ccanetwork

newsletter of the children's craniofacial association
Cher — honorary chairperson
spring 2007

inside

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

getting to know olivia

By Karla Dean

Olivia and I are spending a rainy March Friday morning at Children's Hospital of Philadelphia (CHOP). We managed to schedule three appointments all in one morning. Many long days are spent here at CHOP, as CCA families know only too well! While we are waiting to be seen, we thought this would be a great opportunity to tell Olivia's story.

Olivia is 13 years old and was born on Friday, October 13 1993. She even turned 13 on Friday the 13th of October. We are not superstitious at all though!

She was a full-term healthy baby girl born with great big blue eyes. It turns out that those great big blue eyes were a telltale sign of something that was not diagnosed until Olivia was four years old.

see **olivia,** page 6

message from the executive director

With the year nearly half over, CCA continues to be focused and working toward our goals. Finding ways to better serve our families' needs requires having clear goals and having a clear path to achieve those goals. To that end, the CCA Board of Directors and staff met in January in Fort Worth, Texas, to assess 2006 accomplishments and determine goals and objectives for 2007.

It is important for CCA's leadership to come together, once a year

see **chairman,** page 10

empowering and giving hope to facially disfigured individuals and their families

At left: Bryttani Gore in her second grade photo
Below: Bryttani through the years

meet bryttani gore

Eight-year-old **Bryttani Gore** is a second grader who loves reading, math and writing. After school, you can find her playing games, getting creative with crafts, or enjoying a good book. She also loves spending time with Abbey, her half beagle/half German shepherd dog.

One of Bryttani's hobbies is collecting. She has collections of water globes, piggy banks and porcelain dolls. She and her mom also have a big collection of Barbie dolls that is only to "look at, not touch."

Bryttani likes to watch TV shows, including "Dora the Explorer," which is "cool," "Go Diego Go," "Lazy Town" and "Sponge Bob." Her favorite, however, is "Madeline."

Her all-time favorite movie is "Annie." In fact, she's seen the movie 11 times and knows all the words to the song, "Hard-Knock Life." For her birthday last year, her family surprised her by taking her to see the play Annie at a nearby theater. It was opening night, and Bryttani dressed up in her Annie dress and shoes. She got a huge surprise when the lights went out, the curtain went up and she started to hear the songs she loves. After the show, she got the autograph of the girl who played Annie.

Last October, Bryttani participated in the Special Olympics of Delaware, where she won a gold medal for individual soccer skills. In January, she won a silver medal for bowling, and in March, she won another gold medal for individual basketball skills.

Bryttani went to her first CCA retreat in 2004, where she had fun and made a lot of friends. She and her family look forward to going to CCA's next retreat in the summer of 2008.

Bryttani was born with a facial cleft and is missing one of her eyes. However, she has a tremendously positive outlook on life, and she offers some good advice for other kids with craniofacial differences. **Bryttani believes that she is special because God made her special;** therefore, she believes that others in similar situations are just as special, too. With her positive attitude, she always gives anyone extra encouragement, telling them that they can do it because she knows they can.

ccakid

ccateen

quentin's story


Quentin Zaengle

My name is **Quentin Zaengle,** and I am 14 years old. I was born March 1, 1993.

When my mom was expecting me, she and my dad didn't know I had Apert syndrome. My mom had a few ultra-sounds because they thought my head looked different, but the more ultra-sounds that were done, the more the doctors thought everything was ok.

After being in labor for more than 24 hours, my mom was told she needed to have a C-section. When I was born, the OB/GYN that delivered me specialized in genetics and knew right away I had Apert syndrome.

That night I was rushed to Children's Hospital of Philadelphia (CHOP), where I spent two weeks being evaluated by a team of doctors. I had my first forehead advancement surgery when I was five months old. I had several surgeries on my hands when I was between one and two years old.

When I was 1 1/2, I had a spinal fusion surgery because I had Kyphosis. I spent nine months in a full body brace. I had many minor surgeries after that.

My next forehead surgery was an emergency two weeks before Christmas when I was in first grade. Luckily, I came home Christmas Eve, just in time for Christmas.

My one and only mid-face surgery was the summer going into second grade, where my craniofacial surgeon, **Dr. Scott Bartlett,** inserted internal distracters and my parents turned them with a key. My parents took pictures of me every day since my profile changed with each turn.

