ccanetwork

newsletter of the children's craniofacial association
Cher — honorary chairperson
summer 2008

inside

We wish to thank Bally's, a corporate sponsor, for helping to fund the *CCANetwork*.

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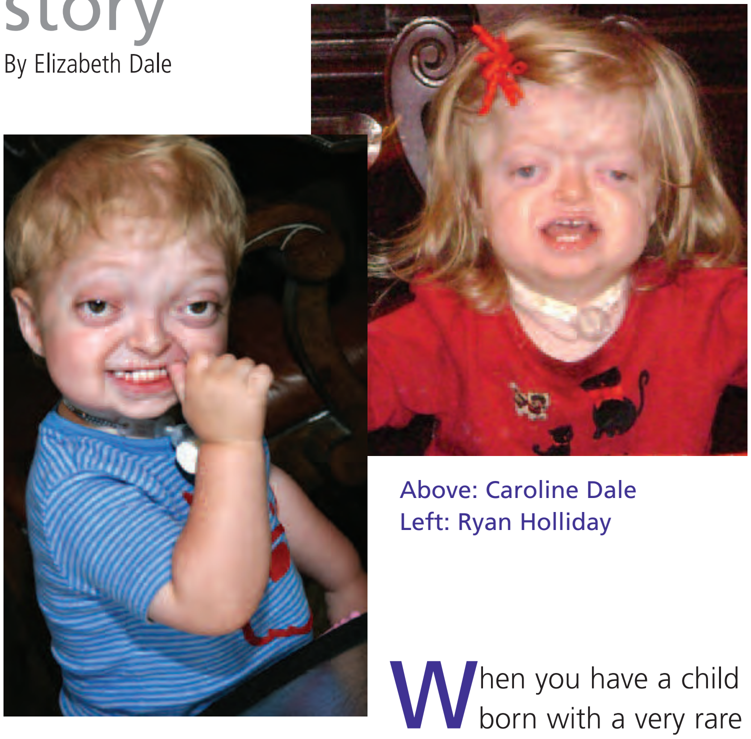
ryan and caroline's story

By Elizabeth Dale



Above: Caroline Dale
Left: Ryan Holliday

When you have a child born with a very rare craniofacial disorder, the last thing you expect is to meet someone "right around the corner" with the same situation. So it's surprising we came to know the Holliday family, yet we're thankful we continue to enjoy their friendship. This story is about **Ryan Holliday** and **Caroline Dale**: two sweethearts with Pfeiffer Syndrome who were born just one month apart and who live "right around the corner" from one another.

Like many families, we had no idea there was anything wrong until our children were born. Ryan Holliday was born on February 7, 2006, and was diagnosed with Pfeiffer syndrome when he was three days old. After nine days in the NICU, his parents took their beautiful baby boy home and began the journey of learning all they could about this rare craniofacial syndrome. Ryan lives with his dad David, mom Michelle and big sister Kathryn in Flower Mound, TX.

see **ryan & caroline,** page 10

message from the program director

OK, let me take a poll. Who wishes they were still in Myrtle Beach, playing in the sand and ocean? If you're like me, I'm sure most of you are raising your hands at this very moment.

I can't believe it's already over. Time sure does fly when you are having fun! Speaking of fun, I hope all of you enjoyed the retreat and were able to make new friends and reconnect with old friends.

This was our largest retreat to date, and we had families join us from

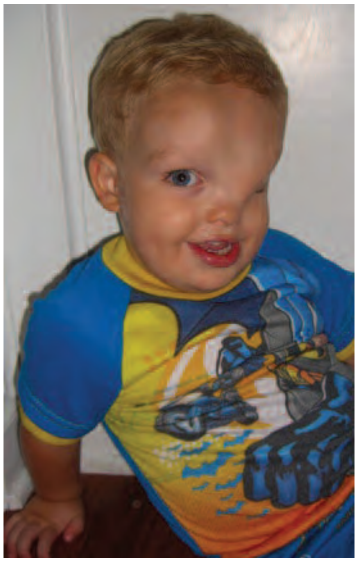
see **program director,** page 9

ccakid

meet rick dornier

Anyone who knows **Rick Dornier** knows he's a truly amazing little boy. This little two-year-old from Baton Rouge, Louisiana, is such a happy kid, always laughing and smiling. His family considers him a total blessing, and it's easy to see why.

His sister, Julia, and brother, Luke, absolutely adore Rick, and Rick feels the same way about them. Rick and Luke are such good friends, always playing together, swinging and even inventing their own games. "What's wrong with his eye?" people will ask, and Julia and Luke are quick to tell them, "That's how God made him. That's how he is. But that's OK. The doctor will give him a new one."



Rick also attends a play group with friends his age. Everyone plays together wonderfully. They often go to the park, his friends' houses and to local kids' indoor play places.

Rick loves to eat graham crackers and could drink milk "all day long." And, like most kids, he's a big fan of chocolate cake and chocolate ice cream.

One of his favorite shows to watch is Baby Einstein's "Baby Dolittle." He's really into the elephants in the show and can be seen doing elephant impressions on occasion, showing off the "trunk" he makes with his arms. He also loves music and enjoys dancing and singing.

And he has a fascination with elevators. This is probably because of all the elevators he has ridden when in the hospital and doctors' offices. He loves riding them and even has a "pretend" elevator at home. Rick and his family went to the beach this past summer. Sure, he loved playing in the sand, but he was particularly enthralled with, you guessed it, the hotel elevator!

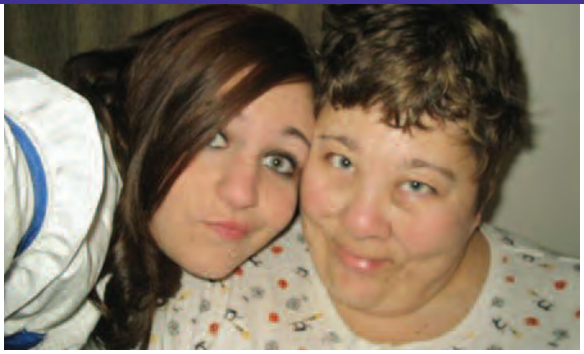
When he was born, Rick had too much fluid in his brain. (This was detected during ultrasounds before he was born.) He had other complications, including a cleft palate and two holes in his heart. His left nostril was very small, and he had no left nasal airway. He was also born without a left eye.

Rick has had five operations with more to follow. He had meningitis last year and had to have fluid drained from his brain. This was life-threatening for little Rick. He had to stay in ICU for 11 days. But he's a really tough kid, bouncing right back after this illness as well as each of his surgeries. Right now, his health is pretty good. It's been a "normal" summer so far.

Rick's cognitive abilities are excellent. In fact, his communications skills are well above average — Rick has been speaking in complete sentences since he was a year old. Walking took a while though, because of all his surgeries and their subsequent recovery periods. However, he's made up for lost time and is walking and running quite nicely.

meet tamara mantlo

Living with Carpenter's Syndrome: One woman's story.



When I awoke April 17, 2008, it was like a dream had come true. That's because I never thought I'd live to see my 40th birthday. When I was three, doctors told my parents I may not live to be 10. But here I am, defying the odds.

