

ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

fall 2007

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katie, what a memory

By Cami Whicker

Katilyn was adopted into our family almost twelve years ago. She was born with a genetic syndrome, Treacher Collins. She has no outer ears or cheek bones, an extra small jaw, and cannot breath through her nose. She had a tracheostomy shortly after birth to allow her to breath. She cannot swallow or chew very well, so she has a gastrointestinal button and is fed with a pump directly into her stomach. Despite all these challenges, she has an incredible personality full of curiosity and is smarter than average. She is very much loved by her adopted family. Here's the story of her arrival into our family, as told by her 15-year-old sister (at the time).

The anticipation was like a mosquito bite that would not stop itching. Scratch, scratch, it became worse and worse the more I played with it. When would they arrive? Would I wake up in time? What if I don't like her? It was 12:07AM, and my nerves were so tense I could not fall

see **katie**, page 10



message from the development director

When my 21-year-old son, **Robbie**, was born with Goldenhar's syndrome in 1986, there was no CCA. He had a large facial cleft caused by the syndrome and only his right eye and right ear.

There were no prior indications. His older brother was fine. We were told that in our case, this was not genetic but just as random as winning the lottery.

All I wanted was to see if there was someone else like him and if so, to know

see **development director**, page 9

in memory of sonny smith

This edition of CCANetwork is dedicated to the memory of long-time CCA volunteer and friend, **Harry "Sonny" Smith**. Sonny was instrumental in the success of the Cher Convention, always working quietly in the background, never seeking attention. We will miss Sonny and always cherish our memories of him.

empowering and giving hope to facially disfigured individuals and their families



meet ashley moulder

my name is **Ashley Danielle Moulder.**

I am 19 years old and live in Mesquite, Texas, with my grandparents Joan and Terry Moulder. I graduated from North Mesquite High School last May.

I will train on the job at a photography studio to learn how to become a photographer. It's my passion to take pictures, and I want to make it a career. I am really excited about starting sometime this summer.

I have Nager Syndrome. When I was born, they had to rotate my index fingers into thumbs on each hand, which means I only have four fingers. I have short arms too. I used to have a feeding tube and a tracheotomy, but I got those taken out. I'm hard of hearing and have to wear a hearing-aid, and I also have a speech impediment.

ccateen

I don't care what people say about me. I am who God wants me to be. If they don't like it, then so be it.

I've had over 25 surgeries, mostly done by Dr. Fearon at Medical City Children's Hospital. Most of them were on my upper body (face, hands, stomach).

I would call myself a miracle baby, only because after everything that I have been through in my life, I've stayed strong for myself and also for my friends and family. They are my support team, and I love every one of them!

In 1997, I met Cher when she was at Planet Hollywood in Dallas, and I appeared in the newspaper with her. Her movie, Mask,

inspired me greatly because it really showed her love and kindness for the kids in CCA.

In my spare time, I love to hang out with my friends and family, drive around, talk on the phone, get on the computer, sing, listen to music, take pictures and just enjoy myself. I have never been to any of the CCA retreats, but I'd love to go to one someday.

And here's my advice to CCA kids: Just be a kid and don't worry about what others do or say about you. You all are beautiful inside and out. Live to the fullest. And mistakes are OK, because they give you chances to learn!



meet emerald rain demor

Emerald Rain Demor is a 12-year-old seventh grader with dreams of becoming a college professor or having a math-related career. Since she has tested in the top 5 percent in the nation for science, math and reading, those dreams most likely will come true.

And when it comes to school, it comes as no surprise that math and science are two of her favorite subjects. She also studies French, where her name in class is Élisabeth.

Outside of her academic studies, Emerald enjoys painting, especially with watercolors. She has been taking swimming lessons for the past five years and just started karate lessons this fall.

Emerald also likes animé books, spending time with her dog Isis (a 175-pound Irish Wolfhound) and playing the Logical Journey of the Zoobinis, a computer game. She has been playing this game for the past six years and is now playing at the most advanced level.

In her spare time, Emerald also helps her mother at work. Her mom owns a pizza restaurant close by where they live, and Emerald helps decorate, keep supplies stocked and takes people's orders. She loves working there and has had a chance to meet a lot of people.

She has met a lot of great friends through CCA. She's been to about five retreats so far. She remembers her first retreat in Washington, DC, with great fondness. It was a turning point in her life. "I had never seen anyone that had Crouzon syndrome before, people who looked like me. I felt like I fit in." She can't wait to go to the next retreat, where she can catch up with her friends and make new ones.



Emerald has had seven corrective surgeries so far. She will undergo one more next May or June. Overall, her prognosis is great.

For the most part, people and things really don't bother her. She says she feels this way because her family provides such strong support. Her mom, dad, and older brother and sisters are there for her no matter what. "They're not going to let anything happen to me."

Emerald also has some great advice for other CCA

kids: "If you feel like you don't fit in, just pretend that you already do." She says this has really worked for her in certain situations. Sending a message to others that you already fit in, that you already belong, changes the way others see you in a situation. "Somehow it happens. You end up fitting in."

ccakid



meet amelia sanborn

hearing, or when we had a visiting nurse and other specialists come to our house, I was always involved playing a game with them or helping them by being ready with a band-aid after a shot. I learned how to measure a head circumference before I was three.

Not long after my sister was born, my Dad gave her a blessing. In the blessing he said that our family would meet many new people and visit and learn more about the country in which we live through our experiences with Olivia's healthcare.

That's happened for sure. I've already traveled to Dallas, Texas, more than six times. I've also met lots of really neat people through my sister. For the past three years, our family has been able to go to the CCA Family Retreats. We went to Nashville, Hershey and Salt Lake City. We've also had many chances to meet other families in Dallas while my sister was there for surgery or checkups.

Some of my good friends are kids who have a brother or a sister with craniofacial syndromes or the kids with the syndromes themselves.

In November, Olivia will be having a surgery in Dallas, and this will be the first time that I haven't gone since I was two. I'll miss her and my family, but I'm going to be brave, and I know I can call or email them anytime.