I've had surgeries since then, but they were minor compared to my mid-face operation. My parents are so grateful for all my doctors and surgeons at CHOP, especially Dr. Bartlett, who has done wonders for my face and made me "one handsome guy" as my mom always says. In April 2003, Dr. Bartlett even invited my mom, dad and me to speak at CHOP's largest fundraiser, Daisy Day, at the Bellevue-Stratford Hotel in Philadelphia. He showed some before and after pictures of me, and mom and dad spoke on stage to tell my story during a luncheon. I even got to talk, too.

I attended Gwyn Nor Elementary School, where I was mainstreamed with all my classmates. I then went to middle school, where I am mainstreamed for all my minor classes; my major classes are taken in learning support.

I have always liked school, and I especially like middle school. When I graduate I want to go to college to be an historian. I like reading history facts about countries, kings and queens. I also like reading biographies and learning about people in history. When I am older, I want to travel to other countries.

In my spare time, I read a lot of history books and Google history dates. I really like to play computer games. I like to visit museums. I play soccer and baseball, and I like to play kickball outside with the neighborhood kids.

I am also a Boy Scout. I recently earned my Tenderfoot rank. I also like camping with the Boy Scouts. I just got picked to be the troop historian, so I get to take pictures on our next trip and maybe help write an article for the scout newsletter.

A few summers ago, I took a kayak lesson with my two sisters and my cousins – it was so much fun! I get to kayak at my Mema and Bepa's who live in Pawling, NY. I like visiting them a lot because they live out in the country. They live near a lake, and they have kayaks and paddle boats that we get to use when we visit in the summer. We fish there, too. Last year I caught a bass and a pickerel.

I especially like to just be with my family and do fun things with my mom, dad and two sisters Annalise, who is 13, and Lea, who is 10.

Lea and Annalise Zaengle

meet annalise and lea zaengle

I'm **Lea Zaengle** and I'm 10 years old, and my sister, **Annalise**, is 13 years old. Our brother is **Quentin**, and he is 14 years old.

Quentin makes us laugh with all the history facts he knows. When we play trivia games, Quentin knows most of the answers. Some day he wants to be an historian, and he should because his favorite hobby is to Google history dates and learn facts.

Our favorite thing to play with Quentin is kickball with the neighborhood kids in our front yard. We enjoy watching movies with Quentin and joining him on the couch when he's watching his favorite shows—anything on the History Channel or Discovery Channel.

Annalise plays soccer for the township and I play volleyball and softball for her school. Both of us swim competitively on summer and winter swim teams, and this year we are playing water polo and really like it. Quentin comes to our matches to cheer us on, and we hear him yelling from the stands, especially when we get dunked. We're going to miss our last match because we're going to see the play, "Wicked," in New York City with our cousins and are staying at our aunt's bed and breakfast.

We go to Mary Mother of the Redeemer school. Annalise is in seventh grade, and I'm in fifth grade. We've never been in the same school as Quentin, so sometimes we have to explain to our friends that Quentin is a brother who has Apert syndrome.

One day a year the three of us get out of school to go with our Dad to his office for "Bring Your Kids to Work Day," and we like that a lot. Our mom owns a Paint Your Own Pottery studio with her sister, and sometimes Annalise helps out with birthday parties. We've been thinking about doing a fundraiser for CCA, too.

We love going to the yearly CCA retreats, where we have met a lot of good friends. We have attended the last four retreats and are looking forward to this year's retreat in Salt Lake City, so we can see everyone again. There are lots of traditions we enjoy, like when **Andrew** sings Cher's song at the dinner dance and the ice cream social. Our family is also planning to stay a few extra days so we can sightsee and visit some of the national parks.

We were too young to know what Quentin went through with most of his surgeries, but Annalise does remember when he came home Christmas Eve with his eyes swollen—that surgery was his second forehead surgery when he was in first grade. Annalise was five years old.

We are lucky to have him as our brother. He adds a special element to our family. Even though we have our usual sibling fights, we are always there for Quentin when someone is not being kind to him.

