

ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

spring 2009

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yoli's story

Michael and Paula Flores, proud Daddy and Mommy of Jolene

I first saw **Jolene (Yoli)** when I went to Adopt Us Kids. When I saw her face I knew I loved her. I got my husband and boys to come see her, and they thought she was adorable. We made contact with her CASA worker, and it seemed like a lifetime before we finally got the call that we had been the family chosen to adopt Jolene. It took almost 3 years from that first contact to bringing her home with us.

When I saw her picture, I thought she had Down syndrome, but after reading about her and seeing she had

see **yoli**, page 8



message from the chair

Last October, the board met and updated CCA's strategic plan, setting the objectives for the organization over the next several years. It will be used to measure our progress and to make sure all our actions are aligned with our mission of empowering and giving hope to individuals and families affected by facial differences.

As we move into 2009, the board and staff are using this strategic plan to focus on what it will take to move CCA through the next 20 years. Four traits figure prominently in this plan.

see **chair**, page 12

meet sara skarshaug

Sara Skarshaug, this issue's CCA Kid, is a 10 year old from Traverse City, MI. She attends a local Montessori school, where she is in the fifth grade. She recently had spring break and enjoyed the time off from school.

While at school, she loves her language classes the best. There she reads, studies grammar and writes stories. Right now, she's reading the Magic Treehouse series and is almost finished with the City of Ember series, two of her favorite book collections.

Her love of reading extends beyond school. Sara has been part of a book club for the last year

and a half and has read many novels, including, *Little Women*, *Inkheart*, *Isle Royal* and *Our Only May Amelia*, among many others.

And that's just the beginning of Sara's after-school activities — most of the week she's going somewhere or practicing something. She takes guitar lessons on Tuesdays, plays tennis on Saturdays and ice skates three days a week. Since this is her fourth year to ice skate, she's moved up to the advanced level. Sara was recently part of a synchronized skating team; last season, she and her teammates won three bronze medals. She hopes to continue skating for a very long time.

Most Friday nights are family nights, where everyone gathers to either watch a movie or play games. Recently, she's seen three movies she's particularly liked — *High School Musical 3*, *Mamma Mia!* and *School of Rock*.

As for music, she likes listening to Guster, Miley Cyrus and the Jonas Brothers. She actually saw the Jonas Brothers in



concert earlier this year and had a fantastic time.

Sara has a younger brother, **Kyle**. (He's featured in this issue's SuperSib article.) He plays tennis in her classes on Saturday and comes to lend his support at her ice skating competitions. Sara says it can be tough sometimes being the big sister as he "doesn't listen sometimes," but all in all she loves him very much.

She and her family have been to some of the CCA Retreats and had a lot of fun at every one of them. Sara has really liked meeting people that have "different symptoms" as well as visiting different places throughout the

country. She's had a chance to make friends at the retreats, with whom she really enjoys catching up every year.

Sara was born with Crouzon syndrome. She has had 21 surgeries/procedures in her life so far with more planned. In fact, her next surgery is scheduled around mid June.

She has some pretty good advice for other kids going through similar circumstances, especially if people stare or make comments. She says that if they think something about you, it's more about them, not you. She also says to just walk away from the situation. That's wise advice that everyone can heed.



ccakid

ccaadult

meet
meg
gray



I was born February 27, 1982, seven weeks early, with Treacher Collins syndrome. This type of syndrome is a facial anomaly that causes an



underdeveloped jaw as well as downward-slanting eyes and other facial features. The doctor who delivered me described my ears as looking like “cauliflower.” With that description, my mom didn’t know what to think. Her only concern was if I were going to be healthy and have a happy life.

I had a tough start in the NICU incubator. I was 4 lbs, 3 oz, and then dropped to 3 lbs, 6 oz. With the help of the doctors and nurses, I was able to get to a healthy weight. I couldn’t eat on my own at first. I had a g-tube.

My parents were able to take me home when I was 100 days old.

I also have moderate conductive hearing loss in that my ear canals are closed. Right now I wear a bone conduction hearing aid. I use American Sign Language on occasion, and it’s a nice backup when I’m in loud places or my battery is running low.

Throughout elementary school, I had a few surgeries to rebuild my ears. I had a rib graft to build my upper ear lobes. Later, I got tired of the very long process and

as a preteen, I decided on no more surgeries. I wanted to enjoy my life.