Having a sister with Pfeiffer Syndrome and some special needs, I've learned a lot about caring for other people. When I was in my first year of preschool, I became very protective of my sister. One of the boys in my class wouldn't let Olivia sit next to him in circle when she and my mom visited the classroom. One day he said to me "your sister is weird looking." I told him that just because you look different doesn't mean that you are weird, it just

continued next page ⇨

hi, I'm **Amelia**. Sometimes people call me Mia or Meemer or Amy. One of my favorite things to be called is Olivia's big sister. Yes, I'm the big sister to **Olivia Sanborn**.

I'm six years old and live in Richmond, Vermont. I'm in first grade and I enjoy doing many things. I like singing, riding my bike, playing Barbies, drawing, doing crafts, playing soccer and baseball, and ice skating. I'm taking piano lessons and starting my first year of Brownie Girl Scouts this year.

When Olivia was born, I was almost two. We've always been really good buddies. When we were

younger, we just liked to play a lot together. Now it's really fun being her big sister, because I get to do things like take her to her classroom at school each morning, ride bikes with her and fight with her in the back seat of the car. She always wants to be like me, because I'm her big sister. We're pretty much like any sisters would be, but we have a special bond because of all the medical stuff she's been through.

When we had home services like speech, physical therapy, or

ccasupersib

cca mugshots



Erick Gorecki takes coffee in his CCA Mug!



Two year-old, Zoe Freeman "mugs" for the camera!

ccasupersib, from page 4

means you are different. I'm glad I stood up to him, because now he's a good friend to my sister and he is always saying hi to her when he sees her at school.

When I grow up I'd like to be a doctor. Just a few weeks ago when we were at a picnic for NICU kids, we talked to the first doctor who took care of Olivia when she was born. I was telling him about kids

that I had met with various craniofacial syndromes and I was discussing skull bones and sutures with him. I guess he was impressed with my medical knowledge, because he asked how old I was now and how much longer before I would be out of medical school, because he wants me to come work for him in the NICU. I told him I'll give him a call.

donor In the spotlight



We're proud to acknowledge **Diana Critchlaw** of Hopatcong, NJ as this issue's 'Donor in the Spotlight.'

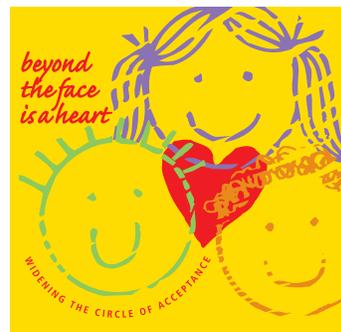
Diana has been an active mom involved with CCA since her daughter, **Amanda**, who was born with Crouzon's syndrome, was just 4. They've attended all but a couple of our 17 annual family retreats. Amanda is now 21.

Diana was our first regular donor to utilize the 'matching gifts' benefit offered by her employer and she's been continuously contributing ever since. Each year we receive a nice check from The Prudential Foundation, matching the monthly donations she made throughout the previous year. Thanks, Diana, for all you do!



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

Please consider a corporate sponsorship. Contact Jill Gorecki, JGorecki@CCAKids.com



craniofacial acceptance month

Beyond the Face is a Heart

The 3rd Annual Craniofacial Acceptance Month was a huge success. Many families participated in helping spread acceptance across the country. There were articles placed in local newspapers, radio stations played CCA's public service announcement, some television interviews were aired and many families participated in the September Sales fundraiser. CCA firmly believes awareness fosters acceptance, so we congratulate all of the families who joined the effort to bring awareness to their communities. Even as September observance has come to a close, CCA will continue efforts year 'round to bring acceptance of every individual with a craniofacial condition. Thank you all!

good news



CCA mom and donor, **Sharon Allbright**, has been named winner of the Chairman's Award at Tempe St. Luke's hospital where she is a nurse. Sharon was nominated by a co-worker who is familiar with her decades of allegiance to craniofacial organizations. The award includes a trip to the Gaylord Opryland Resort in Nashville and provides a \$1,000 donation to the charity of her choice. Sharon has graciously designated Children's Craniofacial Association to receive the contribution in memory of her son, Robbie, who was born with Pfeiffer's syndrome. We are extremely grateful and honored by this gift.



The Great Yogi Berra with Zac Muller

CCA teen, **Zac Muller** was the lucky guest of the New York

Yankees recently. Zac is popular with his high school vice principal, **Leo Smith**, who is a Mets fan and knew Zac to be a Yankees fan. Mr. Smith wrote the Yankees and made a deal with them that he'd relinquish his cherished Mets flags in return for special consideration of their fan, Zac. Zac got the royal treatment as he watched the game on "Zac Muller Day at Yankee Stadium" from the team dugout. Zac met many amazing people and players including **Yogi Berra, Joe Torre, Jorge Posada, Derek Jeter** and **Don Mattingly**...just to name a few! Mr. Smith now has a Yankee's flag hanging in his office!



Zac and Don Mattingly

CCA teen, **Ryan Matney** was crowned the IBO World Trophy Champion at Anderson, IN. This made Ryan's third consecutive win for this title. Ryan shoots for CCA and wears it proudly on the back of his shooter's shirt! Congratulations Ryan!



CCA kid, **Jonathan Grathoff** was recently selected to attend Victory Junction camp in Randleman, North Carolina. Jonathan has been interested in cars all of his life and enjoys watching NASCAR. He participated in many activities while at camp, including changing a tire just like the pit crew does on race day! He even dressed up like Tony Stewart during the talent show. Attending this camp was a dream come true for Jonathan!



Zac and Jorge Posada



a nurse's perspective

What parents should expect when their child goes to surgery

By Cindy Podner, RNFA at Medical City Children's Hospital, Dallas, TX

The thought of your child going through surgery has to be one of the hardest things a parent will ever have to go through. The extent of this fear became much clearer to me when my youngest nephew required a 30-minute outpatient surgery.