Our parents always notice how accepting we are of people with differences and that we are caring too. We're sure a lot of that comes from having a great brother like Quentin and meeting so many different people through CCA.

ccasupersibs

donors in the spotlight

Children's Craniofacial Association highlights the kindness of donor, **Courtney Vincent**. Courtney is an Adapted Physical Education teacher (PE for mentally or physically challenged children). She found out about CCA at a Cher concert and took up the cause. She tells us, "Any child who has some type of obstacle to overcome has a special place in my heart." Courtney donates monthly with automatic credit card contributions. Her ongoing support is why she is this issue's 'Donor in the Spotlight.' Thank you Courtney!

good news

robbie Gorecki has graduated from MMI, Phoenix, AZ (Motorcycle Mechanics Institute), successfully completing the Harley-Davidson Late Model, Early Model and the Dynojet Operations I portions of the Motorcycle Technician Specialist program. Congratulations Rob!

congratulations dealynn boom jamaica!

dealynn is the winner of CCA's Jamaica raffle! She wins a complimentary trip set up by our friends at **Liberty Travel** in Philadelphia to fly Air Jamaica into Montego Bay, Jamaica for a 4-day/3-night stay at the Coyaba Beach Resort, including a set of His/Hers luggage donated by **Levinthal's Luggage** of Philadelphia.

The winning ticket was drawn by **Anita King** at Ascendix Technologies, located in the neighboring suite to Children's Craniofacial Association office headquarters.

Dealynn lives in Rexford, Montana and purchased 30 tickets from **Natalie Wardlaw's mom, Jennifer**.

The Grathoff Family:
Bob, Ann, Jon,
Allie & Emily

Speaking of selling raffle tickets, the **Grathoff family** of Commerce Township, Michigan is our winner for high ticket sales. They will receive a package of goodies including specially chosen items from our web store along with a $50 gift card to Target. Congratulations and thanks!

The effort collected over $5,000 in funds for CCA! Thanks to everyone who bought and / or sold raffle tickets.

Olivia at nine months old

olivia, from page 1

It was brought to our attention by a relative that Olivia's appearance was different. With only spending 10 minutes in the Genetic Department at CHOP they were able to tell us that Olivia had Crouzon syndrome. After her diagnosis, we completed a series of tests and were thankful to find out that her case was very mild. This is why it was missed to begin with. Olivia did have crainosynostosis that was detected with no cranial pressure.

Six months passed, and we came to this very place (CHOP) for a routine eye exam. To our surprise the ophthalmologist detected that Olivia could not see anything from her right eye. She had a normal eye exam at her pediatrician six months prior to this visit. This came as a shock to all of us.

That same day, we had an appointment with our plastic surgeon. When I told him the outcome of Olivia's eye exam he became very concerned and sent us directly up to meet a neurosurgeon.

After an extensive medical work-up, Olivia was scheduled for emergency surgery. The craniosynostosis came into play and caused cranial pressure. The right optic nerve had been squeezed; blindness of her right eye was the result of the pressure. She had also developed a Chiari Malformation, which also was a result of the pressure to her brain.

I'll never forget discussing Olivia's surgery options with her neurosurgeon as he proceeded to show us an X-ray of Olivia's skull to help us understand. Being a CT scan technologist myself, I am familiar with X-rays. The appearance of Olivia's skull resembled that of bubble wrap; it did not have the normal smooth bone appearance. This quickly brought us to realize how serious this really was and how much pain Olivia had to be enduring.

Just four days from the time she was diagnosed with blindness, we were prepared for her surgery. It all happened so fast, and my husband Bill and I were mostly numb through the whole process. Her surgery consisted of three procedures. Her neurosurgeon and plastic surgeon released the cranial pressure by opening both her coronal and sagital sutures. They did some reconstructive work to her orbital margins to make her eyes appear smaller. Then, last but not least, they removed a small part of skull at the base and part of Cervical 1 (C1) to allow the Chiari to dangle freely.

Olivia came out of this nightmare without any complications. Four days after her surgery, she actually walked out of the ICU department with a teddy bear under one arm and the other hand was used to keep open a swollen left eyelid so she could see her way out. Home we went!

We were hopeful of her regaining partial vision to her right eye. We did many hours of eye patching but with no success. The damage to the optic nerve was done.

The only other major surgery Olivia will need is her mid-face advancement. We are planning to possibly have this done next summer, before she enters high school.

Our family was introduced to CCA by **Diana Sweeney**, a liaison for plastic surgery at CHOP. Diana was such a tremendous source of help and comfort to us at a very scary time.

Our first CCA retreat was in Atlanta. **This was by far the best experience of our lives as a family. The friends we have made through CCA could never be replaced.** Being able to connect with families that are dealing with issues much larger than ours has helped us realize just how blessed we really are. Knowing how mild Olivia's syndrome is compared to children we have met through CCA just helps us keep everything in perspective. Olivia has teenager, and I believe CCA has done much to contribute to this.