I was born with Carpenter's syndrome and a congenital heart defect. I had an open-heart surgery at age three to fix a ventricular septal defect, a hole in my heart. After that surgery, the list goes on with removing extra fingers and toes from both hands and feet and separating fingers on my hands. (The first three toes on both feet are still webbed.)

I've had tubes in my ears a few times and eye surgery. Luckily, I didn't have to have any cranial surgeries. The only type of head surgery I've had dealt with a chiari malformation, and that was performed when I was an adult.

I also had reconstructive knee surgery with the chance of never walking again. (Well, that didn't happen.) I am also fighting a constant battle with obesity.

In 1993, one of the best and scariest things in my life happened to me — I became pregnant. I remember praying every day for nine months, "Please let my child be healthy." On March 20th, 1994, my beautiful, healthy daughter, Sarah, was born. Now she's a healthy teenager, which is a little difficult for me because I'm not used to all the things healthy teenagers do. I have tried my best to raise her to accept people for who they are and to see beyond outside differences.

My first CCA retreat was supposed to be in Hershey, but the Monday before we were supposed to leave my heart went into ventricular tachycardia. I was in the hospital for three weeks and had my pulmonary valve replaced with a porcine (pig) tissue valve and a defibulator. I had my heart shocked three times and almost died. And I was upset because I couldn't go to Hershey to have chocolate.

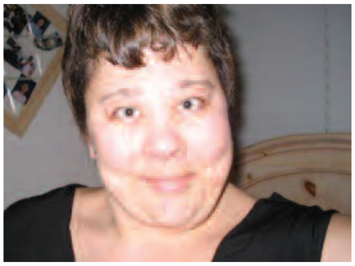
The next summer, Sarah and I drove to Salt Lake City for the CCA retreat, where I finally got to meet all the awesome people I'd been talking to over the last few years on the Apert Listserve.

This was the best experience in my life — I actually felt "normal." All my life I was always the different one, but oh no not here. I was just like everyone else. I stayed up all hours hanging out with new friends. I talked sports with kids in the pool. I was finally able to just be myself around people who actually could say "I know how you feel" — and really mean they know how you feel. Sarah wanted to bring a few of the little kids home with her. (Somehow I didn't think their moms would've liked that.)

For now, I'm getting my bachelor's degree online. I would then like to get my teaching certificate to teach special education because I feel I have a lot to offer.

I'd also like to establish a nonprofit organization to honor my sister, Wendy, who died when she was just an hour old from complications of Carpenter's syndrome. Until then, I'll keep advocating for people with differences and congenital heart defects.

So, yes, here I am, all 40 years of me, still defying the odds. But I wouldn't have been able to live this dream without the love, strength and support of my parents. They would probably tell you I'm one stubborn woman. I'd say, "Thank you, yes I am."



meet julia and luke dornier

Julia is eight years old and will be starting third grade this fall. She's a very caring, smart and fun-loving child who adores her little brother, Rick.

Julia was six years old when Rick was born. Immediately, she took on the role of caregiver for herself and her other brother, Luke, who was just over two at the time. Every morning Julia would make breakfast for herself and Luke. She would ensure that they were dressed and ready to start the day. Julia would entertain Luke by reading to him and playing with him.

She also liked to help me take care of Rick. I truly could not have gotten along without her when Rick was a baby. Rick was not able to breastfeed because of his cleft palate. It took him 45 minutes to bottle feed. It then took me another 30 minutes to pump breast milk for the next feeding. That is what I did all day and night.

Julia became a little mother. She did this selflessly and without us ever asking her to help. She continues to be a tremendous help with her two little brothers. But we try to let her be more of a child and not as much of a caregiver now.

Julia loves to draw and paint and is a wonderful artist. When she was six years old, her drawing of a tiger was published in *Highlights* magazine. Last year, she won the Principal's Choice Award for second grade at her school art show. Julia is constantly drawing pictures for Luke and Rick. Her drawings hang proudly all over their bedroom walls.

Julia also loves to read, dance, play soccer and football, swim, ride her bike, rollerblade and listen to music. She has also been in Girl Scouts for the last three years.

Luke is four years old and will be starting pre-k soon. Luke turned two shortly before Rick was born. He didn't understand why Mommy and Daddy were at the hospital for so long or why Rick couldn't come home. Luke was crazy about his baby brother right from the start. To this day he is still constantly hugging and kissing Rick.

When Luke meets someone for the first time he is shy and reserved. But when he gets to know you, you better watch out! He is all boy! Luke is very rambunctious and loud (much to Julia's dismay). Luke loves to play Star Wars with his friends. He also likes Spiderman, Transformers, Batman, The Incredible Hulk, Power Rangers — basically any superhero.

We have nicknamed him "The Puzzler" because he has a knack for doing puzzles. He can put together 100 piece puzzles without any help. This summer, Luke was very proud that he learned to swim all by himself! Rick even learned how to move his arms and legs in the water from watching Luke.

Luke and Rick are great friends. Rick likes to try to do everything that Luke does. They like to play hide and seek, swing on the swing set together and play with their toys. They also like to make up their own games such as "spit" (again, much to Julia's dismay). Luke can't wait until Rick is old enough to do more things with him.

ccasupersibs

craniofacial acceptance month

Beyond the Face is a Heart

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

New in 2008, as part of the fourth Annual Craniofacial Acceptance Month, CCA will hold National Picnic Day on September 13 (or other date in September of your choice). CCA families across the nation will hold picnics, giving them a chance to get together with other families in their areas while promoting awareness in the communities.

It's not too late. If you'd like to hold a picnic, contact CCA program director Annie Reeves. CCA will invite all of the families in your area and help you organize the event.

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

Please call 800-535-3643 to find out how you can join this important effort!

donors in the spotlight

Left to Right: Annie Reeves, Char Smith, Mary Zimmerman, John Moulton and Jill Gorecki

Elizabeth Moulton

CCA would like to recognize **John Moulton** and his family, including his mother **Elizabeth**, sister **Mary Zimmerman** and nephew **Steven**.

Elizabeth found CCA when her son, who was born with Apert syndrome, was already grown, but she understood the value in attending our retreats nonetheless. The family has been among our "regulars" for many years now.

Although she can no longer attend, Elizabeth still supports this event and CCA with her financial gift. Mary Zimmerman, John's sister, continually seeks donations for CCA from her own social group membership as well as from others.

At this year's family retreat in Myrtle Beach, Mary and John presented CCA with checks, including a generous gift from St. Aspinquid Lodge, through Mary's son, Steven.

Here is a family whose influence moves others to help our cause, and we sincerely thank you!

cca mugshots

a retreat weekend full of love and laughter

By Kathie and Hannah Steinagel

Instead of the usual write-up, the folks at CCA would like to give you a family's perspective of the retreat. Here's a letter from Kathie and Hannah Steinagel. They attended their first retreat this year in Myrtle Beach.

My name is **Kathie Steinagel**, and I'm new to the CCA family. My daughter, **Hannah**, is eight years old, and she was born with hemifacial microsomia and microtia.