Being a nurse, I believed it to be a simple procedure. Not until I heard my sister crying to me over the phone as they wheeled her son back to the operating room, did I realize how upsetting even the smallest of procedures could be.

In my position, I work with children who have craniofacial syndromes requiring surgery. I see the patients in the office, and I frequently assist my surgeon in the operating room, which has enabled me to provide better support to the children and their families.

As many of our patients do not live locally, much of my contact with the families is via the phone or the Internet. I do my best to outline the day of surgery to the parents. I also try and provide names and numbers of other families who have undergone similar procedures.

Here at our hospital, the children go through pre-admission the day or two before surgery. The hospital's child life specialist and a pediatric nurse meet with the patients and their families to explain the process in age-appropriate terms. The final visit of the day typically is with the surgeon, who goes over the surgical plans and expectations. The anesthesiologist calls the family the night before surgery to review his/her role in the surgery.

The morning of surgery, the family arrives at the hospital, and checks into the pediatric ambulatory surgery center to get ready for surgery. Depending on the age of the child, the anesthesiologist may order the child to receive a small oral dose of a mild sedative (Versed), to produce sleepiness or drowsiness and to relieve anxiety, prior to transporting the child to the pediatric "holding" area.

The parents then meet with the surgeon, the anesthesiologist and their operating room (OR) nurse in the holding area. The parents are able to stay at the bedside with the child until they are ready to be

wheeled back to the operating room.

Once in the OR, the child is placed on a pre-warmed bed, and the anesthesiologist administers some "laughing" gas with a mask to put the child to sleep (older children/young adults are given the option of having an IV started to go to sleep). Once the child is asleep and cannot feel anything, the breathing tube is inserted and an IV is started.

The child is then positioned on the bed, covered with warm blankets and prepped for surgery. Depending on the complexity of the surgery, the time from when the child arrives in the OR to when surgery is actually started can vary from 30 minutes to an hour and a half. The OR nurse updates

the family frequently throughout the surgery.

At the end of the surgery, the breathing tube is removed, and the child is taken to recovery. The surgeon then comes to see the family to let them know how the child is doing and the outcome of the surgery.

Although anticipation of the surgery date is extremely difficult, I have found that being able to provide some information about the day of surgery to the family helps them to better expect what the day will hold.

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.

corrective makeup

By Linda Seidel

For more than 30 years, I have been helping people through the art of corrective makeup. In that time, I've worked with virtually every type of skin discoloration, disfigurement or birth defect, and it's taught me a very important lesson: It's all about perception.

When you think about it, visual cues are often what draw us to approach another human being to strike up a conversation or share a thought. If a person feels there is something about their appearance they don't like, it can often cause them to feel that as if the "flaw" is the only thing people see and they become shy, hesitant and withdrawn. Yet, when that same person is given a means to correct the condition, suddenly, they are free to be the person they want the world to see. It has been a life-changing experience for so many of my clients—one that I feel privileged to witness.

When I first tried my hand at corrective makeup years ago, there were no products that could deliver the kind of miracle I knew my clients were hoping for. Most makeup was orange or pink in color—nothing

to do with human skin tones at all!

One day, while sitting in a cafe with my cup of coffee, I realized that human skin tones most resembled a cup of coffee with varying degrees of cream added. It was a revelation, and it set me on the path to working with a chemist who would help me develop a product that not only matched skin tones perfectly, but would act like a "second skin" once it was applied.

The end result of four years of research and development was Natural Cover, my own foundation-concealer. Over the years, Natural Cover has provided a solution for thousands of men, women and children who have used it to camouflage everything from vitiligo and birthmarks to scars and the visible effects of illness or post-surgical healing.

Corrective makeup application can be very challenging, but never more so than when dealing with children. Since children would not normally wear makeup, it is more important than ever for the application to look and feel as much like their own skin as possible. And it has to be easy

enough for them to apply it themselves with success.

Simply having the option of concealing something they don't like seems to be the key to the "healing through concealing" process. Whether they apply the makeup daily or only for special occasions doesn't seem to matter; the fact that they now have control over the situation is key in the development of self-confidence and self-worth.

Learning to use corrective makeup simply provides an option for a child who may be struggling with his or her appearance and longing to simply "blend in" with the world. Ultimately, they might choose not to wear it, but having the choice seems to make a great deal of difference in the child's outlook. I am very proud that in Natural Cover I have provided a solution so perfectly suited for young clients that it can make a lasting impact on their lives even if they don't continue to use it forever. It is a testament to the power of healing psychologically as well as physically.

Corrective makeup is a perfect partner for the advancements in all types of rehabilitative and

reconstructive surgery. It is a desirable addition to patient care for those physicians who want to provide a more holistic approach to treatment.

Again, it all comes back to perception. Studies have shown, and there is plenty of anecdotal evidence to demonstrate, that patients who are pleased with their appearance actually feel better and have more energy to devote to getting back to their normal routines, while patients who look ill tend to feel less energetic and have a less positive outlook on their prognosis for recovery. For this reason alone, I hope that physicians will seriously consider the addition of corrective makeup to treatment plans for some of their patients.

Particularly for facial disfigurements, corrective makeup offers one more tool to complete the transformation that begins with surgery. Makeup can ease the transition between the period of healing and total recovery by camouflaging redness, swelling or uneven skin tone caused by grafts or scarring. Continued use of corrective makeup for some patients may be

desirable, but again, the choice will vary based on the comfort level of each person.

While the addition of makeup to a medical practice may seem a stretch to some, I can assure you that it is simply another method of treatment to be considered. Aestheticians are now firmly established in many surgical and dermatological practices, and to support that trend, I

offer training to professionals in corrective makeup techniques. And if a practice doesn't offer services, I often consult with patients by telephone to help them choose products and learn to use makeup techniques that are best suited to their particular needs.

I am very pleased to be working with the CCA to help raise funds and awareness. You can participate in our program

by using the consultation form posted on ccakids.org. Once you've downloaded the form, call to make an appointment for your personal consultation.

