's Craniofacial** as their **cause** on **Facebook** and especially those who celebrated their birthdays this year with a "birthday wish" on Facebook to donate to CCA! The birthday donations really do add up and this gives CCA a needed boost! Thank you **Annie Reeves, Becky White, Jill Patterson, Scott Guzzo, Jaci Samhammer, Charlene Smith, Jana Peace, Cheryl Swearingen, Erica Mossholder, April Gorman, Rose Seitz, Meg Gray, Casey Deakins, Donna Gossett, George Davis and Kim Sarsi!** (as of this printing)



splash passes available*

*a "Splash Pass" is a day pass to the Great Wolf Lodge Water Park

ATTENTION: Everyone in the Grapevine, Texas **Great Wolf Lodge** Area!

CCA has obtained a limited number of **Splash Passes for 2** from an anonymous donor (not from the Lodge itself) and we have them available **FOR SALE at \$50 EACH**.

This is an incredible deal as Splash passes are only available to hotel guests or

friends of staying guests for \$40 / person! (So, this comes to \$25 / person!)

The Splash Passes are good through February 28, 2011. Weekends and holidays are excluded, but the passes ARE good on Fridays! Contact CCA at 214.570.9099.

Group sales welcome. We will sell to the first inquiries. Feel free to spread the word!

3rd annual jylia's links of love golf tournament



On Monday, September 20th, the 3rd Annual Jylia's Links of Love golf tournament was held, raising **over \$13,000** for CCA! CCA kid, **Jylian Bilbow** is the daughter of **John** and **Kendall Bilbow** and represents CCA at the event.

This year golfers teed off at The Golf Club @ The Resort on Eagle Mountain Lake in Fort Worth, Texas. Assisted by **Tabatha Forsythe** of The Golf Club, CCA volunteers include **Michelle Helton, Jane**



Monelle, Judi Freeman, Rich and Tracy Thomas, and **Caden Reeves** who helped participants register, find their mulligan balloons, and play games.

Golfers enjoyed box lunches compliments of

Chick Fil-A on Bryant Irvin in Fort Worth, beverages from **Ben E. Keith, Coors Distributing of Fort Worth,** and **Andrews Distributing,** along with a dinner donated by **Spring**



Creek Barbeque.

We wish to thank our sponsors, both in-kind and monetary, including, **Emily Harwood of Charles Schwab, Avid Golfer magazine, Dunhill Homes, Fuzzy's Taco Shop, Honda Financial Services, Detective Kyle Sullivan of Ft.Worth Police Dept. Robbery, Direct Strategies, Paragon Sports, Metro Golf Carts, Park Place Lexus, Dallas Laboratories, Team Margaret,** and **Whole Foods.**



Auction donors included **The Texas Rangers, Thee Viron Roe of Neiman Marcus' Halcyon Days Salon & Spa, Chamberlain's, The Chocolate Leopard, Top Golf, Dickey's Barbecue Pit, Four Seasons Golf Resort and Club, Dick's Sporting Goods, Sunglass Hut, Sprinkles, Risky's Barbeque, The Dallas Mavericks, Omni Hotel, Great Wolf Lodge, Fort Worth Harley and The Ranch** restaurant. **Mike Forrester, Richard "Doc" Urso, Greg Patterson** and **Michelle Helton** also generously donated items for auction. And, special thanks to CCA friends, **Jon** and **Erick**



for the fine cigars and accessories donated for our cigar raffle.

Of course, we are extremely grateful to 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 we hope to see everyone again in 2011 for the 4th Annual Jylia's Link of Love Golf Tournament!



4th annual seth's stride for cca

By Stacy Swihart, Volunteer Organizer and CCA mom



The 4th Annual Seth's Stride for CCA was once again a success! Each year I am amazed at the outpouring of support from sponsors, volunteers and participants. Without all of you, none of this would be possible.

This year at Seth's Stride we had a magician, face painting, dunk tank, rock wall, train rides, inflatables, entertainment and lots and lots of food and sweets for the kids to enjoy.

It is always a joy to see the families who drive in each year for the Stride.

Special thanks to **The Granted Wish Foundation** who donated hotel rooms for our CCA families from

out of town. We appreciate your support.

Samantha Klinger and family attended for the 4th year. **Julie Baird** and daughter drove from Kentucky (6-hour drive) to show their support. We also met 2 new local families that have never attended and had just heard about CCA. Awareness is spreading and every year that someone new comes to the Stride, we know we have met our goal and have succeeded... the rest is just a bonus!

Thank you all for your continued support. It is an absolute thrill and honor to be able to hold this event and to help others realize that **"Beyond the Face is a Heart."**





2nd annual Lily's dinner

On Saturday, August 28th, 2010, we held Lily's 2nd annual Craniofacial Awareness Dinner, Silent Auction and Concert. The event was held at Hatfieldadelphia in Lindon, Utah. We had 120 adults and children in attendance this year. The silent auction was a great success, thanks to all of the generous donations and hard work put in to gather donations. We had 125 items in the auction. It was amazing! Even with the downturn in the economy, we raised **over \$7,600** for CCA and Craniofacial Awareness!

Lily has become very active in gathering support for her dinner. She was asking everyone she saw if they are coming to her dinner and if not, why not? Watch out for next year because she wants a cell phone and I think she'll be calling everyone to make sure they attend! She doesn't take "no" for an answer, either.

We are grateful for the support and attendance

of **Dr. Louis Morales** and his wife, **Susan**. We had the pleasure of having 4 of Dr. Morales' patients attend this year: **Grace Boxall, Courtney Jensen, Hope Larson** and **Hailey Sutton**. It was so fun to see the girls enjoying themselves and having fun together. We all had a great time enjoying good food, great company in an awesome venue and dancing to the rock-and-roll music of the Sphinctertones.

