

# ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

summer 2007

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## facing forward

By Deborah Breslow

Chart in hand, Kenny's doctor was ready for his next patient. Approaching the doctor with resolve, Jay asked, "Kenny wondered, actually, we wondered, what happens from here? Can Kenny play baseball without his cage? Can he play goalie in soccer? Is there a chance he could ever play football?"

The doctor folded the chart he was reviewing. "Let me be more clear, Mr. Breslow. Kenny has no restrictions. He can do whatever he wants. He should go out there and be a normal kid."

Did "living normally" fit into the realm of our existence? "Doctor!" I called. "I need you to do something for me." Handing him pen and pad, I began to dictate: "As per our discussion today, January 16, 2007, the chances of a life threatening bleed from the nose are close to zero.

see **kenny**, page 12



## message from the program director

The 17th Annual Cher's Family Retreat is now history. After months of anticipation, it all seems to go by so quickly. I truly enjoyed seeing old friends as well as making so many new ones.

Watching new families interact and get to know one another is truly amazing. Upon her arrival, new-comer Tamara Mantlo located me, anxious to be introduced to the Sanborn family with whom she'd talked numerous times through e-mail.

see **program director**, page 16



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



At left: Nick Wiese doing one of his favorite activities – tubing!

At right: Nick Wiese



## meet nick wiese

hi, my name is **Nick Wiese**, aka “Pickle” to my family. I am 19 years old and I recently completed my senior year at North Allegheny Senior High School in Wexford PA. I walked with the class of 2007 at graduation, but I am going back for another year because of some school issues.

Next year, I plan to concentrate on TV productions. We have a great studio at our high school that was just renovated this past summer. I enjoy broadcasting the morning announcements that we air live to the entire school and community. I hope that I have a chance to do a lot more with the production studio in the upcoming year.

This past year was exciting. I got to do many “senior” things, including going to the senior prom

and banquet. The banquet was held on the Gateway Clipper, and the prom was at the fancy William Penn Hotel.

But the best part of the year was taking my first trip without my family. I went to New York City with my TV class. I got to see the Blue Man Group, and the NBC studio sets of the evening news and “Saturday Night Live.” We saw the “Lion King” musical and a PG13 show that resembled “Sesame Street.” We also saw the site of the World Trade Center and the Museum of TV and Radio. It was a

fabulous trip, and I can’t wait to go back next year.

Although I had a lot of fun this year, I also underwent surgery. I recently completed phase one of four craniofacial surgeries. It was a very long and difficult process.

I was only supposed to be in the hospital for a week, but ended up in the hospital for almost three weeks. Because of complications, I was kept asleep and paralyzed for a whole week! However, the operation was a success. I was fitted with a halo device that helped to move my bones and pull my face

forward. This happened very rapidly.

This device was removed in mid June, just in time for summer and the CCA retreat. It was a lot of fun sharing it with my Aunt Ginny who has a great sense of adventure. I particularly enjoyed being out in Salt Lake City for the first time. I really liked the size of Lagoon Park. I made some new friends, but I want to say hello to all of my friends from last year at Hershey. I hope to see you in Myrtle Beach next year.

And thanks to CCA for giving me a chance to say hello and tell you about myself.

# cca grad



# ccakid

## angel toribio

**a**ngeleah (**Angel**) **Toribio** is almost two years old, yet she has been through quite a lot so far in her life. This sweet little girl from the Philippines was born with Apert

and toes as well as help her mental development. And all of these cost money and a lot of it.

Enter a network of many miracle workers who helped bring Angel, Pol



syndrome, and she has undergone three surgeries so far to release pressure in her head and to separate her fingers and toes.

When Angel was first born, her father, **Pol**, and mother, **Eva**, did not know very much about Apert syndrome. When Pol did some research, he discovered Angel needed surgeries—a lot of them—to help separate her fingers

and Eva to Dallas for the surgeries. Everything was taken care of—visas, medical costs, flights and places to stay. **Dr. Jeffrey Fearon**, the director of the **Craniofacial Center** of the **North Texas Hospital for Children at Medical City Dallas**, performed the surgeries.

Now, little Angel is back in the Philippines with her family, including her new



baby sister, **Ashley**. She has recovered nicely and is now wiggling all 10 fingers and all 10 toes. She loves to dance. She also has a

wonderfully bright future ahead of her.

To find out more about Angel's remarkable story, visit her web pages:

- [www.apert.org/toribio](http://www.apert.org/toribio)
- <http://helppbabyangel.blogspot.com>
- <http://angeltoribio.tripod.com>



Top right: Angel at the beach

Far left: Angel with her new baby sister, Ashley

Near left: Angel has fun riding her toy car.



Left to right: Mike (22), Nick (20), Liz (18), and Dan (15) on vacation at the lake

I'm **Elizabeth Wiese**. I am 18 years old and am preparing to leave my hometown of Pittsburgh, PA for college. I will be attending Virginia Tech to major in Political Science with a minor in Business and possibly Spanish. I hope to play girls lacrosse as I did in high school. I also plan to get involved in student government and the Young Republican's committee.

I am extremely excited to start this new chapter of my life; however, the life I am accustomed to will be very difficult to leave. I love going to Pitt basketball games as well as watching the Steelers—five-time Superbowl champs—play live. I am very attached to my two “sisters,” Lucy and Bella, my Newfoundland dogs. And my friends here are amazing.

Leaving my family behind, however, will be the hardest of all. They have always been my core. Perhaps the most important thing that I have learned from them is to be an accepting and loving individual.

This value was always emphasized in my house because my brother, Nick, has Apert's syndrome. I have never looked at Nick as anything other than what he is: an amazing, smart, caring, wonderful human being. I have been truly blessed to experience his personality as part of my daily routine.

When I was younger, Nick and I went to

# meet elizabeth and dan wiese

different schools. Nick needed special attention for his syndrome. As time went on, we finally got to attend the same school! Sixth grade was so exciting; I had my big brother right there with me at Marshall Middle School. Then came North Allegheny Intermediate and Senior High School. We continued to learn and grow as brother and sister, but also as friends.

This past year, Nick had a major reconstructive surgery. I was amazed at his courage and strength as he took on this procedure with a positive attitude. After a few complications, Nick came out as a brand new kid. His physical changes have given him a new confidence, as if he could have more of that!

When Nick got back to school, he was greeted by a tremendous amount of support. The surgery

helped to show the kids what I have known my entire life—that Nick is a strong and special person.

Graduation was an amazing time, because although Nick has one more year at the Senior High, he walked with the class of 2007 to support us. The year ended and although I was excited, I think Nick was ready to go back to school about a week into summer. He loves to learn and be around people.