Please don't send in the form without speaking to me first! Together, we'll discuss your needs and choose the shades that are right for you, and I'll provide basic instruction in the use of the product. Also, a portion of every

sale made using this form will be donated to CCA.

Helping people through the art of corrective makeup has been my daily work, my life-long dream and my passion. I look forward to working with you and helping you realize your dreams.

For more information on Linda Seidel and Natural Cover, please visit lindaseidelpro.com or call 1-800-471-2601.

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there was something that could be done for them.

One day during those early weeks, from I don't know whom, I received a magazine article showing a grinning little boy sitting with his big brother. The boy had been born with a facial cleft and the photo portrayed a beautiful post-operative face.

This was all the hope I needed to brighten that new tunnel of life we were navigating. I still don't know who sent this anonymous gift, but I express thanks here, even if it is decades later.

It's so wonderful that CCA does exist now for parents who are searching like I was, wanting to know their child is not alone. In fact, with CCA's outreach through our volunteers, we have information disseminated

to birthing facilities across the nation. When a baby arrives with a craniofacial anomaly, parents are immediately comforted in knowing we are here for them.

In 1990, when Rob was three and a half years old, we were introduced to what is now CCA. With this support, we became those who others looked to for hope, and it's a great feeling to hear the relief in a voice on the other end of the phone or expressed in an email message.

Unlike other worthy causes that seem to touch everyone, a craniofacial condition is usually something most only learn about after meeting an individual dealing with it or when it befalls one's family. Also, for the most part, affected individuals are not facing death but must face

life, which is sometimes the more difficult trial when society places so much value on outer beauty.

After 18 years, the children first served by CCA are today, like my Rob, confident young adults making their way in the world. They still attend CCA's annual family retreat. It's like a family reunion for kids who've grown up with the charity. Now, the older kids are helping us bring up the little ones with the same self-confidence and a good self-image to face the rest of the world.

And, of course, I am still deeply involved and believing in the merit of this organization. This is the case over and over with families who find support and encouragement through CCA's programs and services. (Read in our next

issue about many families who helped with CCA's Craniofacial Acceptance Month, which is observed annually in September.)

These programs and services are the efforts being supported by all of you who are contributing funds to maintain this charity and further our mission. As you know, we envision a world where people are accepted for who they are, not how they look.

I strive to know who you, our donors, are and I wish to thank each and every one of you personally. To our CCA kids, you are like the anonymous sender of that magazine article I received so long ago. They may not know all of you, but you do know the comfort and support you bring into their lives.

Jill Gorecki
CCA's Development
Director

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asleep. Questions ran through my head ninety-five miles per minute, so fast I could hardly think about answering them. I looked at the clock again: 12:07 still! Would this night ever end?

It all began the previous year when my parents sat us down for a family meeting. "Girls," my dad started, "we are thinking about adopting a child." Whoa, that was a shocker! "You know how we sometimes feel like someone is missing? Well, we think this is the answer since your mother can no longer have children." Then he went on explaining the little details of the idea. "But since we already have a good amount of kids, we most likely will receive a special needs baby. This could be a handicapped child, a child of another race, or an older foster child." Immediately, I decided I could not handle a handicapped kid! What if it can never leave home, will I have to take care of it for the rest of my life? I don't want to have that kind of responsibility. No one will want to marry me if that is how it will end up! And what if it is a black little girl, how do you do black hair? Everyone will make fun of her because she is in a white family. Interrupting

my intense thoughts, my father concluded with deep emotion, "We feel this is the right thing to do, and we want your consent. We will meet again in a few weeks and discuss what you all think, okay?" My sisters and I, all in a bit of confusion and surprise, agreed to meet again.

For the next two weeks I only thought of myself. I wondered why I had to make this kind of decision. I felt so selfish, but I didn't want to have that kind of responsibility. Would anyone? I became very concerned with the idea of an abused or violent child. How would I handle that? I struggled with these selfish thoughts the entire week.

The meeting came. I still had not made a decision. My dad lovingly sat the family down and began. Mom twiddled her thumbs and slowly studied each one of her daughter's faces, my distraught one included. He finally got to the dreaded point of the meeting and asked each one of us how we felt. I was last; I had a few minutes to think. Everyone else seemed excited and very willing to go ahead with the idea. Why didn't I feel that way? It was my turn. I lied, "I'm fine with it." That was my extensive and elaborate response. I sat down. "Why do I feel so guilty," I thought. The meeting ended soon after

my brave and deep answer. I went to my bedroom. Maybe sleeping would make me forget all about this.

Months past and nothing had happened. No calls from Social Services, nothing. My family did not seem to even worry about it. Soon, a year had gone by. We had moved to Virginia and had been going to school for a good part of the first semester. Everything was going great. School was awesome, and it was getting close to my sixteenth birthday. I had not worried or much less thought about the adoption. Why would a fifteen year old girl as busy as I was worry about that? It was not a major issue anymore, or so I thought.

January twenty-second 1996 in the early evening the telephone rang. My parents came in my basement bedroom after an hour conversation on the phone to tell my twin sister and I that Social Services had a baby for us. Wow, I suddenly felt excited, a little baby! "She does have some handicaps, and they say she is completely adorable," my mother explained in a high voice. My whole attitude changed. I was thrilled with the idea of a brand new baby! Everyone was filled with excitement and anticipation. Then,



suddenly, everything stopped. We did not have her yet, Social Services wanted my parents to fly down to Atlanta, Georgia to see her first. Hmm, I wonder what she looks like? Why did her parents give her up? Maybe her mom was close to my age.

The next morning my parents flew out to Atlanta, Georgia to see the mysterious little girl. My four sisters and I were left home with curiosity galore. They promised to call and let us know what she was like as soon as they found out. Ring, ring...seven hours later the awaited phone call came. They began to explain. The first words out of my dad's mouth were, "We fell in love with her." My dad's specialty was girls, he had five of them already, so he should have known what he was talking about. They explained her personality, "She is bright eyed and completely lovable." Next came the introduction to her handicap:

"She has no outer ears, no cheek bones and cannot breath through her

nose. She has a tracheostomy and has to be fed through a tube down her throat. Most likely she is deaf and can not hear most of what anyone says. At the moment she is paralyzed because she underwent emergency surgery immediately after she was born to get her tracheostomy so she could breathe. The name of her condition is Treacher Collins Syndrome. It is a genetic disorder that is basically a deformity of the face. Mentally, she is very bright and absolutely fine."