I would like to especially thank everyone who came out to support this worthy cause and I am so grateful to everyone who helped out with this incredible night. I would also like to thank **Ron and Maureen Hatfield** for so generously donating the venue for the evening. We appreciate it very much! I am very passionate about these kids. The overwhelming support, love and charity shown to them by attending and donating is awe-inspiring. Thank you!



"I would like to thank American Overhead Door Company and the Dunlevy family for helping Nitro for Charity help CCA!"-Terry Stewart

nitro for charity

Our resident biker kid, **Rob Gorecki**, who's all grown up now, has made lots of friends "in the business" along the way. Among them is the winner of the 2008 AHDR West Coast Drag Bike Championship, **Terry Stewart**, who held a **Stop Traffic for Our Friends** funder this spring and CCA was one of the beneficiaries. Now, Terry has started **Nitro**

for Charity. For a price that goes to charities he supports, he allows a rider to take his Nitro Harley for a "drag"! During the event held at the **San Antonio Raceway** in September, **John Dunlevy** raced to benefit CCA kids, and the **Estrada family** of San Antonio represented CCA and graciously accepted a check from Nitro For Charity for **\$1,000!** Thank you ALL!



From left, Mike Estrada, Hope Estrada, Terry Stewart, Tony Estrada holding Antonio Estrada as Terry presents a check for CCA in the amount of \$1,000.

reagan's rally



On September 5, 2010, family and friends of 2-year-old **Raegan Daugherty** gathered at **Deerassic Park** in Cambridge, Ohio, for Raegan's Rally, a special fundraiser for CCA and in honor of Craniofacial Awareness Month.

The day started with a variety of activities in the main building, including a slideshow of Raegan's journey, a Silent Auction, a 50/50 raffle, and T-shirts and bracelets for sale. Everyone also enjoyed hot dogs, chips and delicious baked goods.

At 3:30, everyone gathered outside for the walk around the park's facilities, seeing deer as well as "thank you"

signs to our donors all along the way. After the walk, we drew the winners for the Silent Auction items. A close friend who is a photographer from **Picture This Photography** came and captured the day for us.

Raegan also had the opportunity to meet a young man named, **Jake**, who also has Apert syndrome. Oddly enough, we found out that he lives just down the road from us!

As for donations, we placed flyers in local businesses. We received numerous cash donations weeks prior to the event. It was truly moving to see the number of people we didn't even know who chose to support this cause. Another instrumental part of early donations came from Raegan's uncle. He lives in Concord, North Carolina (six hours away from us), where he gathered donations from his friends and co-workers at **Charlotte Motor Speedway**.

Some of the donations for the Silent Auction included miscellaneous Ohio State

memorabilia autographed by **Coach Jim Tressel**, massages, **McDonald's** Extra Value Meals, \$50 gas cards, oil changes, car detailing, gift certificates to local restaurants, and so much more. The employees of Deerassic Park also collected donations for the auction.

Raegan's grandmothers arranged all of the auction items into nice baskets, a beautiful display. We also had a painted a picture of me holding Raegan's hand printed onto bookmarks, 8x11 prints and postcards — everyone received one of these items.

The day was a huge success. Raegan is truly blessed to be surrounded by so many people that care so deeply for her. The support she received from family, friends and the community even prior to the event has been unbelievable. A huge thank you also goes to **Mark Meeker** (director of Deerassic Park), his wife **Amanda** and their family, as they played an integral

part of making this event so successful.

All in all, everyone's efforts helped make the day one we will we never forget. We cannot wait for next year's event!



donors, january 1 – september 30, 2010*

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Listed are **monetary donations of \$100 or more through 3rd quarter, 2010.** We are extremely grateful for these and all other fees, purchases, fundraisers and in-kind donations not individually recorded here. (Note: For space consideration, 2010 donations under \$100, CCA "Supporters," will only be published in our year-end list. Cumulative \$100+ donations and all In Honor or In Memory dedications will continue to be published in each quarterly issue.)

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

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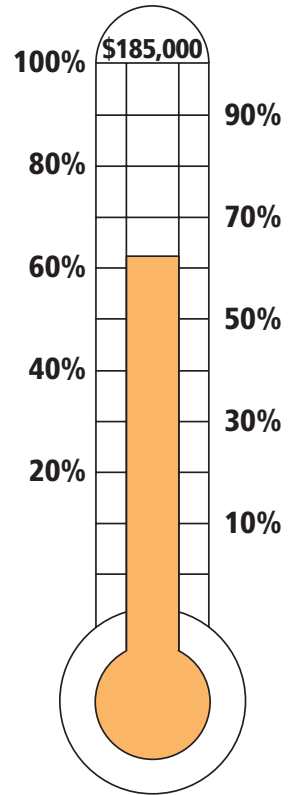
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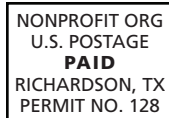
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3 cheers for volunteers!

Often nobody knows about the many people who are helping behind the scenes by volunteering services CCA would otherwise have to pay for. **Margaret Price** is one such kind person. She works in the suite next door to Children's Craniofacial Association's office in Dallas, and is a commissioned Notary Public. Many times we're

in need of this service on documents and applications and Margaret is kind enough to be there at a moment's notice. She is a busy gal but always makes time for us and always refuses her stipend. We can't thank her enough and we hope she knows how much this means to everyone at CCA. Three Cheers and a big "THANK YOU," Margaret!



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