Nick, or Pickle as I lovingly call him, deserves most of the credit for my willingness to meet new and different people. I feel prepared to be an accepting friend at college because of my experiences. I will very much miss my family, especially my partner in crime, Nick. Love you, Buddy!

continued next page →

# ccasupersibs



# governor rick perry proclaims september craniofacial acceptance month

In a proclamation from the office of **The Honorable Rick Perry, Governor of Texas**, the month of September has been officially designated “Craniofacial Acceptance Month” throughout the state of Texas. CCA’s plans for the month include press releases to state-wide media, awareness campaigns in the schools and communities and fundraisers conducted by families affected by craniofacial differences. Our goal is to foster acceptance of individuals with facial differences through education and awareness.



## craniofacial acceptance month

### Beyond the Face is a Heart

This year marks the third 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 of individuals with facial differences. The goal is to create awareness that beyond the face is a heart and the true person within.

In addition to raising awareness and acceptance, CCA is raising funds to support programs and services available to all individuals with facial differences as well as their families. Besides the ideas for raising funds mentioned in this newsletter, CCA has dedicated a specific plan for September’s observance, which will be fun and easy for all families and friends to try.

We hope you will join this important effort! Please contact CCA about raising funds while educating the public. Call 800-535-3643 or email Jill at [JGorecki@ccakids.com](mailto:JGorecki@ccakids.com).

### ccasupersibs, from page 4

hi, my name is **Dan Wiese**. I am 14 years old and I live in Pittsburgh, PA. I play lacrosse, and I am the leading scorer for my team.

I could never achieve these goals without the support of my family—especially my brother, Nick. He is at every game!

Nick is truly an amazing person. He is fun, loving and passionate towards

everyone. My life has drastically changed having Nick as an older brother. He and I do almost everything together. He is definitely my brother, but he is also my best friend! Love ya, Nick!

# second-biggest cca retreat!

Kiddos with magician

CA's 17th Annual Cher's Family Retreat was the second-largest retreat to date, with families coming from 37 states and one family from Canada! Twenty-eight of the families were first-time retreat attendees.

Then each family was asked to look at a small slip of paper placed in one family member's name badge. On the slip of paper was the name of an animal. Family members had to walk around the room making their animal's sounds, finding their groups by the animal sounds each person was making. The kids really got a kick out of this exercise. And the adults? Well, let's just say they did a great job!

Afterward, everyone in the "animal groups" traced their hand on paper, cut them out and used them in a creative artistic design for each hand. Little America's **Chef Fred**, who was the contest judge, awarded the Cat group overall winners. They designed flowers by using their hand cutouts as stems. The saying "Loving Hands Help Us Grow" adorned the bottom of the poster.

Held in Salt Lake City, Utah, the retreat started on Thursday with registration followed by an ice cream social. The Little America Hotel had two beautiful ice cream sundae bars complete with carousel horses for decoration.



Friday morning, the group headed out to Lagoon Amusement Park, where the daring rode roller coasters, the small fries enjoyed the kiddie park and many took advantage of the water park, Lagoon-A-Beach, to beat the hot summer sun.

That evening, everyone kicked back and enjoyed family night. After a pizza dinner, a magic show entertained children and adults alike. The kiddos, smiling from ear-to-ear, eagerly participated in the magic tricks! After dinner, the teens headed off to their own private showing of the original *Pirates of the Caribbean* movie in a pirate-themed room separate from the rest of the group. This was the second year to feature a teen night at the retreat, and it looks like it will

remain on the schedule as it seems to be a big hit.

While the teens hung out together, the rest of the gang anticipated hearing their names called during the Chinese raffle. This year, the raffle prizes were an item or basket the families brought, that represented their hometowns or states. Everyone did such a great job and we thank all of you who participated. Two of our new families, who became best friends during the retreat, won each other's baskets!

Saturday was a very nice and relaxing day. We were able to enjoy a fun-filled day of swimming at the pool party complete with a hot dog lunch. Little America closed off the entire pool area for our group, so we had it all to ourselves! Families enjoyed visiting with each other



Garrett Smith & Amelia Sanborn dancing



Game of volleyball during pool party



and catching up on some much needed rest and relaxation.

Saturday evening was the much anticipated dinner-dance. The kiddos had their own special buffet with chicken fingers, French fries and jello, while the adults dined on a very nice dinner buffet. Once the DJ started playing music, the dance floor filled up. Everyone danced the night away! **Scott Guzzo** led everyone in the



Dr. Morales a member of CCA's Medical Advisory Board

Sunday morning, everyone met for the farewell breakfast, which is always filled with lots of emotion. The room is filled with hugs, smiles, tears along with much talk about the next retreat. The retreats are such an emotion-filled weekend and truly mean the world to the families and CCA staff. We have heard time and time again the retreat is the most important service CCA provides, and we could not agree more. Seeing families bond and knowing they have made life-long friends over the course of the retreat is truly priceless. We enjoyed meeting all of you and look forward to seeing you June 26-29, 2008, in Myrtle Beach, South Carolina!

More dancing!



Locomotion time



Group of teen girls during dinner/dance



Burzio family



Magic show



Lisa & Ashley Bock

locomotion and **Andrew Perry** sang "Believe;" two events that have become staples at the retreat. The dinner-dance wouldn't be the same without them!



# surviving Rigid External Distraction

By Lia Burton

getting a paper cut, stubbing a toe, getting shampoo in your eyes—how painful life can be! And don't you just hate it when people complain about how one of these things is "oh my gosh, the worst thing everrrrr!"



suffering, I'd often rather not think about it.

While the traditional mid-face advancement involves moving the mid-face forward all at once in a single operation, RED involves moving the mid-face forward gradually by turning screws that are

part of the physical RED system. The screws are turned once or twice a day for however long the surgeon prescribes, thus moving the mid-face forward and allowing the resulting bone gaps to heal gradually.

RED is often preferred to the traditional method as results typically last longer and bone grafts are not

necessary to hold the advancement in place. After the screw-turning period, the RED is left on for a few weeks as a retention device while the bone continues to heal. Once things are stable, it is removed in a relatively minor surgery.

Like many of you reading this, I was born with a



craniofacial syndrome (Pfeiffer's) and was predestined to have lots of surgeries and constant unwanted attention in public. But in general, I was a pretty happy kid. Surgery and getting stared at everywhere was just part of everyday life.

Fast forward several years and several surgeries and it

was time for a mid-face advancement.

Even in 2001, RED was still relatively new and controversial in the craniofacial community. One of my surgeons firmly believed in preserving the traditional all-in-one surgery and disliked the idea of RED, so I was horrified when a new surgeon said I would need to go through the distraction process soon. However, I would only need the less-obtrusive internal distractors instead of RED. But after a rough two weeks of complications with the internal distractors requiring extra surgery, I had the RED installed after all.

We spent a month living at a Ronald McDonald House from the time they





installed the internal distractors to when we stopped turning the screws on the RED.