Whoa, how exciting but terrifying. Soon after, they ended the conversation and said they could be coming home the following night.

A week later my sisters, Tara, Jami, Alison, Lyndsey, and I were so excited we could barely handle it. My parents would come home with Katie, our new little sister that night. Unfortunately they could not find an early flight so would not be arriving until two or three AM. If I would just go to sleep the night would go by faster and I could see her...Katie. 12:08AM, the clock seemed to be broken. "Go to sleep! You have school tomorrow," I kept telling myself. Finally, after a moment of relaxation I fell asleep.

Beep, beep, beep, beep-5:00AM. I rolled over in my warm bed pretending I did not hear the annoying awaking machine in hopes that my twin would turn it off. Wait...it is morning and my parents should be home! I threw my quilt and sheets off and ran up the stairs as my twin followed. First, we checked my parent's bed. Yes, they were home. Then we ran down the hall to the new baby's room. I turned the corner. The room smelled of a recently sanitized hospital. There in the brand new crib we set up just a few days earlier laid a little lump underneath a blue and pink blanket. Sound asleep, this little angel without ears laid on her stomach with her legs tucked under herself slightly projecting her tiny bum into the air. Her fuzzy wavy dark brown hair covered her entire head except for a little round bald spot on the back of her head (most likely from being in a hospital bed so long). I touched her. How could I have ever doubted this? She was perfect. I felt her love; she took mine. What an experience. In just a few minutes I learned a life long lesson that most people never have a chance to learn. Life with added love and an open heart is three times the happiness.

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

calendar of events

date	event	contact
December 8	CCA Dallas Holiday Party Wyndham Garden Hotel Dallas, TX	AReeves@CCAkids.com 800.535.3643
December 15	Midwest Holiday Party Brat Stop/Parkway Chateau Wisconsin Room Kenosha, WI	JGorecki@ccakids.com 800.535.3643
March 2	Cleft Palate Foundation Scholarships College scholarships offered for students with craniofacial anomalies. Deadline for submission is March 2, 2008.	info@cleftline.org 800.242.5338
June 26-29	18th Annual Cher's Family Retreat Myrtle Beach, SC	AReeves@CCAkids.com 214.570.9099 800.535.3643
August 23	Third Annual Wendelyn's "Course of Dreams" Golf Challenge Country Club of Arkansas Mauvelle, AR	wendelynnvonne@hotmail.com
October 11-18	Disney Cruise 2008	www.apert.org

second annual wendelyn's course of dreams golf challenge



Wendelyn Osborne hosted her second fundraiser, raising more than \$7,500 for CCA! Her Course of Dreams Golf Challenge took place Saturday, August 25, 2007, at Country Club of Arkansas in Maumelle, AR, just 10 minutes from Little Rock.



This event was a lead-in to September's National Craniofacial Acceptance Month. Twelve teams (48 golfers) participated in this year's scramble and enjoyed a nice lunch catered by Trio's. The drinks were donated by **Arkansas Coca-Cola Bottling Company**, novelties by **Blue Bell Creameries** and Apples by **Ben E. Keith**

Food Distributors. There was a successful silent auction after the tournament while the golfers enjoyed their lunch.

This event also helped to heighten awareness of craniofacial anomalies. Eighteen photos surrounded the scoreboard, doubling as a teaching tool. Each photo represented a hole while highlighting a particular craniofacial condition. In addition, each hole was marked with a craniofacial fact on a hole sign!

Wendelyn knows first-hand about facial disfigurements. At 10 months, she was diagnosed with craniometaphyseal dysplasia (CMD), a disease with a life expectancy of 14 years.

Yet, she's beating the odds at 41 and believes it's important for everyone to understand that CCA is there for those affected individuals and their families.

"As we grow up, our looks may be improved with various reconstructive procedures, but all the challenges one faces do not go away," said Wendelyn.



Wendelyn extends her gratitude to her volunteers: **Roberta Long, Frank Olinde, Jana McKnight, Jill Gorecki and Greg Patterson**; generous individual and corporate supporters, including **Lindy Blackstone** and her associates at **103.7, Laura Eddins at Radio Disney, the BUZZ sports radio** (who promoted the event) and **Donna Terrell**, anchor for **Fox16 news**, who covered her story and also promoted this event; **Andy Southern** from **Arkansas**

Coca-Cola Bottling Co.; **Doug Hutchins** from **Blue Bell Creameries**; and **Tom Pangburn** from **Ben E. Keith Food Distributors.**

A special thanks goes to **Tim Jenkins**, owner of **Country Club of Arkansas**, for offering his course; **Sam Custer**, owner of **Sir Speedy Printing** in Little Rock, for donating printing for this event; and **Golf Carts of Arkansas** for providing a Hole-in-One competition.

Even though the weather could not have been better,

the golfers still had a wonderful time riding in air-conditioned carts. They also plan to bring more of their friends with them for next year's tournament.

The 3rd Annual Wendelyn's Course of Dreams Golf Challenge is scheduled for **Saturday, August 23, 2008**, at Country Club of Arkansas. So, mark your calendars now and help Wendelyn heighten awareness throughout Arkansas—and the country!

seth's stride for cca



netted more than \$12,000 for CCA!

Here's what Stacy had to say about the events:

After sharing the idea of Seth's Stride with my family, I got a call from my brother Rick, who lives in South Florida, saying he had an idea. Turns out Rick wanted to do a South Florida "Seth's Stride for CCA."

I have to say that my brother is a very special man with an enormous heart full of so much love for his nephew. When talk of the Stride came up, he jumped on the idea and dove right in, never giving it a second thought.