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Olivia at three years old – still not diagnosed!

Olivia at two years old

Olivia has an older sister and brother, **Leah** and **Jordan**, who keep a very protective watchful eye out for their baby sister. Olivia is a typical teenager who is always on the go! She loves to spend time with her many friends and family. She attends a small parochial grade school and has been with most of her friends since kindergarten. There has never been an acceptance issue because of her appearance since day one. Her friends never really have viewed Olivia as being different. She is in seventh grade and is a straight "A" student who works very hard.

If she is not on the computer, listening to music, reading, watching movies, cooking with her grandmother or goofing off with her friends, you can be sure to find her dancing! This is Olivia's passion. Olivia has taken dance lessons of all types since she was six years old. She currently takes modern dance and ballet lessons. Growing up in Philadelphia has given her many wonderful dance opportunities.

Well, our morning is coming to an end at CHOP, and we are making good progress. We left the ENT Department and are headed to Orthodontic/ Plastic Surgery. Olivia will be receiving an even brighter smile today—she begins the first phase for braces.

Hope to see you all in Salt Lake City with our brightest smile ever!

Olivia at twelve years old with two friends at the 2006 retreat in Hershey, PA. All three girls have been diagnosed with Crouzon's.

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.

anthropology and craniofacial anomalies

By John C. Kolar, PhD

Children with craniofacial anomalies show a wide range of cranial and facial features. For a surgeon whose goal is to reconstruct the heads and faces of these children, it is very important to understand as precisely as possible what kind of problems they are dealing with, what the results of their surgical procedures are and how these children grow, so they can produce the best results possible from these surgeries. All of this requires some way of measuring the heads and faces of their patients.

Taking measurements

There are many ways to take measurements. The most common is cephalometry, taking measurements from x-ray films. This is standard practice in orthodontics and jaw surgery. Measurements can be taken from both 2-D and 3-D CT scans and new 3-D camera systems that allow measurement of surface dimensions of the face from computer-generated images. All of these methods of measurement have developed from a much older system of measurement known as anthropometry.

What is Anthropometry?

Anthropometry is the measurement of the human body and its parts, which includes the head and face. The technique was invented more than 350 years ago and is the foundation of all later systems of measurement. Anthropometry was invented by a German anatomist named Johann Sigismund Elsholtz when he was a graduate student at the University of Padua in Italy. Elsholtz was interested in studying the symmetry of the human body but there were no instruments or standard techniques to do this, so he had to create them. He invented an instrument he called an anthropometron. This was a vertical rod which he divided into six equal parts he called pedis (feet). He then subdivided each foot into 12 equal parts he called uncias (inches). Elsholtz finished his device by attaching a horizontal slide to this rod and mounting the whole thing on a wooden base.

The examination

An anthropometric examination is relatively simple, inexpensive and non-invasive. To be accurate, it should be performed by someone with training in the techniques, preferably an anthropologist with a graduate degree and experience in taking the measurements. Most of the measurements are taken with standard anthropometric calipers and a tape measure, but there may be a few special gadgets used, depending on the exact set of measurements taken.

The examination itself involves a set of surface measurements of the head and face. The number of measurements varies from center to center, depending on the preferences of the person doing them, but can range upward from as few as 20 to 25 to as many as 75 to 125. The greater number provides more detailed information about your child's head and face but also increases the length of the exam. The time involved can be as short as 15 to 20 minutes and requires little more of your child than to sit in a chair and be measured. The measurements are taken in short sets, two to three at a time, so there is plenty of time to fidget in-between and for you to ask questions. Children usually regard this with interest or tolerance, though very young children may become impatient.

The first set of measurements provides a baseline that is used to track your child's growth and development from then on. Ideally, it should be performed before any surgery is done. The measurements, and a series of proportions that are calculated from them, only begin to have meaning when they are compared to normal standards which are matched to the sex and age of the patient. This gives your surgeon a numerical description of your child's anomalies which is more precise than visual observations.

The timing of the next measurements will depend on your surgeon's recommendations for treatment. If your child is not having surgery immediately, they would be re-examined in a year. By comparing the two sets of measurements, we can see how their head and face and all its parts are growing. This information can help your surgeon decide on the timing, nature and extent of the surgery they recommend.