Once things were stable, I was able to go home to finish out the retention period. Most of the pain involved with RED comes from the stress put on the muscles lying across the mid-face that are being stretched as the screws are turned. So, by that point, since I was no longer turning the screws, the pain was minimal and RED became more of a nuisance than anything else. A few weeks later, I was on a plane back to Sacramento to have it removed.

No surgery is ever fun, but these surgeries were particularly tough. It was a big pain (both literally and figuratively), but with lots of medicine and support, it was tolerable. Now that I'm on the other side, I can say that everything was definitely worth it.

Since then, I've been able to breathe through my nose (a once-impossible task), talk more clearly, and not have to worry about injuring my eyes as much. It certainly was not the last surgery I would have, but it yielded some of the most significant benefits. And as an extra bonus, the teasing and staring I was so used to started to subside.

Let me emphasize again that the change in

appearance was only a bonus. While you probably will look more "normal," don't expect to love your new face right away. First of all, change always takes getting used to. Second, you'll still be slightly swollen even after a few months, so give it time. Third, it is common to "over-correct" the degree of mid-face advancement since doctors expect that your lower jaw will continue to grow while your mid-face remains static. So embrace your new overbite and know



that it is probably not permanent.

Most important, remember that the purpose of RED is to get you breathing normally with protection for those beautiful eyes, so it's worth claiming victory when those two goals are accomplished.

Since RED, I've had several more surgeries, gotten a license to drive, earned the right to vote,



finished my first year of college and enjoyed all kinds of other fun stuff. I also put up a website devoted to this topic. I've been very blessed to only have to go through it once, but I know some of you have had it multiple times, and I am humbled by how much you guys have had to endure.

The truth is, no one looks forward to RED, and with all the hype about it on the Internet and in newsletters like these, it's easy to get stressed out about this procedure and not know

what to believe. On the one hand, you've read the brochures saying that this procedure is easy, virtually pain-free and minimally invasive. But then on the other hand, you have probably also heard the rare horror story of the surgery-gone-wrong that is enough to terrify any patient or parent.

My main advice is just to relax and give it over to God. In the end, what will happen will happen and you will get through it. I have never met a craniofacial kid who wasn't

see **RED**, page 11

**RED is often preferred to the traditional method as results typically last longer and bone grafts are not necessary to hold the advancement in place.**

# fifth annual pete's scramble



mingling with friends, and view pictures from the Nashville and Hershey retreats.

The scramble was held on May 19th with 53 players enjoying a fun day of golf and camaraderie. Raffles, prizes, and a silent auction followed the golf and all contributed to raising almost \$7,000 in direct donations to CCA. Everyone who played received a "Pete's Scramble for CCA" t-shirt and a CCA ball

marker clip to help spread awareness and acceptance for people with facial difference.

The Dankelsons wish to send their thanks and gratitude to all of Pete's generous individual and corporate supporters as well as several PGA and NASCAR professionals who graciously donated memorabilia for the silent auction and raffles. Thanks also to the Detroit Red Wings and the Detroit Tigers for their continued donations of auction items.

Pete's Scramble is primarily focused on

spreading local awareness and acceptance of craniofacial differences. Peter, along with photographs and a video from the 2006 retreat in Hershey, stole the hearts of players, many who have returned year after year to play in and support the event.

Mark your calendars for next year's outing scheduled for **May 17, 2008**, once again at Beacon Hill in Commerce Township. All levels of golf and support are encouraged to participate!



**t**he Dankelson family recently hosted "Pete's 5th Annual Scramble for CCA" at Beacon Hill Golf Course in Commerce Township (Detroit), Michigan. The event kicked-off with an opening night reception held at Baker's banquet facility in nearby Milford. Several out-of-town and local supporters were able to bid on silent auction items,





filled to the brim with endurance. You've been through tough surgeries before, and you can definitely get through this too.

If you want more reassurance, talk to other people who have already gone through RED. I am no more qualified to write this article than anyone else who has ever gone through it, and no two people have ever had the same experience with RED. I'm sure some people do not agree with my point of view in this article, so it might help to get multiple perspectives. But when it comes down to it, don't think too hard. Do something fun the day before the surgery and pig out on your favorite crunchy foods. Then just take every day after that one at a time.

I am nearing the maximum word-count, but I have so much more I would love to share with you guys. Everything from food suggestions to RED fashion pointers to basic tips can be found on my website: <http://REDSurvival.tripod.com>, so I really hope you'll come by for a visit!

And if you ever want to ask questions, chat, or need to vent about something, drop me a note at [Lmburton@usc.edu](mailto:Lmburton@usc.edu). I love hearing from you all! Stay strong and best wishes for all those going through RED.

## Lia's 12 tips for a better RED experience

1. **Don't plan on going to school while wearing the RED.** A select few have done it, but it wasn't even a question for me. Take my advice: Stay home and focus on recovering. You have enough to deal with already.

2. **Interrogate your surgeon.** There is no such thing as a stupid question when it comes to your health, so ask away. If you don't understand something, you have every right to stay in that office until you do. And if anything doesn't seem right during any part of this whole process, speak up and don't back down until your concerns are resolved.

3. By the same token, **if you need something, just ask.** This applies to any point in the process, but especially while you're in the hospital. More pain medicine, something to drink, more blankets, another pillow, a new Mercedes, whatever it is you want, just let the nurses know.

4. **Grab a handful of wide-tip syringes** before leaving the hospital. They are the answer to getting liquid into a mouth that can't be seal closed.

5. **Invest in a small blender** and harness the power to puree virtually any food

product. You should also load up on Ensure (or your protein drink of choice). Make sure to allocate a good portion of the day to eating and getting those recovery calories.

6. **Keep disinfectant on hand** at all times and very gently clean the pin sites (where the halo of the RED is attached to the head) regularly. You do not want an infection. Ask your surgeon if you have more questions about how to protect the pin sites.

7. **Get a new wardrobe.** You will need to shop for button-down shirts and wide-neck tank tops that will comfortably go over the rather cumbersome RED. As stylish as they are, turtlenecks simply do not complement the RED.

8. **Keep a chart of all your meds** and plan out when you will take each pill. Then use pocket-size alarm clock to keep you on schedule. You won't want to accidentally miss pills or let the pain get out of hand by delaying the pain meds. Along with pill-planning, you need to decide when you will turn the screws and stick to the same time(s) each day. Try to keep things as consistent as possible.

9. **Experiment with pillows** of all different sizes and shapes. Sleeping is not

super comfortable, since you can't move around much and have to stay on your back. Some people have found success with neck pillows; I used a small home-made pillow that fit between the back ends of the halo. In addition, you will need to keep lots of pillows under your entire back to keep your head elevated for at least the first week or so to help with the swelling.