I have always felt that Hannah was perfect. For the most part, she has had positive experiences sharing her story with other people and helping those around her understand what a gift it is to have such a special ear. That all changed this year, when she began the multi-surgery process of getting a new ear.

Her first surgery was more difficult than we expected, and her hospital stay was much longer than we planned. Hannah became more and more frustrated with her life, her ear and her challenges.

When she was finally free to go home, she struggled with what the "new ear" would look like, as she was so in love with her baby ear. The bandages accidentally came off while she was playing at a friends' house, and when the other girls her age saw her ear, they reacted negatively. Hannah was devastated. Luckily I was there, and she came to me and cried and we talked it out.

From that day forward, she kept begging me to help her find a friend like her, who understood how hard it is to be a little different from other people, someone who knew how challenging surgeries and hospital stays are, someone who would just love her for her. As a family, we all love and adore Hannah, and it was so hard to hear her say that we weren't enough. But that request led us to CCA.

After some Internet research, I found CCA. I called the 800 number, and within a day Annie Reeves called me back. Annie informed us of the annual retreat that was just a few months away and invited us to come.

My husband and I were so unsure of whether or not we could afford the trip, and we went back and forth trying to decide if the benefit of the retreat would offset the cost. Finally, we decided that Hannah really needed this group, and we had to find a way to get her to Myrtle Beach. So, on a wing and a prayer, Hannah and I flew to South Carolina.

There really aren't words to describe what we felt while we were with the CCA kids and families at the retreat. I could try and describe the immediate sense of belonging, the shared sense of love and concern for our children, the highs and lows we all face through intense medical care, but I can't seem to find the right words. I guess we just felt like we were home. It was wonderful.

A special note from Hannah

"It was a neat experience meeting my new friends … and inside each one of them is so special … and when I met my new friends I felt happy and it was so special to me. I think we can all use our gifts to make the world a better place."

Hannah was able to sing at the talent show, and it was so great for her. She has an incredible love of music, and it was so fun for her to share that with her new friends. The night after the talent show, as I was putting her to bed, she said "Now all of my dreams have come true. I met new friends just like me and I got to sing on stage!"

continued next page ⇨

The rest of the retreat, so many of her new friends and their families complimented her on her song. I can't begin to tell you how that built her self confidence! Thank you for knowing what she needed!

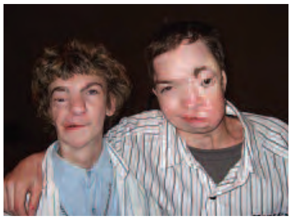
My first retreat was incredible, so much so that I told my husband I hope we never miss another one. As we were leaving Saturday night and Hannah said her last goodbyes, I kept thinking of how much I would miss all of the new, beautiful faces I met. I can't believe how much they mean to me, and now I get why this really is a family.

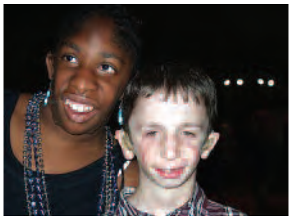
I was grateful for the moms that I met. I have always felt very blessed to have Hannah, and I think the best part of the retreat for me was finally meeting parents that feel just like I do. I feel that everything about Hannah is a gift. I feel so lucky to be the recipient of this little girl. Paula Guzzo reinforced that with me, and I felt a million little light bulbs go off in my mind as she told me how she feels about her son, Scott.

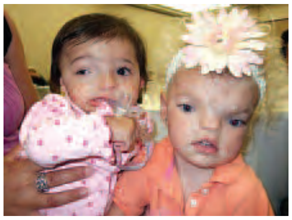
So, obviously, I can't say enough about the retreat. I was a skeptic at first, and now I am a firm believer — *these children need this retreat!* It was perfectly perfect! I am so grateful to the individuals and organizations that donate time and money to make this happen for these kids!

I wish you could have seen them all together, living, loving, laughing — not at all worried about acceptance or appearance. I wish you could read my heart and know how much it means to me that we have a place to go every year, where Hannah can let her hair down and just enjoy being her without having to worry about feeling out of place or different.

The staff is incredible for doing what they do. I hope they could feel the love and the appreciation from me and so many others while we were together! This retreat and this organization is a safe haven for Hannah and for us, and we simply can't wait for next year!







see **more retreat photos,** page 13

the jorge posada foundation heroes 4 hope gala

CCA is proud to have been invited to join the **Children's Hospital at Montefiore** and **National Foundation for Facial Reconstruction** in the Circle of Beneficiaries for the **Heroes 4 Hope** gala Monday, June 16, in New York City. The event was hosted by **Jorge and Laura Posada** and their children **Jorge, Jr.**, and **Paulina**.

Kelly Ripa and her husband, **Mark Consuelos**, emceed throughout the night, and other notable attendees included many of Jorge's **New York Yankees** teammates, **Rudy Giuliani**, **Spike Lee**, and George Steinbrenner's son, Hal who was presented an award for his father.


Jeremy Dale with masters of ceremony, Mark Consuelos and Kelly Ripa


JR and friends congratulate the winning bidder for the Johnny Pag Motorcycle, autographed by the entire NY Yankee's team.

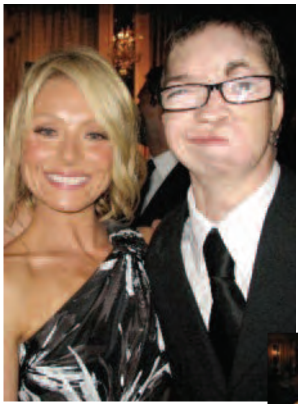
An online auction corresponding to the gala began a week before and ended a week afterward, but a few of the items were brought to auction during the evening. The highlight of the night was a motorcycle donated through CCA by **Johnny Pag Motorcycles** and signed by the entire Yankees team that was auctioned to a winning bidder for **$27,000**.

We're extremely grateful to all of our friends at the **Jorge Posada Foundation** for this incredible opportunity to raise funds while promoting awareness of craniosynostosis and other craniofacial conditions.


CCA loves JR Pagnini, who donated a motorcycle for auction.


Gala diners from the Redwoods Group table for CCA


Laura and Jorge Posada pose all night long with gala attendees, including Rob Gorecki.


Rob Gorecki meets Kelly Ripa.


Kris, George and Jeremy Dale with CCA staff


Jorge Posada, Jr., hangs with new buddy, Jeremy Dale.


Annie, Char, Greg and Jill

Paul Tessier

Pioneering plastic surgeon whose influential work heralded a global revolution in the field of craniofacial techniques

Paul Tessier, died on June 13 aged 90. He was a highly influential surgeon who originated the field of craniofacial surgery; this brought together a number of other specializations to allow the treatment of many previously inaccessible conditions, including severe birth anomalies affecting the development of the brain, the visual axis, the airway and dentofacial growth.

Tessier's techniques and surgical expertise brought him many admirers and disciples worldwide. His influence now pervades and unites the surgical specialities of maxillo-facial surgery, neurosurgery, ophthalmology and plastic surgery, which he brought together into the single speciality of craniofacial surgery.