If your child has surgery very soon after their examination, the follow-up

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changes. Their next exam would be about six to eight weeks after surgery. This allows time for their postoperative swelling to go away and the surgery to heal, but is close enough to their first examination that growth will not affect the measurements. The postoperative exam is much shorter and focuses on the area of the surgery. This allows us to see exactly how the head or face has been changed, which means that when your child is seen again in a year, we can see how growth is affecting the surgical results.

The anthropometric examination should be repeated annually until your child is fully grown. This isn't always practical, but it is a goal to aim for. As your child gets older, and growth of the head and face slow down, they may skip a year or two without any affect on their treatment plan.

Advantages and disadvantages

Anthropometry has several advantages over more complex techniques for collecting information about craniofacial anomalies. A skilled anthropologist can gather much more information about the size and shape of the head and face with these measurements than is possible at present using computer imaging techniques, whether CT-based or 3-D camera systems. Because it is non-invasive, it can be repeated whenever needed without much cost and risk.

On the other hand, it has one important disadvantage. Because these measurements are taken directly from a patient, they cannot be duplicated because that patient grows and the measurements change. Computer-based measurements can be taken from stored data, so they can be re-done at a later date as measurement techniques change and improve, and are becoming more and more important to our understanding of craniofacial anomalies. The foundation of these techniques, though, remains anthropometry.

In the long run, all of this data provides a benefit to many more people than a single child. As we gather this information from larger and larger groups of patients, we can separate the data by diagnosis and combine the results for individual syndromes to re-define the characteristics of each syndrome. We also learn about the growth patterns in each syndrome, which can help the surgeons refine their surgical techniques. All of this will benefit children with craniofacial anomalies well into the future.

in memory of pauline

This issue of the CCA Network is dedicated to the memory of **Pauline Burzio**, 13, who went to be with the Lord on April 8, 2007. Pauline and her family attended the Annual Family Retreat and the Burzio family is very involved with CCA. You may remember that Pauline was featured in the winter 2007 *ccanetwork.* Pauline was a fun loving girl and always had a smile on her face. Pauline lived in Berryville, VA, and is survived by her parents Bret & Catherine and three brothers, Ashton, J.B. and August. Pauline will be greatly missed by all of us. We would like to leave you with the lyrics to one of Pauline's favorite worship songs.

My Savior, My God

by Aaron Shrust:

I am not skilled to understand
What God has willed,
what God has planned
I only know at his right hand
Stands one who is my Savior

I take Him at His word and deed
Christ died to save me this I read
And in my heart I find a need
For him to be my Savior

That He would leave
His place on high
And come for sinful man to die
You count it strange, so once did I
Before I knew my Savior

My Savior Loves, my Savior Lives
My Savior's always there for me
My God He was, my God He is
My God He's always gonna be

Yes living, dying let me bring
My strength, my solace
from this spring
That He who lives to be my King
Once died to be my Savior

That He would leave
His place on high
And come for sinful man to die
You count it strange, so once did I
Before I knew my
Savior

chairman, from page 1

outside of regular bi-monthly board of directors meetings, to look at our strategic plan and make sure we are staying on track. As we go about our work, our focus is on our families and their needs. When we make decisions developing our plan, we are mindful of what is important to our families and what they have told us they need. We are also mindful to fulfill our mission **to empower and give hope to individuals with facial disfigurement and their families.**

So, in 2007 we will continue to "get the word out" so we can reach many more families. Our most important goal is to double the number of families CCA serves by 2009. To accomplish this goal, we will enhance our national outreach program, increase the number of syndrome booklets in our series, provide booklets for our Spanish-speaking families and offer more scholarships to the annual retreat. In addition, we continue our networking program, help our families with financial assistance to travel to quality care and, as you have determined most important, continue to hold the annual retreat.

As baseball great Yogi Berra said, "If you don't know where you're going, you'll end up someplace else." Trust that your leadership at CCA is diligent about knowing where we are going and determined to get there.

Charlene Smith
Executive Director

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.

planning a vacation?

There's a new way to support your charity! 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.

calendar of events

date	event	contact
June 28-July 1	**17th Annual Cher's Retreat**	AReeves@CCAkids.com 214.570.9099 800.535.3643
July 15-20	**Camp About Face** Bradford Woods Outdoor Education Recreation and Camping Center Indianapolis, IN	contact? 317.274.2489
July 22-24	**2007 North American Craniofacial Family Conference** Alexis Park Resort Las Vegas, NV	debbie@aboutfaceusa.org 888.486.1209
August 25	**Second Annual Wendelyn's "Course of Dreams" Golf Challenge** Country Club of Arkansas Maumelle, AR	wendelynyvonne@hotmail.com
October 13	**Third Annual Friends of Jeremy Golf Event** Willowcreek Golf Club Big Flats, NY	gdale@stny.rr.com www.friendsofjeremy.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** 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.)