10. **Make your own heating/cooling pack** with raw lentil beans in the soft comfy sock of your choice. This is smaller and lighter than the average hot/cold pack and much easier (and safer) to use with the RED on.

11. **Demand fan mail.** Make sure friends and family know what's going on and let them know you would appreciate letters of encouragement (or large wads of cash) while you recover.

12. **Get a hold of every funny movie you've ever wanted to see.** Reading's a challenge with a bar in front of your eyes, contact sports aren't an option, and you certainly don't want to sit thinking about how much you hate the RED, so keep your mind as busy as possible.



Kenny, before his surgery

## kenny, from page 1

The progression of disease has ceased. The worst is over."

His face softened. "You don't need it in writing, Debbie. What you need is to start believing it. It's time to greet the world facing forward."

I stood still, taking in what he'd said. "C'mon Kenny," Jay called, "let's get you back to school." Following them out to the parking garage, I sensed Kenny's quiet. Did he hear everything we heard? Did he comprehend the good news?

"Everything okay, Ken?" I asked, mussing up his hair. "Not really," he said. "It hurt when he was pinching my nose."

We drove home from New York, each in our own thoughts. The ride was uneventful: lighter traffic, lighter hearts.

Greet the world facing forward. Admittedly, this concept was foreign to me. And, on a deeper and

more personal level, how much was this about Kenny's need to move ahead as it was about mine?

## Looking Back

There are strings attached to giving birth to a child with a rare medical condition. At first you blame yourself. The guilt consumes you. You want to retreat but you can't. Your better sense prevails; "I must find out what's wrong with my son and how best to treat him. I am determined to find the right doctor, the best hospital ..."

Twinges of remorse are replaced by anger and self-pity: "Why me?" Then, miraculously, your inner voice takes over. You begin to reach a higher awareness.

Then you take action. You become the researcher, communicator, facilitator, educator and advocate.

You may refer to your child as 'sick.' Though this is unfair (as most labels are), it is a way to let others know that your life is different from theirs. You want to convey that you have been tested in a way that perhaps they have not.

When people tell you "I don't know how you do it" or think you're a saint, you remind them that, if they were dealt the same hand

of cards, they would act accordingly.

When the child is a baby, you feel as though you are experiencing what {he is} they are. His cries of pain are felt in your body. You rationalize by hoping that because he is so young, he won't 'remember' fear, pain, blood, sutures or scars.

Soon you become more thick-skinned. When speaking about a part of your child's body, you become "detached." Medical discussions take place as though you are speaking about an inanimate object, not your child.

On days that you feel you can no longer put one foot in front of the other, you reach out for help. Your child's illness has a ripple effect, and family, friends, caregivers and clergy come to your aid.

Being in crisis, living in crisis becomes the norm. Plans are made to be broken. You thrive on adrenalin. All the time, tasks, energy and effort associated with taking care of that child are yours. You forget where you end and he begins.

## Moving Onward

After nine years of continuous medical intervention, I am certain that Kenny has moved on faster than I. Ongoing medical treatment has

resulted in countless life interruptions. Bearing a facial difference has evoked unkind behavior from others: teasing, staring, hurtful whispers and remarks.

Yet, his level of acceptance and resilience is unsurpassed. His experience has offered him a greater understanding of life. He rolls with the ups and downs and continues to land on both feet. He excels in academics, athletics and art; he is sensitive, funny and surrounded by friends. Psychosocial intervention during the early years of diagnosis and medical treatment helped to foster healthier reactions to his personal trials and the insensitivity of others,

Taking a moment to reflect, I consider the concept of letting my guard down. If Kenny is no longer sick, and the situation is no longer acute, this mindset of fear and worry can no longer be.

I decided to speak to another mother who has dedicated her adult life to the support and advocacy of children with rare craniofacial conditions. She reminds me about "cautious optimism," a middle ground.

When sharing Kenny's news, she shares the experience of her adult

continued next page ⇒



son. Having undergone 17 years of medical intervention, he is now married and living a normal life. Reflecting on her role in his life then, she admits that it overtook her; it was her identity.

Expressing her role in his life now, she believes she has moved on. She so much as told me, "That was another country and I'm outta there!" This does not mean she no longer cares for her son. She would do anything to support him. But she has made peace with the fact that the responsibility for coping with his birth defect and subsequent residuals are his.

Following our conversation, I am struck by the notion that though

younger in years, Kenny has also faced life with grace. He sees his life and personal circumstances as being just what they are. He has learned to accommodate. I may have contributed some to this framework, but it is Kenny who has prevailed. He has taken the adversity and turned it into something great. He is a better person for it and, undoubtedly, I am too.

Deborah Breslow is a freelance writer and the mother of three boys: Robbie (11), Kenny (10) and Danny (7). She lives in Wyckoff, NJ with her husband, Jay. Visit Ms. Breslow's website at <http://members.aol.com/djbreslow/funnyface/index.html>.



Kenny and his mom

## you can make a difference

**C**ongressman Mike Ross has once again introduced legislation to the US Congress that will guarantee insurance coverage for craniofacial patients. This legislation (HR 2820) was proposed because insurance companies often label reconstructive care as "cosmetic" and deny coverage for this or other reasons. The Reconstructive Surgery Act seeks to guarantee that insurance companies meet their obligations to cover medically necessary care.

**If this legislation is ever to become law we need the help of ALL of our readers.** By doing something as simple as signing a petition, making a phone call or writing a letter, you can make a huge difference for families who struggle with insurance issues. In fact, you don't even have to compose the letter; it has been done for you. Please visit [www.aica-advocates.blogspot.com](http://www.aica-advocates.blogspot.com), copy the letter on the left-hand column, omitting paragraphs that might not pertain to your situation and/or adding pertinent personal experiences. Then, if you don't know who your legislators are, enter your zip code in the box in the right hand column and you will get all the information you need. It's that easy. Now fax or mail the letters to your elected officials and you will make a difference.

In addition to the letter campaign, on September 26th during Craniofacial Acceptance Month, we will have a national call day. We ask that each of you call your US Representatives, mention that you previously wrote them (if applicable) and ask them to support HR 2820. Please visit our website [www.ccakids.org](http://www.ccakids.org) or call us at 800-535-3643 for information and instructions.

One more thing you can do is sign the on-line petition in support of HR 2820 that will be sent to each member of congress. After you have signed the petition send this link to everyone you know. Numbers speak volumes, so let's show congress how we feel.

[www.thepetitionsite.com/1/craniofacial](http://www.thepetitionsite.com/1/craniofacial)

# 3cheers for volunteers!

CCA has formed a network of regional coordinators and volunteers across the country who have banded together in an effort to educate and inform the public about craniofacial conditions.

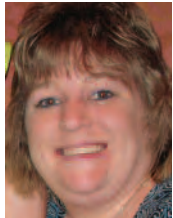
CCA would like to thank the regional coordinators as well as the local volunteers for all their efforts!