Many of our CCA kids have had consultations with this remarkable man, and his caring expertise made a vast difference in the lives of those we know and love.

program director, from page 1

27 of the 50 states, Canada, Mexico, New Zealand and Australia! There were several first-time retreat families. For many, this was their first time to meet another family with a child who has a craniofacial difference. To see a child finally meet someone else who "looks like them" is priceless. Many of the families belong to Internet support groups and were able to finally meet the families with whom they talk online.

Everything started Thursday evening with an ice cream social and an ice breaker. The families were separated into 24 groups, and each group had to design a surfboard. This was a great way for the families to instantly connect. A hotel employee judged the surfboards, and soon after, the winner was announced.

On Friday, we ate breakfast outside in the South Carolina sun. Afterward, we went to Ripley's Aquarium and saw everything from sharks and swordfish to turtles and sand crabs. We all wore our CCA Retreat T-shirts, which was such a neat experience — CCA T-shirts everywhere you looked!

Friday night, we held a talent show, teen night and our chance raffle. Let me just say, our CCA families are talented! We had kids get up on stage and sing, dance and jump rope. We even had a few adults sing for us! Meanwhile, the teens enjoyed some time away from their parents and danced the night away at the Teen Night Luau.

For the third consecutive year, we held a chance raffle. Families brought baskets from their hometowns, cities and states. Attendees bought raffle tickets and deposited them in the bags corresponding to their favorite baskets and then anxiously awaited the drawing.

After breakfast Saturday morning, everyone headed to the beach for some fun in the sun — a day full of swimming, laughing and building sandcastles! After washing off all of the sand (some had more than others), everyone got dressed up for our most popular event — the dinner dance. While adults were filling their plates with food, the kids were already out on the dance floor. Families danced the night away!

During the dinner dance, first-time attendee **Rebecca (Carlisle) White** came up and gave me a big hug. She told me how she had literally been crying since they arrived and how much the retreat meant to her entire family. She said words could not explain how she was feeling. **Ryan Broomé**, a second-time retreat attendee stated how seeing his daughter interact and dance with other kids brought tears to his eyes. More tears followed Sunday morning as everyone had to say goodbye.

We are truly one big, happy family. If you have never attended a retreat, you should really consider it. You can read about our retreats in the newsletter, but until you experience one in person, it is hard to understand the benefits.

CCA will be turning 20 next year, and I hope you will help us celebrate our anniversary! Please join us for our 19th Annual Family Retreat in Grapevine, Texas. Registration is now open, and you don't want to miss this one!

Annie Reeves
Program Director

ryan and caroline,
from page 1

Caroline Dale was born on March 2, 2006, and we were initially told she had Crouzon syndrome. The nurses were huddling over her right after she was delivered, so all I could see was her beautiful pink cheeks. It wasn't long before I knew something was wrong and Caroline was whisked away to the NICU. In the NICU, I noticed that her head was misshapen and that her eyes looked "puffy," but otherwise she seemed fine to me.


Caroline at one year old


Ryan (above) and Caroline (left) at eight and seven months old.

Fortunately, we live in the Dallas, TX, area, which is home to a major craniofacial center, where Caroline was moved the day after she was born. Although we were still very scared, it was a very different experience when we arrived at Medical City. Most of the doctors examining Caroline had seen many other craniofacial children and told us to treat her like the normal baby she is. It was at Medical City that we were told Caroline most likely had Pfeiffer syndrome, which is very similar to Crouzon. After eight days in the NICU, we took sweet Caroline home.

Caroline lives with dad Randy, mom Elizabeth and big brother Brandon in Highland Village.

How We Met

During one of our visits to the pediatrician, our doctor said, "I'll probably never see another situation like this in my entire career, but we have another baby coming to our office that is close in age to Caroline with Pfeiffer syndrome." I agreed to share my phone number with the other family and soon called the Holliday family to introduce myself.

On our first meeting at a nearby park we discussed our children and all the things we had in common. Our oldest children were one month apart in age and had been in the same preschool class together when they were two years old. We had the same family physician, went to the same church, lived two miles from each other and our Pfeiffer children were both being cared for by Dr. Jeffrey Fearon at Medical City Dallas.

When your child is born with a rare disorder you wonder what is normal for your child. Both children snorted a lot while drinking their bottles because of the tiny nasal canals typical of Pfeiffer. When we first met, it was reassuring to hear another child sound the same way. The similarities we saw helped us understand what may be more typical for Pfeiffer. Before we left the park, a woman walked by and noticed our two tiny babies and asked, "Are they twins?" We laughed and said "no," but it was only the first of many times we were asked that very same question.

Surviving the First Year

The first year was very challenging, and while we had many things to be joyful about, there were lots of tears along the way. At our first meeting in the park, we both had no idea how much lay ahead of us and how our relationships would become a source of strength and support. Ryan and Caroline had their first cranial vaults with Dr. Fearon just two days apart when they were four and five months old. During those first six months of their lives, we supported each other by talking about the emotions involved in going out in public and adjusting to the stares and hurtful comments.

That support helped us navigate tougher times: surviving what seemed to be endless doctor visits, hearing issues, feeding issues, cranial vaults, hydrocephalus, chiari malformations and tracheostomies. Both Caroline and Ryan were diagnosed with some hearing loss and both have had BAHA Divino bone conducting hearing devices since they were seven months old.

By age two, Ryan had an anterior cranial vault, shunt, a g-tube and nissen fundoplication, tracheostomy and a combination posterior cranial vault and chiari decompression. Caroline had an anterior cranial vault, g-tube and

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Ryan with his sister, Kathryn

correction of intestinal malrotation, tracheostomy and two third Ventriculostomies. She also had her second anterior cranial vault, tear-duct stints and eye-muscle surgery and g-tube closure. Caroline has had eight laser surgeries on a large port-wine stain that covers her right thigh and lower back, though this is unrelated to her Pfeiffer syndrome.

Compared with children their own age, Ryan and Caroline were labeled as "developmentally delayed." They both sat up, started scooting (not crawling) and eventually walking around the same time.

It's so important for any family going through this experience to have some type of support group. Not only will it help emotionally in understanding what to expect those first few years, but the information learned can make a difference in managing your child's care. The more information you are armed with, the better able you are to discuss concerns with your doctor regarding their treatment.

Eventually our circle widened and we came to know other families with craniofacial children. We met many families seeking treatment in Dallas while at Medical City, as well as those at other centers across the U.S. in an online support group. We had asked many of our online friends when their children first walked, since our children were nowhere close to walking in the typical 11-to-15-month age range. The range was pretty much from 18 to 24 months, so it was reassuring to know that a child undergoing many of these surgeries may typically be expected to walk somewhere in that range.

Two and Beyond

Now we have the joy of seeing two children developing and growing and being pretty much like other "normal" two year olds, tantrums and all. Since they are walking and out on their own, Ryan and Caroline are noticed even more than before by other children. We try to help others understand why our kids look as they do or why they have "that thing" in their neck (trach). We hope that this awareness will help them to not be afraid or just stare at a Pfeiffer child, which is a common reaction when we're out.