Unexpectedly, two days before Seth's Stride, my mother passed away from a heart attack. In the midst of our grief, there really wasn't a question of whether to do the Strides or not—we had to. My mom would have had a fit

The First Annual Seth's Stride for CCA was held on September 15 in observance of CCA's Craniofacial Acceptance Month. Seth's mom, **Stacy Swihart**, of Canton, OH, planned a 5K walk and recruited her entire family to help, including her brother **Rick** in South Florida who held a simultaneous stride in his town. With friends and family, **this amazing duo**



if she was the one to get in the way of this special event. We did it for Mom, and it turned out to be an awesome day.

It's amazing how love can drive us to do things we have never done before; how it places intense motivation and passion in us; how it can move mountains and the hearts of individuals; how nothing is impossible and how people band together as a result.

Yes, although it was tragic losing our mother, it was also one of the most beautiful days I have ever experienced. We look forward to many more years of Seth's Stride for CCA and will never forget that not only was this event to honor all children and adults with differences

but also to honor a woman called "Mamaw."

Seth's **Aunt Michele** about the Ohio event: Over 80 people came together to show our affection, love and support of our favorite little Seth and all individuals who live with facial disfigurements. Our purpose is simple: to help remove the stigma of looking "different" to others, also a goal of CCA.



fundraising news

More news of families and friends raising funds during the September observance of Craniofacial Acceptance Month will be published in the next CCA Network newsletter, 1st quarter, 2008.



Rose Seitz, CCA Board Chair

Rose Seitz of Poland, Ohio, held a "fun" raiser, "Girl's Night Out" at her home. She served up some appetizers and adult beverages and took up a collection for CCA. This easily-duplicated effort garnered over **\$1,000!**



Kim & Don Rogers with one-year old daughter, Katherine, who was born with Craniosynostosis

Between other ongoing fundraising works, **Kim Rogers**, one of our parent volunteers in Bradley, Illinois, held a candy sale for CCA. She and her husband, Don, contributed the candy and have already sent CCA over \$100.

The **Waukesha West High School Cheerleaders** held the 2nd Annual Cheers for Kids' carwash and raised **\$200** for CCA kids.



Carol & Kevin Moriarty with (L-R) Anna, Ben, Helena & Emma

The **Moriarty family** held "Helena's Book Sale for CCA," contributing **\$140**, a percentage of their online sale of gently used books. Thank you!



Six-year-old **Gracen Smith** of Allen, Texas, presents a weekly talent show when her extended family gathers for Sunday dinner. One week she passed the hat for CCA kids and came away with **\$108** worth of applause! Thank you Gracen!

Our friends at **Wellpoint Next RX**, in Plano, Texas, held a hot dog lunch sale, added in their company snack cart



Administrative Assistant Amy Oliver, Manager Rashunda Young, CCA Development Director, Jill Gorecki, & Diversity Ambassador, Renata Brown

profits and had the first day's sales matched by one of the managers. Organizer **Renata Brown** stopped at our Dallas office headquarters with associates to present almost **\$700** in checks to CCA. Thank you!

2nd annual spooktacular contest winners

CCA is happy to announce the winners of our 2nd annual Halloween Costume Contest. Congratulations to all of our winners!



Thirteen-year-old **Cubby Baird** of Louisville, Kentucky was the winner of the 13-18 age group. He dressed up as a ghoul!



Eleven-year-old **Katilyn Whicker** of St. George Utah, was the winner of the 6-12 age group. She dressed up as a Pirate! Argghh Matie!



Four-month-old **Sydney Rose Ford** of Alabaster, Alabama was the winner of the 0-5 age group. She was a little Princess!

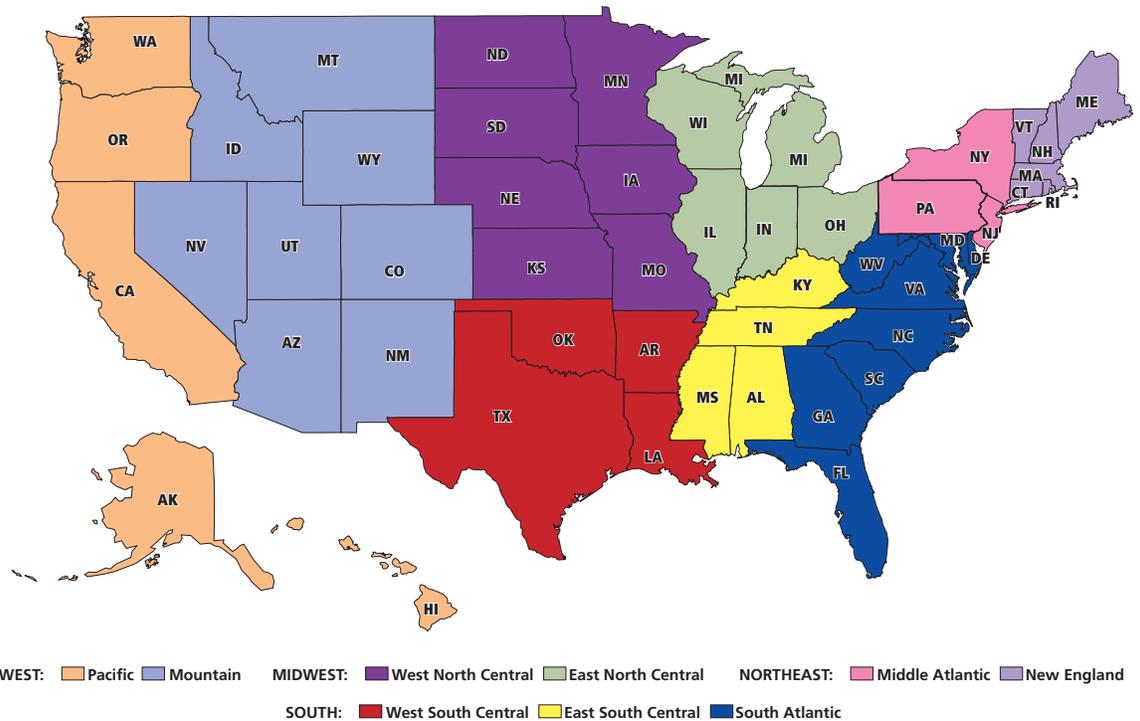
regional volunteers

Public awareness about craniofacial conditions is important on several levels.