Thanks to them, they help ensure that:

- Families find quality medical care
- Healthcare professionals are aware of the special medical and emotional needs of Children and adults with facial differences
- The public understands and accepts facial differences
- Individuals with facial difference are accepted

## Regional Coordinators and Volunteers

### Pacific: (WA, OR, CA)



#### Regional Coordinator

LeeAnn Adams

#### Volunteers

Yael Blasberg  
Julie Sanchez

### Mountain: (MT, ID, WY, NV, UT, CO, AZ, NM)



#### Regional Coordinator

Tanya MacLennan

#### Volunteers

Elizabeth Schlecter  
Brian Smith  
Tosha Walker

### West North Central: (ND, SD, MN, NE, IA, KS, MO)

#### Regional Coordinator Needed

#### Volunteers

Tammy Freeman  
Cara VanNess  
Lori Erickson  
Theresa Hospodka

### West South Central: (OK, TX, AR, LA)



#### Regional Coordinators

Jana Peace  
Stacey Atkins

#### Volunteers

Lisa Bock  
Cheryl Whitten  
Jennifer Guerra  
Brenda Siebert  
Natalie Criswell  
Jessica Dornier  
Teri Collins  
Melanie Howington

### East North Central: (MI, WI, IL, IN, OH)



#### Regional Coordinator

Rose Seitz

#### Volunteers

Dede Dankelson  
Nell Gozdowski  
Dena Kramer  
Diana Weber  
Bob & Paula Guzzo  
Rochelle Samborski  
Marti O'Brien  
Lisal Heral  
Julie Demor  
Tisha Warrick  
Meg Gray  
Stacy Swihart

### East South Central: (KY, TN, MS, AL)



#### Regional Coordinator

Donna Gossett

#### Volunteers

Chandra Holland  
Jackie Simmons  
Lisa Crawford  
Colleen Balkcom  
Julie Baird

### New England: (VT, NH, ME, MA, CT, RI)



#### Regional Coordinators

Malcolm & Laura Beeler

#### Volunteers

Kathy Hubbard  
Laurel Sanborn  
Liz Prince  
Karin Perry

### Middle Atlantic: (PA, NY, NJ)



#### Regional Coordinator

Cindy Samhammer

#### Volunteers

Mary Manganiello  
Harlena Morton  
Bev Grim  
Laurie Scimeca  
Molly Lytle  
Margaret Bordonaro  
Janis Macut  
Kelly Younkin

### South Atlantic: (MD, DE, WV, VA, NC, SC, GA, FL)



#### Regional Coordinator

Carolyn Hudson

#### Volunteers

Angela Nixon  
Carol Sharisky  
Marilyn Werback  
Sandy Deakins  
Debbie DeLong  
Jamie Hopkins  
Judy Mosher  
Gwen Sanders  
Carrie Ingram  
Bonnie Lincavage  
Connie Goodwin  
Ann Christensen  
Alison Hawse



# hot tips!



Express Medical Supply, Inc.  
Product: 3M Coban Self-Adherent Wrap

after we found this wrap (at the surgeon's office) we couldn't live without it when our son, Jon, had hand and feet surgeries. It keeps the bandages clean, and more importantly, intact. ~Submitted by Brenda Siebert

an easy way to get the goop out of hair after a sleep study is, USING ONLY WATER, rub the spots (of goop) until they are gone. (If you add shampoo first they will harden.) After the spots are rubbed in, shampoo as usual. ~Submitted by Lisa Bock



## cca mugshot

this issue's "mugs" are Ray and Dorothy "Ann" Poindexter of Chesterfield, VA who are regular shoppers at our CCA web store as well as online donors. Thanks!

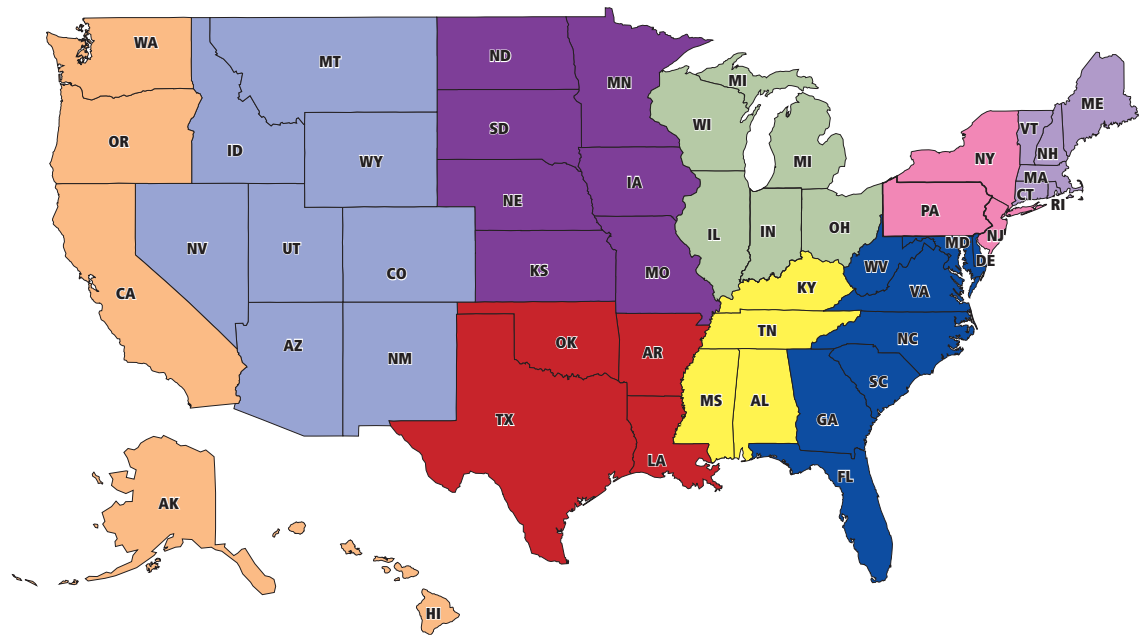
## regional volunteers

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 difference are 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



WEST: Pacific Mountain MIDWEST: West North Central East North Central NORTHEAST: Middle Atlantic New England SOUTH: West South Central East South Central South Atlantic

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 AReeves@CCAKids.com.

## program director, from page 1

Another family walked up to me with the retreat program in hand, wanting to meet two families who have children with the same syndrome as their child. I cannot put into words how important and beneficial the retreats are to our families. Instead, I will let you hear it from one of our teenage attendees. This is an essay written by **Elizabeth Hubbard**, age 15 who was born with Neurofibromatosis.



### Let me tell you a fairy tale...

Once upon a time, there was a young girl named Lizzy. Lizzy had a disorder that caused tumors to grow in her body, and more noticeably, in her face and neck. Her mother kept telling her she was very beautiful so Lizzy didn't understand why kids and some adults would stare and whisper or giggle when

they saw her in places like the grocery store.