Oftentimes, when children learn about the disorder and some of the surgeries our kids have to go through, they begin to react more positively towards Ryan and Caroline. We educate as many people as possible in our community about our children, particularly within the schools because our older children are also affected by Pfeiffer syndrome. The older siblings have to deal with the staring and hurtful comments other children make about their sibling whom they love unconditionally. They also worry about their brother or sister when they have surgeries.

It's hard to imagine how strong our children have been, but it amazes me to see how far they have come. Now, when Ryan sees Caroline he gives her a hug and signs friend and Caroline happily proclaims "Rye's home." There were times we wondered when, if ever, they would walk or talk, and we have been fortunate to see those things happen. It's reassuring to know that even if our kids don't do everything at the same time, they will get there eventually. Though they don't realize the significance yet, it's amazing that Ryan and Caroline are able to grow up together. As they get older, we hope that their unique friendship will enable them to support one another. We look forward to many more happy times ahead, and, as we write this article, we're looking forward to a trip together to Myrtle Beach and meeting other families at our first CCA Retreat!

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.

Insurance Coding

Hello to all CCA families from Janis and Doug Macut. Here's what we spoke about at the dinner/dance Saturday night at CCA's retreat in Myrtle Beach.

We have all, at one time or another, had problems with adequate insurance coverage because of coding confusions. (Is a procedure reconstructive or cosmetic?) I truly got tired of all the hassles, the time involved and jumping through hoops with insurance companies, so we decided to do something about it.

In August 2007, we met with the Vice Presidents from the **Pennsylvania Medical Society** and **Capital Blue Cross Insurance Company** to discuss coverage problems, coding confusions and the use of modifiers. The Pennsylvania Medical Society was very interested in our ideas and contacted the **American Medical Association**. They, too, were very receptive to the ideas for change and realized such changes were necessary.

Before we left to come to the retreat, I received a letter from my contact at the Pennsylvania Medical Society.

> "As we all know, there has been an ongoing issue with medical services being considered cosmetic in nature versus medically necessary reconstructive procedures. Because of this, we have seen a delay or denial of services. This problem, unfortunately, is escalated due to the fact that surgeries are sometimes done years apart by multiple physicians.
>
> The Pennsylvania Medical Society and the American Medical Association have joined together in a grass-roots effort to address this issue. They will work with insurance carriers across the country to recognize that procedures associated with specific diagnostic codes for craniofacial conditions should automatically be deemed medically necessary and not cosmetic in nature. This will help eliminate the excess time, money, and resources spent by all parties involved in denying services, appealing claims, and sending and reviewing records, all of which will allow for more prompt and efficient quality care for all."

What this means is, once the AMA clarifies all the codings with the proper modifiers — this is in the works now — all doctors, hospitals and insurance companies in all states will be required to comply. We are hopeful this will be in place by 2010.

This will save both time and hassles for families and extensive cost to insurance companies. A huge added benefit would be that craniofacial conditions are recognized as lifelong journeys and need to be treated as such.

We feel very passionate about this issue and will stay very close to the process to assure everything is put into place. Should any families have any questions or want to offer any input, please feel free to contact us at JDMacut@comcast.net. We'll also keep you posted through the CCA website.

children's craniofacial association

NEW! cca's Kids Klubs

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

Contact Annie Reeves for a Kids Klub application today!

cca webinars

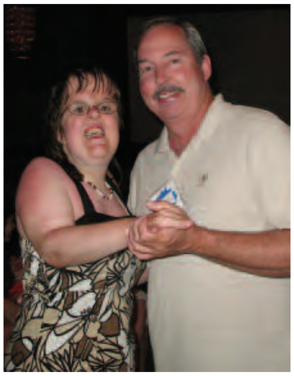
NEW in 2008

SEPTEMBER
Arletha Miller
Social Worker

NOVEMBER
Dr. Rick Redett
Pediatric Plastic Surgeon

DATES AND TIMES TO BE ANNOUNCED.

more retreat photos, from page 7



calendar of events

date	event	contact
September 13	**2nd Annual Seth's Stride for CCA** Canton, OH	mythreekids@neo.rr.com Stacy Swihart www.firstgiving.com/sethsstride
September 20	**Alexa's Appeal for Craniofacial Awareness, Dinner/Auction** Center Plaza Modesto, CA	www.firstgiving.com/ccaawarenessdinner
September 22	**Jylian's Links of Love for CCA, Celebrity Golf Event** White Stone Golf Course Benbrook , TX	JGorecki@ccakids.com JyliansLinksofLove.com 800.535.3643
October 4	**4th Annual Friends of Jeremy Golf Tournament** Country Club of Corning Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com
October 5	**Chocolate Festival** Aventura Mall Aventura, FL	ChefRick2@aol.com
October 11-18	**Disney Cruise 2008**	www.apert.org
Jun 24, 2009	**Craniofacial Symposium** Great Wolf Lodge Grapevine, TX	AReeves@ccakids.com www.ccakids.org 800.535.3643
Jun 25-28, 2009	**19th Annual Family Retreat** Great Wolf Lodge Grapevine, TX	AReeves@ccakids.com www.ccakids.org 800.535.3643

ccaprograms

and services in the spotlight

Families of craniofacial patients often call CCA to seek emotional support, discuss problems and identify resources. Through our database, we are able to network families with support groups and/or others who have similar conditions and experiences. We also keep a list of helpful resources and are always willing to listen and offer emotional support to family members who need a shoulder upon which to lean. For further assistance or information call Annie Reeves at 800-535-3643 or email AReeves@ccakids.com

programs we offer

- Toll-free hotline
- List of qualified physicians
- Information and support
- Educational booklets
- Financial assistance
- *CCA Network,* a quarterly newsletter
- www.ccakids.org website
- Annual Cher's Family Retreats
- Public awareness
- Family networking
- Advocacy

how to raise funds for cca

CCCA depends on funds donated by individuals, proceeds from family and friends' fundraising efforts, corporate giving and foundation grants. The need is great as we grow to provide programs and services to many more affected individuals and their families. Any help our readers contribute is most appreciated. Here are some ways to help.

- **www.goodsearch.com (Powered by Yahoo)**
  Enter Children's Craniofacial Association as your beneficiary charity. (You only have to do this the first time. You may add others if you wish.) CCA will receive up to a penny each time someone uses the GoodSearch search engine.
  In addition to "searching" for CCA, you can **"goodshop"** online by clicking thru to **GoodShop.com**, a new online shopping mall which features hundreds of great stores including Best Buy, Macy's, Apple, and Orbitz. It's easy, just go to GoodShop, click on the store's logo and then shop as your normally would! You get the same prices, but a percentage comes to us!
- **Cash for Trash!**
  Save your discarded cell phones and empty laser / ink cartridges and CCA can turn them in for rebate funds. Call us at 214-570-9099 or 800-535-3643 for more information.
- **Matching Gifts**
  Many companies offer a matching gift program that could double or even triple your gift to CCA! Contact your human resources office to find out if your company has such a program.
- **Planned Giving**
  Tax preparation time is also a good time to consider long-term tax savings. When you consult an attorney or investment professional regarding your wishes for distribution of your assets in your will, consider a provision for CCA. Your planned gift in the form of an endowment will live on after you.
- **CCA Web Store**
  You can now shop at CCAKids.org for your T-shirts, mugs, caps and more. So shop now and shop often!
- **Clubs / Hobbies**
  Have your club organize a benefit for CCA. Use your hobby or something you love to do to raise funds.
- **Denim Days**
  Raise funds at work for CCA. Establish a special day or days for employees to make a designated donation (cash or check) to CCA in return for wearing blue jeans. The donation is usually $1 to $5, depending on how often the event takes place (for

example $1 for a weekly donation, $5 for a monthly donation). Any higher amount would be at the discretion of the donor.