Looking for ideas?

Contact Jill Gorecki at
J.Gorecki@ccakids.com

NEW IDEA!

- **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

Alex Smith, 4, poses for this issue's "Mug Shot" with his CCA mug purchased by CCA Friends, Kent & Stephanie Smith of Dallas, TX.

cca mugshot

When you purchase a CCA Logo Mug, send us a snapshot of you with your mug for a "Mugshots" section… each newsletter we'll post new mugshots!

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

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.

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!

Kent Smith is "dashing" in his royal blue CCA tie!

tie one on for cca

Vineyard Vines, well-known producer of 100% fine silk ties and other products sporting whimsical motifs, has created a tie especially for CCA donors and friends, using the happy faces on our charity logo.

These high-end quality ties come in a choice of two popular background colors, light blue or royal, and may be purchased for $100 each, gift-boxed and delivered.

The first 100 CCA logo ties were produced to observe the month of September, proclaimed by CCA as "National Craniofacial Acceptance Month" and some are still available.

Please, wear one in support of your charity and to raise awareness that fosters acceptance of individuals with facial difference. Call our office or go online to order your ties!

Peter's dad, Darin Dankelson, sports the light blue CCA logo tie.

fundraising news

Brenda and George Siebert, Melissa and Jon

CCA expresses apologies for this late "kudos" and special thanks to **Brenda Siebert** and her business, **Fine Design**. Last fall Brenda had an anniversary sale advertised to the public donating 10% of every Christopher Radko ornament sold to CCA. Sales of $1,500 garnered a donation of **$150**. Her effort was part of our September observance of Craniofacial Acceptance Month.

BEAUTICONTROL.

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!

Wayne Smith entertains as Cher's "Laverne" character

Ivana Tramp portrays Tina Turner to help raise funds for CCA

Wayne Smith as Cher

tony's Wine Warehouse and Restaurant was the setting where Cher Convention volunteer and CCA favorite, **Wayne Smith** portrayed the diva herself at a wine tasting dinner and auction and raised more than **$3,000** for Children's Craniofacial Association. Wayne entertained as Cher and as her alter-ego Laverne for more than 3 hours and even got his friend, **Ivana Tramp** to make a guest appearance as Tina Turner. Thanks to Wayne, Ivana, and everyone at Tony's!

regional volunteers

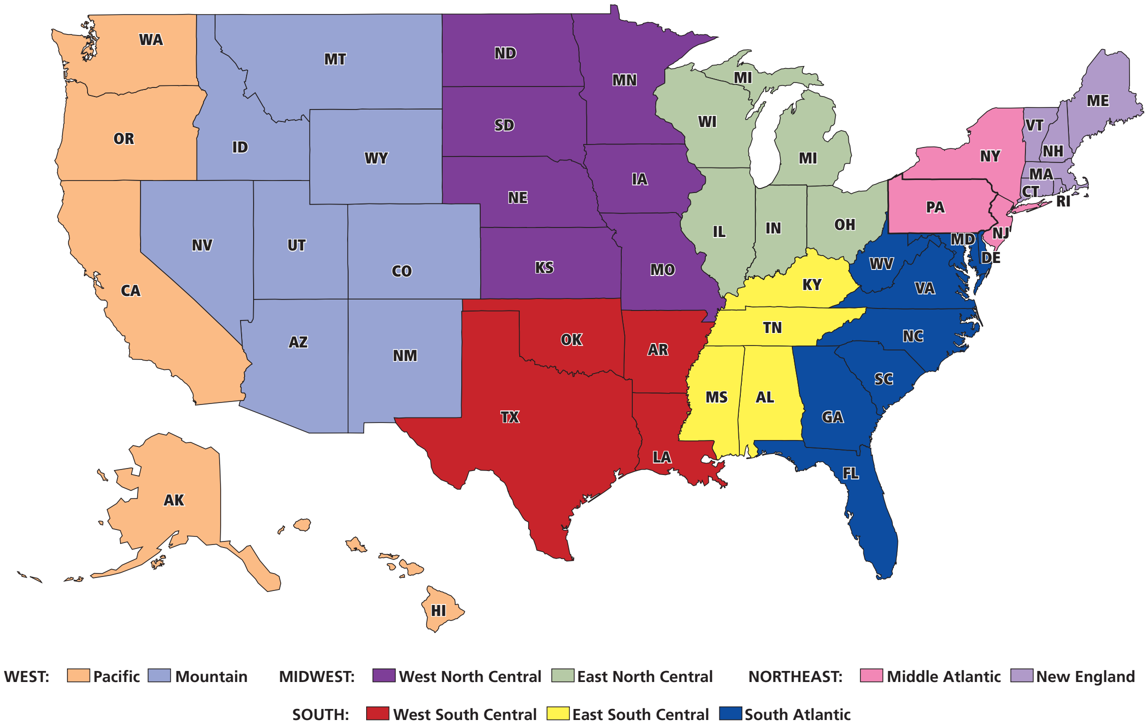
Public awareness about craniofacial conditions is important on several levels.