Soon, Lizzy started school, and she was teased by kids and didn't have many friends because she looked different. She coped with this by trying to please everyone, especially adults, and looked forward to adult attention. When Lizzy was home, she would stare at her face in the mirror and wonder why she didn't look like the other kids. She would cry as what the other kids did and said hurt her tremendously. Her mother comforted her and arranged for her to see a counselor. Unfortunately, the counseling didn't seem to help her and the crying and teasing continued.

One day, the mail came to Lizzy's home. In the stack was a flyer from Children's Craniofacial Association (CCA) in Dallas, inviting the family to their annual retreat. Her mother thought it might help, so they went to Texas for the long weekend trip. Lizzy, her mom and grandmother traveled to Dallas to see other kids and families.

For the first time in her short life, she was accepted by everyone and not teased...even Tweety Bird, who followed her

around the hotel! One young boy chased her around the retreat saying, "she's soooooo beautiful!" Lizzy even got to meet Cher and discuss nail polish techniques with her. She met kids from around the country who also lived with facial differences. She made friends and was accepted by all.

When they got home, everyone noticed the improvement in Lizzy's outlook. She was happier. She didn't cry in the mirror anymore. She looked forward to her medical appointments. When her plastic surgeon asked if she wanted her face fixed, she replied, "No, it's what makes me, me. I like how I look."

Since that first retreat, she has only missed the annual event one time. It has been Lizzy's annual "booster shot" to get her through the next 12 months. She no longer gets upset or discouraged by her appearance. She is more outgoing and more able to speak up and defend herself. She no longer tolerates teasing or bullying in any form from anyone. She has lots of friends. Life is good!

I am grateful to CCA and its members/families for their support and encouragement. Without

them, I don't know what I would have done. CCA families and friends taught me that beauty comes from within, and everyone has special gifts to give.

Many of the kids at the retreat have endured significant surgeries and lived through them. They helped me see that I am not alone, I have a lot to offer and that my opinions and thoughts are valued. Others look forward to seeing me and my family every year. We all keep in touch by phone, e-mail, IM and letters. Cher sends each of her "kidlets" a holiday gift each year. She even remembers me by name!

Because of CCA, I have the confidence to tell others my story, to empathize with other kids who may look or act different and comfort others who have to experience similar situations such as mine, and I feel that this "gift" that I have been given makes my career choice in the medical profession an ideal fit for me.



# good news

**Bianca Moon** of Australia was recently invited to the Dalai Lama's Australian Business Leaders Luncheon because of the work she has been doing with her charity, Truly Beautiful. In Bianca's words,



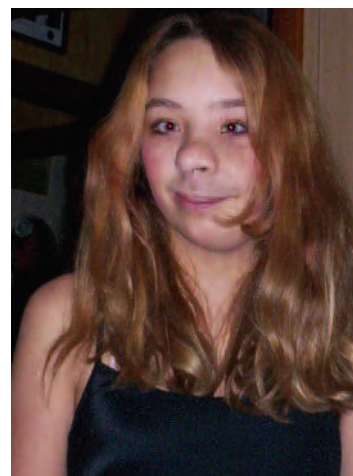
"When His Holiness walked into the room, there was absolutely nothing I could do to stop myself from crying—it was such an emotion-filled room. He is such an amazing man, and I feel so special to have been in his immediate presence."



**Paula Guzzo** of Evansville, IN, has been awarded a Jefferson Award for her work as a parent advocate of children with disabilities. Paula began advocating for her son **Scott**, now 23, before he was born. "Life is a journey. We control as much as we can that happens to us," Guzzo said. "Attitude is one of the hardest things I

come up against because you can't buy it and you can't legislate it. It has to come from within a person." Today, her voice reaches across state lines and even to the national level. She's a parent advocate, trainer, consultant and regional program specialist for IN\*SOURCE, the Indiana Resource Center for Families with Special Needs.

**Elizabeth Hubbard** of Fairfax, VT, was accepted into the MedQuest program this summer through the University of Vermont/Fletcher Allen! She learned about health-related careers for a week in July. (See page 16 to read an essay written by Elizabeth!)



Jylian Bilbow with dad, John

**CA kid, Jylian Bilbow** turned 5 years-old just in time to play Miracle League Baseball in her hometown of Arlington, TX. The Miracle League field is adapted for wheelchair use, and each player uses a "buddy" as they field, hit and round the bases. Jylie's dad, John played along as her baseball buddy. Jylian had a busy spring. In addition to baseball she also participated in the preschool choir at church.

# 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**

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.laurynhenry.com) phone: 209.664.0500



- **Buy Gifts from BeautiControl** at [www.BeautiPage.com/ccafriends](http://www.BeautiPage.com/ccafriends) and CCA gets the agent profit! Questions? Email Rose Seitz at [rseitz@directed-tech.com](mailto:rseitz@directed-tech.com). These gifts cause no clutter, because they get used up!

## NEW IDEAS!

- 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](http://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](mailto:zibadoo@juno.com) to learn more about how to raise funds for CCA.

## Looking for ideas?

Contact Jill Gorecki at [J.Gorecki@ccakids.com](mailto:J.Gorecki@ccakids.com)

# north american craniofacial family conference

CCA once again was proud to sponsor the AboutFace USA's NACFC. For the third consecutive year this important event provided educational workshops and plenty of fun for families of individuals with facial differences.

Workshops for parents, teens, kids and affected adults were designed to inform, educate and entertain. Keynote speaker **Ronald P. Strauss, DMD, PhD**, opened the conference with an engaging and inspiring presentation. Renowned artist **Metin Berketli** provided a special experience in art for the kids. Many workshops during the conference gave each member of the family opportunities for learning, sharing and enjoyment.

CCA congratulates AboutFace, USA staff, **Debbie Oliver** and **Joyce Bentz** and Board President, **Dr. David Reisberg** for another successful conference. Job well done!



## planning a vacation?

There's a new way to support your charity! Book all of your travel needs at [www.ytbtravel.com/ccakids](http://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.