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

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

CCA Regional Map



If you would like to help educate your community and take part in this national awareness effort,

call or email CCA Program Director, Annie Reeves at 800-535-3643 or ARees@CCAKids.com.

how to raise funds for cca

CCA 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.

- **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.)

- **Southern Living at Home**

Run a Southern Living at Home catalog party and raise funds for CCA. It's fun and easy to do!! 25% of all of the retail sales will be donated. Plus you will be rewarded with product for your efforts. Contact Rachel Johnson, CCA Mom and Director with Southern Living at Home email: southernrachel@sbcglobal.net (please also see www.lauryhenry.com) phone: 209.664.0500

- **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.

Looking for ideas?
Contact Jill Gorecki at J.Gorecki@ccakids.com

national call day

during the Month of September, Children's Craniofacial Association held a National Call Day in support of the Craniofacial Reconstructive Surgery Act of 2007 (HR 2820). On that day families, friends, coworkers and interested individuals across the United States called their US Representatives and urged them to cosponsor and support HR 2820 that will require insurance companies and HMOs to

cover medically necessary care for craniofacial patients of all ages. **Even though the day was successful and another Representative signed on to cosponsor this important piece of legislation, our work is not done. We must continue to call and write our congressmen.** We are gaining steam but unless we continue with our efforts, it is for naught. If you need direction please

call the CCA office and we will help you find your Representative's contact information and help you get your letter together and/or tell you exactly what to say in a brief phone call. So, if your congressman hasn't yet agreed to support HR 2820, please make that call, and write that letter. You will be helping many deserving children and adults with craniofacial conditions.

take advantage of tax-free IRA distributions before it's too late!

Interested in making tax free distributions from your IRA? There is a way, and it has more than just a tax benefit. In fact, using this tax provision before it expires can allow you to distribute as much as \$100,000 tax free (\$200,000 if married) as long as you do it before the end of 2007.

The Pension Protection Act of 2006 created a law that, under certain circumstances, allows eligible IRA and IRA Rollover owners to make distributions without having to pay taxes. Sorry, no SEPs or SIMPLEs.

The IRA distribution must be made before the end of 2007, and must be made directly to a "qualified charity."

The benefit? You pay no taxes on the distribution, get to help someone or something important to you, and charity receives 100 percent of the gift. No tax for you and a bigger benefit to charity creates a win-win situation.

A couple more qualifiers. You have to be at least 70-and-a-half years old at the time of the distribution. The proceeds must be paid directly to the charity, and the charity must receive the distribution before December 31, 2007.

This is a great strategy for those who are already making large or small gifts to charity. It can help those who are forced to make mandatory IRA distributions under the age 70 and a half minimum distribution rules, where

there's no real need to make the distribution to begin with.

Interested in how this might benefit you? CCA can help point you in the right direction. If you'd like to consider making this type of tax-free distribution and want to include CCA, we'd be happy to help. Please call or email our director, Charlene Smith for more information. She can also help you find an expert in this area of tax law, who will work with you to evaluate your options.

As always, when it comes to legal, tax and accounting issues, please make sure you consult with your attorney, CPA and/or tax advisor. CCA is not providing legal, tax or accounting advice and/or services.

donors, january 1 – september 30, 2007*

Gifts from Individuals

CCA Supporters (\$25 to \$100)

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Estate of L. Katsafouros

CCA Benefactor (\$5,000 +)

Estate of Jacqueline M. Conybear

Memorials / In-Honor Gifts

Sharon Allbright, in memory of Robbie Dick

Anonymous, in honor of Freddie Seitz, "A courageous and brave kid!"
Ann & William "Doug" Burgin, in the name of Rick Dornier
Larry Carpenter, in honor of Cher's birthday
Susan & Tom Casamassima, in memory of Becky Conrad
Lee & Linda Conway, in honor of Quentin Zaengle
John Dalton, in memory of Kevin Dalton
Dede & Darin Dankelson, in memory of Pauline Burzio
Maria & Mike Estrada, in honor of Antonio Estrada from Grandpa & Granny Estrada
Kathleen & Michael Farneth, in honor of Jacob Farneth
Bonnie Fenton & Rhonda Diggs, in memory of Victoris Suwalski
Dan Freeman, in honor of Robert Gorecki
Sidney Goldman, in honor of grandson, Evan Goldman
Jill Gorecki, in honor of Char Smith
Jill & Robbie Gorecki, in memory of Pauline Burzio
Annabelle Hartman, in honor of Brendan Walsh
Roni Heinze, in honor of Cher's birthday
Jim & Arleen Heirty, in honor of Marilyn Genthner
Jim & Arleen Heirty, in memory of Dorothea Saether
Jim & Arleen Heirty, in memory of Jayne Sheldon
Jim & Arleen Heirty, in memory of Sarah Burger
Jim & Arleen Heirty, in memory of Mary Stackley
Jim & Arleen Heirty, in memory of Douglas Meyer
Andrea Herbert, in honor of Caroline Dale
Mandy Hiznay, in honor of Freddie Seitz
The Industrial Company, in honor of Ryan MacLennan
Martin P. Koop, in honor of Brendan Walsh
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John P. Leson, in memory of Victoria Suwalski
Donald G. & Ann Lucas, in honor of Brody Lucas
Don & Ann Lucas, in honor of Brody Lucas, from Nana & Papa William & Juanita Luyben, in honor of Cole Macasieb
Peggy McDannel, in honor of Jill & Robbie Gorecki
Ellen McPadden, in honor of Jeremy Dale