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.

CCA has formed a network of regional volunteers across the country who have banded together in an effort to educate and inform the public. The regional volunteers and CCA will now turn to local areas to recruit volunteers who will distribute educational materials throughout their communities.

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.

CCA Regional Map



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

donors, january 1 – march 31, 2007*

Gifts from Individuals

CCA Supporters
(up to $100)

Anonymous
Dianelis Adams
Sharon Allbright
Estate of Charles & Wilmetta Allen
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Milton Orin Smith
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Ted Verdone, Jr.
Stephen Wright
Donald & Anna Zaengle
John Zaengle

CCA Friends
($100 +)

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Lee & Linda Conway
Diana Critchlaw
Jerry Lynn & Dianne Erwin
Maria & Mike Estrada
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Greg Parkinson
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Glenn Eugene Thomas
Courtney Vincent
Gregory Wesley
Kenneth Wilson

CCA Extended Family
($500 +)

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($1,000 +)

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!"
Lee & Linda Conway, in honor of Quentin Zaengle
Maria & Mike Estrada, in honor of, Antonio Estrada from Grandpa & Granny Estrada
Sidney Goldman, in honor of grandson, Evan Goldman
Jill Gorecki, in honor of Char Smith
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
William & Juanita Luyben, in honor of Cole Macasieb
Harry "Sonny" Smith, in the name of Wayne Smith
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 Thomas B. Weber
Gregory Wesley, in honor of Chase Ingram
Willamette Christian Center, in honor of Brenna Johnston

Corporate / Foundation Gifts

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

America's Charities (Employee Giving Funds Management)
American Express Company (Employee Gift Matching Program)
American Express Company (Employee Giving Campaign)
AT&T (Employee Giving Program)
Birds Rotisserie Chicken Café
Cher Convention
CFC Principal Combined Fund Organization, San Antonio, TX
United Way, New Orleans CFC contributions
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United Way of Fresno County
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CFC of South Puget Sound,Tacoma, WA
Funding Factory
Houston Katz's
The Industrial Company, by Marsha Chivers
Network for Good (donors listed separately)
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The Prudential Foundation (Employee/Matching Gifts)
The Prudential Foundation, Matched Gift of Diana Critchlaw
Safeway, Inc. (purchases percentage incentives)
Sarah Hall Productions
Schoolpop, Inc. (purchases percentage incentives)
United Way of Tarrant County (directed donations)
United Way of Tucson and Southern Arizona
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)

A grant from The Minneapolis Foundation, recommended by Travis & Christa Rymal and Family
Vivo Brothers, Inc.

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

A grant from Fed Ex

Fundraising Events

Up to $1,000

BeautiControl / Rose Seitz, CCA Volunteer
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

Tony's Wine Warehouse "Cher the Love" Event / Wayne Smith, CCA Volunteer

$5,000 or more

CCA Jamaica Rafle

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*Listed are Monetary Donations of $25 or more through 1st 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.

3cheers for volunteers!

natalie Criswell has become a very active volunteer for CCA after attending her first retreat in Hershey, PA. She and her son, three-year-old **Guerin**, who was born with frontal nasal dysplasia, helped our regular newsletter volunteers label the February newsletter.

Natalie is also a local volunteer in CCA's national awareness effort. In that capacity, she distributes packets to local Dallas-area hospitals. Natalie and Guerin are becoming regulars at the CCA office, helping out with a variety of tasks. Many thanks to Natalie for all of her volunteer efforts!

children's craniofacial association
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