- **Civic Organizations** Public awareness leads to contributions. Contact and solicit opportunities to speak to your local civic organizations such as Rotary Clubs, Kiwanis Clubs, even HOG organizations (CCA has many 'biker' supporters). Distribute brochures and/or newsletters or other CCA-sanctioned materials for awareness and information. Ask for contributions.
- **Friends / Family Letter Appeal** Draft letter to family, friends and acquaintances—anyone who has met or encountered your child. Contact CCA for a sample letter.
- **Kitchen Shut Down** Raise funds by raffling off chances to win meals for every day of the week, so the winner can "shut down" their kitchen. Local restaurants can donate meals or coupons. This idea could be used for a week of entertainment, such as movie rentals or theater tickets. Call CCA for more information.
- **Collection Cans** Ask local businesses to place a can or box (provided by CCA) to collect donations or take a can around to collect donations.
- **Get On Board!** Read our newsletter and learn about and participate in the events, raffles and funding efforts of CCA and our supporters. Pass the donor envelope to someone you know looking to support a charity. And when you are finished with your copy of our newsletter, spread the news! Pass it along or leave it in a waiting room. (Remember to remove your address label.)
- **MonaVie**
  Raise Funds for CCA with MonaVie, an amazing product packed with antioxidants. Four ounces per day has the antioxidant capacity of 13 servings of fruit and veggies!!
  Contact CCA mom, Rachel Johnson to find out how you can help CCA and yourself with this outstanding gift from the rainforest.
  www.mymonavie.com/TJandRachel
  phone: 209.664.0500 or 209.505.1673
- **Buy Gifts from BeautiControl** at www.BeautiPage.com/ccafriends and CCA gets the agent profit! Questions? Email Rose Seitz at rseitz@directed-tech.com. These gifts cause no clutter, because they get used up!
- **Book all of your travel needs** at www.ytbtravel.com/ccakids including flights, cruises, hotels, rental cars, even your passport. A percentage comes back in funds for CCA. And, you may rest easily, knowing the site is powered by reliable Travelocity.
- CCA supporter Dan Freeman is a **Lifelock** affiliate (the service that protects your identity from theft) and will generously donate $15.00 per sale to CCA when buyers enter the promo code: CCA. See www.lifelock.com to find out how the service works and to help raise funds!
- **Tupperware** now has a formal fundraising program and you may contact CCA mom, Kathy Hubbard, zibadoo@juno.com to learn more about how to raise funds for CCA.
- **www.itzybitzy.com** Itzy Bitzy sells infant and toddler squeaky shoes. Children love to wear these shoes that squeak when they walk, and they also serve as a great therapy tool in helping little ones learn to walk properly. These shoes also help parents keep track of their little ones. 10% of Sales go to CCA.
- **FirstGiving**
  We're pleased to provide a free customized CCA 'firstgiving' site for anyone who wants help raise funds for CCA.
  Log onto firstgiving.com/ccakids and tell your personal story or post an event you're having. You can even set a goal and track success! When you tell your own story about your CCA Kid or why you are involved with CCA, folks will respond because they know YOU!
- **Currentfun.com**
  -Go to currentfun.com
  -Click on "start shopping now"
  -Buy what you want
  -Click "proceed to checkout"
  -Choose Texas for the State
  -Then click on Children's Craniofacial Association
  -Then finish the order as you would any order
  Folks can also order catalogs through that site if they want to go door to door instead of the internet. CCA receives 50% of what folks order this way. The catalog changes seasonally, so it's not a one-shot fundraiser ...people can go in at any time (as long as they go into currentfun.com (not the regular Current sight).
  -Place and order and CCA will benefit from it.

New Ideas

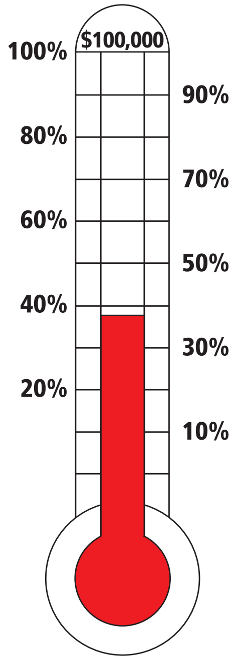
- **Pampered Chef** CCA mom, Amanda Keeton will assist anyone who wants to raise funds using Pampered Chef. There is a program in place to support charities like CCA with 10-15% of sales and/or Amanda will work individually with anyone wishing to host a cooking show. She will also donate 10% of her commission.Go to www.pamperedchef.biz/amandakeeton or email her at Jesusluvsu2005@gmail.com

Looking for ideas?

Contact Jill Gorecki at J.Gorecki@ccakids.com

fundraising news

2008 FAMILY FUNDRAISER GOAL THERMOMETER



CCA's family fundraising goal for 2008 is $100,000. By the end of the first quarter our families had raised $13,363.50. By the end of the second quarter you had raised a total of $37,631.66. Keep up the outstanding work! The goal is in sight and you are hot on its trail! Thanks so much for all you do!

big-hearted CCA kid, **Chase Ingram**, celebrating his eighth birthday, asked for donations to CCA instead of presents. He also contributed priceless hugs all around at the retreat. We love you too, Chase!

freddie Seitz of Poland, OH, enlisted his local **Starbucks** and a great group to put in more than 100 volunteer hours. Teaming up with the **United Way Youth Day of Caring** in Youngstown, OH, CCA will benefit from the successful initiative. Thank you!

nick Wiese of Baden, PA, held an **educational fundraising initiative** at his high school, enlisting his craniofacial plastic surgeon, **Dr. Joseph Losee**, and orthodontist, **Dr. Lisa Vecchione**, to inform students about craniofacial conditions. Nick entertained the crowd by showing a movie that evening, his way of thanking all the donors. Thank you, Nick, for spreading awareness that fosters acceptance and for contributing **more than $2,000** for CCA kids!

miss **Antasia Hart**, 6, of Baytown, TX, whose baby brother, **Wade White**, was born with Pfeiffer syndrome, reached out with friends in her community and held a rock sale for CCA. Thanks, Antasia. *You* rock!

continued next page ⇨

the **Gulich Family** of Big Flats, NY, started their **Ryan's Road** (named for son, **Ryan Jr.**, who was born Apert syndrome) fundraising effort, which included a candle sale that has raised **more than $800** so far for CCA. Thank you!