## calendar of events

date	event	contact
September	<b>Nationwide Observance of Craniofacial Acceptance Month</b> General Information Fundraiser Information	214.570.9099 800.535.3643 <a href="mailto:AReesves@ccakids.com">AReesves@ccakids.com</a> <a href="mailto:JGorecki@ccakids.com">JGorecki@ccakids.com</a>
September 15	<b>First Annual Seth's Stride for CCA</b> Canton, Ohio	Stacy Swihart <a href="mailto:mythreekids@neo.rr.com">mythreekids@neo.rr.com</a>
September 20	<b>Fosse's September Sale for CCA</b> Dallas, TX	Jana Peace <a href="mailto:brunellob@sbcglobal.net">brunellob@sbcglobal.net</a>
October 13	<b>Third Annual Friends of Jeremy Golf Event</b> Willowcreek Golf Club Big Flats, NY	<a href="mailto:gdale@stny.rr.com">gdale@stny.rr.com</a> <a href="http://www.friendsofjeremy.com">www.friendsofjeremy.com</a>
June 26-29	<b>18th Annual Cher's Retreat</b> Myrtle Beach, SC	<a href="mailto:AReesves@CCAkids.com">AReesves@CCAkids.com</a> 214.570.9099 800.535.3643
October 11-18	<b>Disney Cruise 2008</b>	<a href="http://www.apert.org">www.apert.org</a>

# fundraising news



The Romero family, John, Catherine, Matthew (8), Carson (22 mos, held by Dad) and Ellie (6)

**Catherine Romero** of Birmingham, Alabama, and her family, raised funds for CCA by holding an “estate sale” of stored furniture and odds and ends they no longer used. They raised **\$3,000** and contributed in honor of son, **Matthew’s surgeon, Dr. Jeffrey Fearon**. Catherine says helping others through Children’s Craniofacial Association was a way to give back for the gratitude they felt about a good outcome for Matthew.

A huge “Thank you!” to the Romero family and Dr. Fearon!



**f**or the second year, **Olivia Dean** of Philadelphia, PA, with the assistance of mom, **Karla**, held a Bingo event with her elementary school friends to raise over **\$500** for CCA. Thank you!!!



**Black Elementary** 3rd Graders in Mesquite, Texas, performed “Chores for Charity” at their school just before the summer break and raised over **\$200** for CCA. The fundraiser was organized by their teacher, **Ms Wendy Salin-Valle**. Most of the contributions were solicited from generous teachers and many of the “chores” were actually singing performances! Our CCA kids are grateful for anything those creative students were willing to do to raise funds to help other kids!



Jason and Amy Cosmay, Suzanne, Joyce and Eric Ronczka

**Suzanne Ronczka’s sister**, Voorhees, NJ teacher, **Amy Cosmay**, garnered **\$1,000** in funds for CCA with the help of Director, **Leta Strain** and the **Drama Club** at **Voorhees Middle School**, where Suzanne attends. Thanks Amy!





Katilyn Whicker (left), winner of a Ty basket during Chinese raffle, with CCA Program Director, Annie Reeves

## more fundraising news...

The 'Chance' Raffle, held during the CCA Annual Family Retreat raised almost **\$1,000** in just a few hours. Wonderful gift baskets from hometowns and states across the nation were provided by retreat attendees along with miscellaneous goodies by other families and donors. Each family received their first ticket free at registration and after that, tickets were purchased in strips of 20 for \$5 and dropped into the drawing for whichever prize one wished to win. The drawing was held during the retreat Family Night and winners spent the rest of the weekend figuring out how to haul their goodies home! The event was lots of fun and we all learned that the more you enter, the more you win!

**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](mailto:AReeves@ccakids.com). As an added bonus, the online version is in full color!

# 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](mailto: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](http://www.ccakids.org) website
- Annual Cher's Family Retreats
- Public awareness
- Family networking
- Advocacy

## ira charitable rollovers

### did you know?...

During 2006 and 2007, the newly enacted IRA rollover provision permits individuals age 70 1/2 and above to make charitable donations of up to \$100,000 from Individual Retirement Accounts (IRAs) and Roth IRAs without having to count the distributions as taxable income. The IRA Charitable Rollover is intended to benefit donors of all incomes as well as nonprofit organizations like CCA.

Now is your opportunity to take advantage of this valuable incentive as only contributions made between January 1, 2006 and December 31, 2007 are eligible for the enhanced tax benefit. Contact your tax advisor or check online at [www.treasury.gov](http://www.treasury.gov).

# donors, january 1 – june 30, 2007\*

## Gifts from Individuals

### CCA Supporters (\$25 to \$100)

Anonymous  
Sharon Allbright  
Estate of Charles & Wilmetta Allen  
Carolyn Alloway  
Lynn Arthur  
Julie Baird  
Donna Ball  
Peggy J. Banks  
Glenn A Berard  
Eleanor & Charles Berglund  
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Mina Mulvey  
Janell Nelson  
Stan W. Nelson

Patsy Ng  
Hugh Ann Payne & R. Tucker Attebery  
Greg & Margaret Patterson  
Dorothy "Ann" Poindexter  
Marie Quaranta  
Annie Reeves  
Ronald & Dianne Remillard  
Joseph Robison  
Christine & Pedro Rodriguez  
Paula Scheffman  
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Richard & Mary Skoumal  
Charlene Smith  
Cheryl Smith  
Harry E. Smith  
Milton Orin Smith  
Frances Stanford  
Herbert Stentzel  
Christopher Stokes  
Paul & Ginny Tague & family  
Irina Temkin  
Robert Vargas  
Maria Guadalupe Vazques  
Ted Verdone, Jr.  
Diana Weber  
Michelle White  
Stephen Wright  
Susan E.R. Yelton  
Donald & Anna Zaengle  
John Zaengle

### CCA Friends (\$100 +)

Anonymous  
James Antoun & Jamie McMillin Antoun  
Douglas Bolduc  
Wendi Borges  
Ann & William "Doug" Burgin  
Lee & Linda Conway  
Sharon Couzens  
Diana Critchlaw  
Dede Dankelson  
Dianne Erwin  
Maria & Mike Estrada  
Hope Evans  
Vincent Farina & Leigh M. Soda  
John & Carrie Follett  
Mary Garber  
Charles Michael Gerber  
Jill Gorecki  
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Paul Schmidt  
Rose & Fred Seitz  
Glenn Eugene Thomas  
Harvey Weiner  
Gregory Wesley  
Cynthia Wills  
Reed Wills  
Kenneth Wilson

### CCA Extended Family (\$500 +)

Fred & Judi Freeman  
Mary Lytle  
Jana & Hugh Peace  
Neal E. & Margaret R. Schmale  
Kevin & Jennifer Trapani  
Courtney Vincent