Today, I work in an Individual Options Waiver program, where I provide care for those with special needs. I enjoy spending time with my significant other, friends and family. I also like working out with Wii Fit, bike riding, seeing movies, traveling, reading and blogging.

firstgiving fundraising proposal to cca families

There's still time to get a free hotel stay for the 2010 retreat

In conjunction with the 2009 20th anniversary of Children’s Craniofacial Association and September’s Annual Craniofacial Acceptance Month, we propose a special way to reward **CCA families who raise funds for CCA.**

Beginning right after this year’s retreat and through 2009, any family raising more than \$5,000 for CCA will be awarded one hotel room at the next retreat they attend (2010) for the three-day retreat period!

This invitation is extended to everyone already holding events throughout the year and includes any type of effort, not just Firstgiving.

All those who wish to participate will be asked to sign a confirmation of understanding of the provisions of this program. Please call 800.535.3643 or email Jill Gorecki, JGorecki@ccakids.com for the forms to sign up!

Giving Back with Firstgiving

We’re pleased to provide a free CCA-customized “firstgiving” site for anyone who wants to help raise funds for CCA. Log onto firstgiving.com/ccakids and tell your personal story of why you support CCA or post an event you’re having. You can set a goal and track success. Folks will respond with contributions because they know you! This is an especially easy way to “ask” for donations if you’re uncomfortable with the face-to-face approach.



meet kyle skarshaug



I'm **Kyle Skarshaug**, and I'm eight years old. I'm in the second grade at The Children's House Montessori School in Traverse City, MI. I live with my mom and dad and my sister Sara, who is the latest CCA Kid.

My favorite things to do are swimming, BMX racing, Tae Kwon Do and snowboarding.

I just made our local swim team in December

and love swimming freestyle in competitions. I have been racing BMX bikes at our local track for three years now. In the winter, I love to snowboard at Crystal Mountain Resort near our house. This season was my first one with a snowboard. Before I just skied.

I play the drums and love all kinds of music. My favorite band right now is Flogging Molly. They are an Irish Rock Band. I also like

to read. My favorite books are the "Diary of a Wimpy Kid" series.

My sister Sara has Crouzon Syndrome. She is going to be 11 this summer. It is really hard when we have to go to the hospital for two weeks; it feels like it is forever for me, so it must be really hard for Sara. She has been going to the hospital since she was a baby. It is a four-hour drive for us so we spend a lot of time in the car going back and forth to Ann Arbor to see Dr. Buchman.

ccasupersib

calendar of events

date	event	contact
Jun 24, 2009	Craniofacial Symposium Great Wolf Lodge Grapevine, TX	ARees@ccakids.com www.ccakids.org 800.535.3643
Jun 25-28, 2009	19th Annual Family Retreat Great Wolf Lodge Grapevine, TX	ARees@ccakids.com www.ccakids.org 800.535.3643
Jul 19-22, 2009	NACFC Tuscany Suites and Casino Las Vegas, NV	www.ameriface.org
Jul 23-17, 2009	Camp About Face Bradford Woods Martinsville, IN	317.274.2489
Jul 18, 2009	Jaci's Country Dance Bash Morrisville, PA	JSamhammer@gmail.com
Aug 2-5, 2009	Camp Courage Winder, GA	www.CHOA.org/campcourage
Aug 22, 2009	4th Annual Wendelyn's Course of Dreams Golf Tournament Country Club of Arkansas Maulmelle, AR	wendelynyvonne@hotmail.com
September 2009	2nd Annual Ryan's Road Big Flats, NY	ngulich@yahoo.com
Sep 5, 2009	3rd Annual Seth's Stride for CCA Canton, OH	mythreekids@neo.rr.com Stacy Swihart www.firstgiving.com/sethsstride
Sep 10, 2009	Heroes4Hope Gala Jorge Posada Foundation New York, NY	JGorecki@ccakids.com www.ccakids.org 800.535.3643
Sep 12, 2009	2nd Annual National Picnic Day in observance of Craniofacial Acceptance Month Flag Pole Hill, 10 AM-1 PM Dallas, TX	ARees@ccakids.com
Sep 12, 2009	Alexa's Appeal Dinner/Auction, 5-10 PM Modesto, CA	deniserast@sbcglobal.net
Sep 21, 2009	Jylian's Links of Love Golf Tournament Whitestone Golf Club Benbrook, TX	JGorecki@ccakids.com jylianslinksoflove.com 800.535.3643
Sep 27, 2009	Strike Out Differences in Memory of Wendy for CCA Kids 3pm-6pm Crosley Bowling Lanes Vancouver, WA	tiger32094@yahoo.com Tamara Mantlo
Oct 3, 2009	5th Annual Friends of Jeremy Golf Tournament Corning Country Club Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com

good news

2009 marks the 20th anniversary of Children's Craniofacial Association! This continues a year-long commemoration of 20 years of giving hope and a celebration of CCA's "birthday"!