peter **Dankelson** and his elementary school, St. Patrick's in White Lake, MI, held a **Casual Day** for CCA and raised **$230**. Thanks, Pete!

high schooler **Taylor Bishop**, of Birmingham, AL, held a **Denim Day** raising **$825** for CCA. Thanks, Taylor!

good news

no matter what your political preference, there's no denying it's pretty cool meeting a candidate! **Scott Guzzo** and his family got up close and personal with **Senator Hillary Clinton** and even got a mention in her speech on the evening news. Just another amazing adventure for one of our CCA kids!

the **Dankelson family** was recently invited to Washington DC for **Family Advocacy Day**, which is sponsored by the **National Association of Children's Hospitals**. **Children's Hospital of Michigan** invited them to attend. They were one of 30 families representing children's hospitals from across the country. While there, they were able to meet with **Congressman McCotter** as well as three other legislative offices. **Peter** was a perfect politician…shaking hands and introducing himself. What an amazing experience!

save the date

September 22, 2008
Whitestone Golf Club
Benbrook, TX

CCA will hold the first annual **Jylian's Links of Love** benefit golf tournament On Monday, September 22, at Whitestone Golf Club in Benbrook, TX. The tournament will begin with a shotgun start at 1:00, and will end with a dinner and silent auction. Visit **www.jylianslinksoflove.com** for registration and sponsorship details. Come join us!

save the date

June 24-28, 2009
CCA's 19th Annual Family Retreat
Grapevine, TX

the 19th Annual Family Retreat will be in Grapevine, TX (10 minutes from DFW airport) June 25 – 28, 2009. **CCA will also hold a one-day craniofacial symposium June 24.** See you next year in Texas!

donors, january 1 – june 30, 2008*

Gifts from Individuals

CCA Supporters

($25 to $100)

Jeffrey & Amy Abernathy
Susan & Bill Addison
Deborah Allen
Carolyn Alloway
Anonymous
Catherine Arnold
Donnie Balentine
Trevor Bartley
Glenn Berard
Douglas Bolduc
Mildred Bonneau
Philip & Judith Bressler
Lynn K. Britt
Stephen Bronski
Ann Byrd
Alexandra Chambers
Marsha Chivers
Brian Scott Cook
Arlene Coudare
Murray Covens
James & Nancy Cutler
Grace & Gary Deily
J. & C. Delmonte
Sergio Dominguez
Scott Ensign
Patricia Ernst
Kimberly & Mark Fanguy
Richard Ferle
Francis Fisher
Gary Fitzsimmons
Thomas Flores
Theresa Fouts
Mary Kay & Thomas Gardin
Alison Gelbman
John Ghiconides
R.M. Gill
Sidney Goldman
Dr. William Green
Garrick & Jennifer Groves
Nicole & Ryan Gulich
Maurice Gutzler
Jennifer & Michael Hastings
John Hermanek & Mary Drill
John & Theresa Hospodka
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Scott Montgomery
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John Moulton
Mina Mulvey
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Julianna Nicholl
Ron & Jackie Nierman
Ralph Nuckols
Ann Patterson / Howard Langner
William John Luyben
Mary Ann Nowicki
H. R. & JoAnn Olien
Sandra Peckinpah
Anne Peterson
Ann Ranfranz
Annie Reeves
Mark Roberts
Jere Robertson
Amy & Barry Rochus
Kim & Frederick Romeo, Jr.
Gail & Walter Rook
Iris Schell
Michael Schlehuber
William & Jessica Schwerd
Jeffrey & Lana Servatius
Mary Ann Silvestro
Richard & Mary Skoumal
Cheryl Smith
Stephen Smith
Duane D. Stanley
Herbert Stenzel
Erin & Crispin Stephens
William & Nancy Suwalski
Laura Talmus
Stephen & Jennifer Taylor
Susan Thomas
Amy Thornton
Kay Van Cleave, PH.D.
John & April Wharton
Lawrence Whitler
J.B. & Cynthia Wills
Eva & Steven Wilms
Stephen Wright
Casey Wyse
Carol Yash-Debow
John Zaengle

CCA Friends

($100 +)

Carol Anthony
Mari-Jo & Paul Batchelor
Phyllis Breeden
Michael Budish
William "Doug" and Ann Burgin
Nancy Burson
Thomas Callahan
Larry Carpenter
Roger Chin, DDS, PS
Diana Critchlaw
Kristine & George Dale
Gerald & Ruth Dankelson
Anthony & Sandra Deakins
Jess & Alice Evans
Vincent Farina & Leigh M. Soda
Robert Feinstein
John & Carrie Follett
Dudley Godfrey
Margaret Grupp
Sarah Hall
Ebby Halliday Acres
Carol & Mike Hazelgrove
John "Jim" & Arleen Heirty
Pauline Hicks
Elizabeth W. Jones
Roger & Carolyn Lamb
Rear Admiral Lloyd & Junia Moffit
Sarah & Dean Moor
Elizabeth Moulton
Robert & Ottie Paslay
Chris Riener
Randolph Schaefer
Roberta & Robert Schini, Jr.
Jessica & Frederick Schwerd
Eileen Serafine
Pat & Robin Shannon
Michael Slusher
Margaret Smith
Brent & Shelle Summers
Elizabeth Sweeney
Bradley Thompson
Kevin & Jennifer Trepani
Lynn Yetra & Donovan Ambrose
Paula Wagner
Kenneth Wilson

CCA Extended Family

($500 +)

Martha & James Brown
Fred & Judi Freeman
Jill Gorecki
Robert & Julie Horn
Jonathan & Deborah Kantor
Donald & Ann Lucas
Robert Nordness
Paul Pokladnik
Shareall
Courtney Vincent

CCA Sponsor

($1,000 +)

Michael Carr
Jane L. Goodman
Greg Luetkemeyer
Bill & Christine (Condino) Mecklenburg
Charlene & John Smith

CCA Benefactor

($5,000 +)

Mark Hagen
John & Sheryl Paul

CCA Guardian

($10,000 +)