### CCA Sponsor (\$1,000 +)

Jane L. Goodman  
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!"  
Bebensee Elementary first grade teachers, in honor of music teachers Ms. Scott and Mrs. Atchley  
Ann & William "Doug" Burgin, in the name of Rick Dornier  
Larry Carpenter, in honor of Cher's birthday  
Lee & Linda Conway, in honor of Quentin Zaengle  
Dede & Darin Dankelson, in memory of Pauline Burzio  
Maria & Mike Estrada, in honor of, Antonio Estrada from Grandpa & Granny Estrada  
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  
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  
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  
Freda Phifer, in honor of Jeremy Dale  
Catherine & John Romero, in honor of Matthew Romero & Dr. Fearon  
Dorothy Poindexter, in honor of CCA Children  
Rainbow Club, in honor of Jeremy Dale  
Annie & Tommy Reeves, in memory of Pauline Burzio  
Jere C. & W.A. Robertson, Jr., in honor of Jane Monell  
Paul Schmidt, in honor of Peter Dankelson  
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  
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)  
AT&T (Employee Giving Program / United Way Campaign Employee Giving)  
Bank of America (United Way Campaign Employee Giving)  
BeautiControl by Debbie Furman, Manuela Shields, Diana Weber, Lynn Esposito, Patty Wyant  
Birds Rotisserie Chicken Café  
Century Lodge No 492, Order of Odd Fellows  
Cher Convention  
CFC Baltimore  
CFC Central Florida Area  
CFC Central Texas  
Cherry Point CFC, UW Coastal Carolina  
CFC Chicago Area  
CFC Community Health  
CFC Community Health, Baltimore, MD  
CFC Eastern Massachusetts  
CFC Fort Campbell Area  
CFC Gateway  
CFC Global Impact, Overseas  
CFC Greater Douglas  
CFC Greater Southwest Texas  
CFC Hawaii Pacific Area  
CFC Huntington, Greater Cleveland, OH  
CFC Huntsville, AL  
CFC Kitsap & Mason Counties  
CFC LA Area  
CFC Maricopa County  
CFC Mid Georgia  
CFC Newark, NJ  
CFC New York City  
CFC Niagara Frontier  
CFC Northern Alaska  
CFC Northwest Louisiana



CFC Oak Harbor, WA  
 CFC Orange County  
 CFC Philadelphia Area  
 CFC Pikes Peak Region  
 CFC Principal Combined Fund Organization, San Antonio, TX  
 CFC Quantico  
 CFC San Diego  
 CFC San Francisco  
 CFC South Hampton Roads  
 CFC of South Puget Sound, Tacoma, WA  
 CFC Southeastern MI  
 CFC Southeastern NC  
 CFC Southern Alaska  
 CFC Southern Nevada  
 CFC Southwestern Idaho  
 CFC United Way of Yellowstone County  
 Coachella Valley Twenty-nine Palms Area CFC  
 Consolidated Sales and Engineering by Mike Wiese  
 Directed Technologies, Inc. by Fred & Rose Seitz  
 Funding Factory  
 Green Tomatoes Craft & Antique by Sandra Morisseau  
 Hewlett-Packard (Employee Giving)  
 Hiznay & Associates by Mandie Hiznay  
 Houston Katz's  
 The Industrial Company, by Marsha Chivers  
 Neal Oral & Maxillofacial Surgery, PLLC  
 Network for Good (donors listed separately)  
 Osteomed, LP  
 Penn, Schoen & Berland Assoc., Inc.  
 The Prudential Foundation (Employee/Matching Gifts)  
 The Prudential Foundation, Matched Gift of Diana Critchlaw  
 Rainbow Club, by Doadie Wyshock  
 Romeo & Associates, by Fred & Kim Romeo  
 Safeway, Inc. (purchases percentage incentives)  
 Sarah Hall Productions  
 Schoolpop, Inc. (purchases percentage incentives)  
 Schwab Charitable Fund (funds management for donor)  
 Simrick Inc., Taco Bell  
 Steve's Discount Muffler by Steven & Joell Johns  
 Superior Bonding by Victor & Debi Montoya

Three Rivers CFC  
 Tri-Community CFC  
 United Way of Brevard, CFC  
 United Way of Buffalo & Erie County, CFC Niagara Frontier, NY  
 United Way of Central Maryland (directed donations)  
 United Way of Fresno County, CFC  
 United Way of Jackson County, CFC  
 United Way of Metropolitan Atlanta, CFC  
 United Way of Metropolitan Dallas, CFC  
 United Way CFC, New Orleans  
 United Way of Northeast Florida, CFC  
 United Way of Palm Beach County, CFC  
 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 Funds Management  
 Wells Fargo Community Support Campaign (Employee Giving)  
 YTB Travel Network, Inc. (purchases percentage incentives)

### CCA Corporate / Foundation Sponsors (\$1,000-\$5,000)

CFC Global, National Capital Area  
 A grant from CVS Pharmacy  
 A grant from The Minneapolis Foundation, recommended by Travis & Christa Rymal and Family  
 The Redwoods Group (Matched Gift of Bill Mecklenburg)  
 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

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  
 Katz's Deli Fundraising Table / Jennifer Guerra, 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  
 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  
 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  
 Pete's 5th Annual Scramble for CCA / Dankelson Family

# more workplace contributions to cca!

## America's Charities

CCA is a member of America's Charities, a respected leader handling employee giving campaigns that represents more than 125 of the nation's most known and trusted charities. Since 1980, America's Charities has distributed more than \$300 million to more than 3,000 charities.

Member charities must demonstrate fiscal responsibility and deliver effective services meeting genuine needs in areas such as education, the environment, and health.

## your fair share

### did you know?...

When the United Way Campaign at work asks you to contribute your fair share or any amount, you can designate that funds go to Children's Craniofacial Association by indicating our nonprofit # 75-2265649 on the form. That way you'll be helping your workplace reach their goal as well as helping your charity and this important cause! Thank you!

## 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.

\*Listed are Monetary Donations of \$25 or more through 2nd 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)

# donor in the spotlight

This issue, the **Mecklenburg family** "shines" as donors making a big difference for CCA. **Christine (Condino)** and **Bill Mecklenburg** donate yearly and also have their donations matched by Bill's employer, **The Redwoods Group** (Bill is the COO at this North Carolina firm that offers commercial specialty insurance; the CEO there also donates to CCA, in honor of **Morgan Mecklenburg**, Christine and Bill's 11-month old daughter, who was born with craniosynostosis.)

Along with their cash donations and the giving they've inspired in others, the family supports our cause in any way they can. Christine started a buying trend in the family with a purchase of, among other items from our web store, a **CCA silk tie** for Bill (see photo!) to celebrate their anniversary a few months back. Bill liked his tie so much he bought 5 more to give to others.

Most recently, the Mecklenburgs helped sponsor our Annual Family Retreat by providing all of the Retreat T-shirts needed for every attendee. They even found a supplier, their friend **Steven King** at **The**



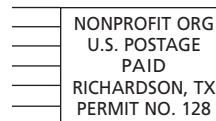
**The Mecklenburg Family: Bill, Christine and Morgan**

**Cotton Exchange**, who had the quality shirts produced to CCA specifications and delivered to the event city, already folded! That saved CCA staff and volunteers hours of time as well!

We are truly grateful for the Mecklenburg family, our Summer 2007 Donor in the Spotlight.

## children's craniofacial association

13140 Coit Road, Suite 517 • Dallas, TX 75240



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Cher

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