George & Hope Nohejl, in honor of Natalie Wardlaw from Grandparents of Maggie Berger
Matthew Pantaleno, in honor of Ava Marie Beeler
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Dorothy Poindexter, in honor of CCA Children
Rainbow Club, in honor of Jeremy Dale
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Patricia & Steven Schneckenburger, in memory of Victoria Suwalski
Rose & Fred Seitz, in memory of Pauline Burzio
Charlene & John Smith, in memory of Pauline Burzio
Harry "Sonny" Smith, in the name of Wayne Smith
Paul & Ginny Tague & Family, in honor of Mrs. Berman, a wonderful teacher
Kevin & Jennifer Trapani, in honor of Morgan Mecklenburg
Ted Verdone, Jr., in honor of Lara Verdone
Vivo Brothers, Inc., in honor of Sadie Vivo
Lucille S. Weaver, in memory of Marie Ackerman
Diana Weber, in honor of Thompson B. Weber
Gregory Wesley, in honor of Chase Ingram
Michelle White, in honor of Freddie Seitz
Willamette Christian Center, in honor of Brenna Johnston
Cynthia Wills, in honor of Reed Wills
Reed Wills, in honor of Cynthia Wills
Susan E.R. Yelton
Donald & Anna Zaengle, in honor of Quentin Zaengle
John Zaengle, in honor of Quentin Zaengle

Corporate / Foundation Gifts

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

America's Charities (Employee Giving Funds Management)

American Express Foundation (Employee Gift Matching Program)
 American Express Company (Employee Giving Campaign)
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 CFC Austin, TX
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 CFC Central Florida Area
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 Cherry Point CFC, UW Coastal Carolina
 CFC Chicago Area
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 CFC Greater Southwest Texas
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 United Way of Northeast Florida, CFC
 United Way of Palm Beach County, CFC
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 United Way of Tarrant County (directed donations)
 United Way of Tucson and Southern Arizona (directed donations)
 United Way of Wyoming Valley, CFC
 A Grant from WalMart, Dallas Wellpoint Foundation Funds Management
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 YTB Travel Network, Inc. (purchases percentage incentives)

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A grant from Bally's Gaming for newsletter sponsorship
 A grant from The Brotman Foundation
 CFC Global, National Capital Area
 A grant from CVS Pharmacy
 GE Foundation (Matched Gift of Beth Abel)
 A grant from The Minneapolis Foundation, recommended by Travis & Christa Rymal and Family
 The Redwoods Group (Matched Gift of Bill Mecklenburg)
 Speedway Children's Charities
 Vivo Brothers, Inc.
 A grant from WalMart, Midway Dallas
 A grant from WalMart, Garland
 A grant from WalMart, Salt Lake City

CCA Corporate / Foundation Partners (\$5,000 or more)

A grant from Fed Ex
 A grant from Jorge Posada Foundation

A grant from the May & Stanley Smith Trust
 A grant from the Max & Victoria Dreyfus Foundation

Fundraising Events

Up to \$1,000

Balentine Bake Sale/Raffle for CCA / Balentine Family
 BeautiControl / Rose Seitz, CCA Volunteer
 CCA Chance Raffle
 Chores for Charity / Black Elementary 3rd Grade / Wendy Salin-Valle, CCA Volunteer
 Dean Bingo Fundraiser / Olivia & Karla Dean / CCA Volunteers
 Fine Design Christopher Radko ornament sale / Brenda Siebert, CCA Volunteer
 Helena's Book Sale for CCA / Moriarty Family
 Katz's Deli Fundraising Table / Jennifer Guerra, CCA Volunteer
 Rogers' Candy Sale for CCA / Kim Rogers, CCA Volunteer
 Sarah Orne Jewett / Mary Zimmer, CCA Volunteer
 Smiley Face email campaign / Peggy McDannel, CCA Volunteer
 Valley View School Staff "Dress Down Day" for CCA in honor of Ava Beeler
 Voorhees Center Genesis Healthcare, in honor of Eric Ronczka and Suzanne Ronczka
 Willamette Christian Center / Brenna's Raffle Fundraiser / Robyn Johnston, CCA Volunteer

\$1,000-\$5,000

Denim Day in honor of Maya Rodriguez, CCA Kid / Christine Rodriguez, CCA Volunteer
 Estate Sale / Catherine Romero, CCA Volunteer
 Fossee's CCA September Event / Jana Peace, CCA Volunteer
 Girl's Night Out / Rose Seitz, CCA Volunteer
 Tony's Wine Warehouse "Cher the Love" Event / Wayne Smith, CCA Volunteer
 Voorhees Middle School Drama Club / Amy Ronczka-Cosmay, CCA Volunteer

\$5,000 or more

CCA Jamaica Raffle
 Wendelyn's "Course of Dreams Golf Challenge" / Wendelyn Osborne, CCA Volunteer

\$10,000 or more

Friends of Jeremy Golf Tournament / Dale Family
 Pete's 5th Annual Scramble for CCA / Dankelson Family
 Seth's Stride for CCA / Stacy Swihart, CCA Volunteer, Rick Chiavari

WE'VE MOVED!
 13140 COIT ROAD, SUITE 517
 DALLAS, TX 75240

download the newsletter

If you are currently receiving the newsletter by mail, but would rather download it from CCAKids.org, let us know by sending your email to AReeves@ccakids.com. As an added bonus, the online version is in full color!

*Listed are Monetary Donations of \$25 or more through 3rd quarter, 2007. We are extremely grateful for these and all prior donations, raffle ticket 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)

3 cheers

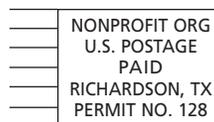
for volunteers!



Pictured left to right: Front Row: Joann Turano, Ana Zysko, Elena Welch & Beverly Butera
Back Row: Kay Laurenzi, Toni Parigi, Rae Gene Munglioli, Ben Parlapiano, Gina Lecca, Barbie Gumin & Kathy Miller

CCA wishes to thank the Italian Club of Dallas for volunteering their time to help with our newsletter mailing. We would like to recognize and sincerely thank each of them for their hard work! Grazie!

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