Marie Florence Desrosiers Trust Bequest

Memorials / In-Honor Gifts

Kevin Alicbusan, in honor of Aaron Nocum's 1st Birthday, by Caroline Mingoa
Trevor Bartley, in honor of Rocky, with love in our hearts
Renee & Wayne Baxmann, in honor of Robbie Gorecki
Angelic Bruns, in honor of Cher's Birthday
Doug & Ann Burgin, in honor of Rick Dornier
Larry Carpenter, in honor of Cher's Birthday
Alexandra Chambers, in memory of John Michael Chambers
Gerald & Ruth Dankelson, in memory of Gordon Nielsen
Gerald & Ruth Dankelson, in memory of Elaine Petsche
Grace & Gary Deily, in honor of Jeremy Dale
J. & C. Delmonte, in memory of Betty Smith
Thomas & Shelley Flores, in honor of Braxton Flores
Garrick & Jennifer Groves, in honor of Ella
Hearts and Hands O.C.C.L., in honor of Kathryn Hopkins
Jim & Arleen Heirty, in memory of Margaret Lux
Jim & Arleen Heirty, in memory of Lois Witkowski
Jim & Arleen Heirty, in memory of Dave Cody, Sr.
Law Offices of Steve Howen, in honor of Brian Scott Cook
Sarah Erb & Andrew Keller, in honor of Olivia Sanborn
Donald & Ann Lucas, in honor of Brody
Donald & Ann Lucas, in honor of Brody Lucas on our 43rd Anniversary
Ellen McPadden, in honor of Jeremy Dale, from Aunt Ellen
Bill & Christine Mecklenburg, in honor of Morgan
Jim & Maryjo Montalbano, in honor of their daughter, Jennifer's 33rd birthday
Jessie & Theodore Morgan, in honor of Morgan Baldwin from Nana
Ralph Nuckols, in honor of Jeremy Dale
Andrea Richard, D.O., in memory of Ram Nath Pathlak
Jere Robertson, in honor of Jane Monell
Gail & Walter Rook, in honor of Scott Guzzo
Jessica & Frederick Schwerd, in honor of Megan Cronin
William Schwerd, in honor of Megan Cronin
William & Nancy Suwalski, in memory of Marvin Mandel
John & April Wharton, in honor of Amber & Brooke McAnnely
J.B. & Cynthia Wills, in honor of Reed Wills

Corporate / Foundation Gifts

CCA Corporate / Foundation Friends

(up to $1,000)

America's Charities (Employee Giving Funds Management)
American Express Foundation (Matched Gifts of Janell Nelson)
AT&T United Way Employee Contributions
Bank of America (United Way Campaign Employee Giving)
Century Lodge No 492, Order of Odd Fellows
Charitable Auto ResourceS (CARS) vehicle sales incentive program
Cher Convention
Cleveland Bakers Local No.19
CFC Baltimore
CFC Central Florida Area

CFC Central Texas
CFC Chicago Area
CFC Coachella Valley Twentynine Palms Area
CFC Eastern Massachusetts
CFC, Fresno County
CFC Global Impact, Overseas
CFC LA Area
CFC Maricopa County
CFC Middle Tennessee / Nashville
CFC New Orleans
CFC New York City
CFC Niagara Frontier
CFC Southeastern Connecticut
CFC Southwestern Idaho
CFC Yellowstone County
Department of Social Services, Sisseton, SD
Dream Kitchens, Inc. by Keven & Terri Schmidt
Financial Alternatives
Funding Factory
Gonser & Gonser by Cleo Gonser
Hearts and Hands O.C.C.L.
Italian Club of Dallas
Jim Wade Investments
John Ryden Construction
Justgive (donors listed separately)
Kroger (purchases percentage incentives)
Law Offices of Steve Howen
Nature's Enterprises dba Euronat by Michael Carr
Network for Good (donors listed separately)
Office Depot (Rebate)
PASCO
Pfizer (United Way Campaign Employee Giving)
The Prudential Foundation (Employee/Matching Gifts)
The Prudential Foundation (Matched Gift of Diana Critchlaw)
Safeway, Inc. (purchases percentage incentives)
Sarah Hall Productions by Sarah Hall
Schoolpop (online purchases percentage program)
Triangle Foundation
United Way of Brevard
United Way of Cedar Valley
United Way of Fresno
United Way of Metro Dallas
United Way of Tucson and Southern Arizona
Verizon (Matched gift of Robin Chupurtinov)
A grant from the Gil & Dody Weaver Foundation
Wellpoint Foundation Funds Management
Wells Fargo (Employee Giving)

CCA Corporate / Foundation Sponsors

($1,000-$5,000)

Grant from Max & Victoria Dreyfus Foundation
The Redwoods Group (Matched Gift of Bill Mecklenburg)
Matching Grant funds from Sam's Club
Grant from Starbucks Corporation
Recommended grants from Triangle Community Foundation
Vivo Brothers, Inc.
Wal-Mart Corporation

CCA Corporate / Foundation Partners

($5,000 or more)

Association Works by John & Sheryl Paul
Grant from Jorge Posada Foundation
Grant from Stemmons Foundation

Fundraising Events

Up to $1,000

Alexa's Appeal for CCA, Denise Rast, CCA Volunteer
Cash Collection Cans placed for CCA / Kim Rogers, CCA Volunteer
"Current.com" Catalog Fundraiser / Mark & Laurel Sanborn, CCA Volunteers
Italian Club of Dallas Collection for CCA
Ryan's Road for CCA / Gulich Family, CCA Volunteers
Sarah Orne Jewett Collection for CCA/ Mary Zimmer, CCA Volunteer
Smiley Face Campaign Collections / Peggy McDannel, CCA Volunteer

$1,000-$5,000

Cash Collection for CCA / Margaret Jenna, Dalton Family, CCA Volunteers
Retreat "Chance Raffle" held at CCA's Annual Family Retreat in Myrtle Beach, SC
Starbucks February Community Clean-Up / Emily Tipton, Organizer w/Jana Peace, CCA Volunteer
Wendelyn's 'Course of Dreams' Golf Challenge / Wendelyn Osborne, CCA Volunteer

$5,000 or more

Cher Convention

$10,000 or more

$25,000 or more

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

*Listed are **Monetary Donations of $25 or more** through 2nd quarter, 2008. We are extremely grateful for these and all other donations, fees, purchases, fundraisers and in-kind donations not recorded here.

We do our best to accurately recognize donors. If you notice an error, please let us know.
CFC (Combined Federal Campaign, federal-employee giving)

new booklets

CCA is happy to announce our latest booklets! We now have "A Guide to Understanding Pierre Robin Sequence" and "A Guide to Understanding Cleft Lip and Palate."

Spanish Booklets:

CCA is now offering our booklets in Spanish! These booklets can be found on our website (www.ccakids.org).

3cheers

for volunteers!

Dr. Carlos Barcelo

Adrianna Napolis

Monina Gilchrist

CCA has a circle of volunteers who help improve the delivery of our services to our Spanish-speaking families.

Adrianna Napolis is one of these volunteers. She communicates with families in Spanish, so their needs are made clear to CCA's staff. She's always available and willing to give her time.

In addition, CCA has a team of volunteers who translate our syndrome booklets for our Spanish-speaking families and healthcare providers. CCA board member **Erica Crabtree-Mossholder** heads this project and has recruited **Meliza Ramirez** to translate the booklets. Meliza, who lives in Tuscaloosa, AL, has a PhD in Spanish. Then **Dr. Carlos Barcelo**, a craniofacial reconstructive surgeon from Dallas, TX, reviews the translations for medical accuracy. After that, **Monina Gilchrist** of **Monina's Enterprises** in Carrollton, TX, checks them for consistency. So far, 10 of CCA's 11 booklets have been translated and are in various stages of publication.

It continues to amaze and please the CCA staff and board that so many people donate their expertise to help others. CCA could never provide the vast number of services without these incredibly generous people!

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

VOICE 214-570-9099
FAX 214-570-8811
TOLL-FREE 800-535-3643
URL CCAkids.com *or* CCAkids.org

If you no longer wish to receive this newsletter, please email your wishes to AReeves@CCAKids.com or mail the label to the CCA office and ask that 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.