Our limited edition 20th Anniversary Logo T-shirts are available for purchase at \$20 each plus \$5 priority shipping (for more than one shirt, actual shipping-weight charges will be quoted). Or one T-shirt is free upon request with a single donation of \$100 or more.

Initial production of the special celebrative shirts comes in adult sizes, S, M, L, XL, 2XL, and 3XL.



Giving Back

CCA is proud of a new cause-related marketing alliance with Permission products, a new line of men's skin care, just introduced.

"Permission formulas help you face the world with new confidence, and you'll be helping others do the same. A portion of proceeds from each product go to benefit Children's Craniofacial Association..."

Our friends at Permission offer a 15% discount on all products if you mention CCAkids with your order!

www.permissionskincare.com



Henry's March for CCA

By Rachel Johnson



the Second Annual Henry's March for CCA was a huge success — **we raised \$21,000!**

We had a strong feeling that our race was going to be fantastic when the race registration forms started pouring in. Last year, we had less than 100 people pre-register for our race. In fact, in 2008 we hoped that we'd reach 100 runners by race day. This year, we had more than 350 people pre-register for our event and many more register the day of the race.

Our event was featured in the local press, including **The Modesto Bee**, **TurlockCityNews.com**,

Turlock Living Magazine, **"Good Day Sacramento"** and **MyTurlock.com**.

The biggest surprise this year was when *The Modesto Bee* story was picked up by **Yahoo** and ran nationwide on their homepage! We received more than 90 emails from across the country from people moved by the story or who also had children with a craniofacial condition. *The Modesto Bee* website had so many hits on the story that they had to disable the comment boxes due to system overload! Wow — who would have guessed that a photo and story of two little boys would draw so much attention?

Race day was amazing! **California State University, Stanislaus**, once again played host to our event. We had vendor booths, face painting, music, awards and a raffle. The mayor of Turlock, **John Lazar**, fired the starting shot.

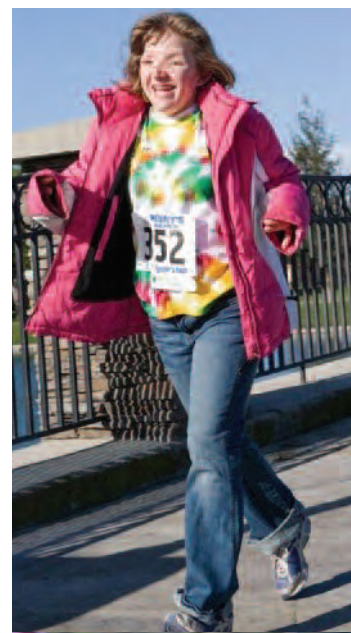
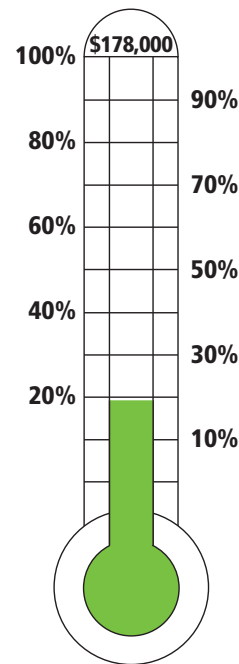
The children had a blast running in the Kids' Dash, and, once again, the

Mascot Race was a highlight of the day. We added a one-mile course, with **Mike Boyer** taking first place at 5 minutes, 14 seconds. Our 5K was especially thrilling when **Miguel Nuci** crossed the finish line with a new Henry's March record of 15 minutes, 22 seconds!

We would like to thank all of our sponsors and a special thank you to **Foster Farms** for their continued support and generous contribution to CCA. In these rough economic times, every dollar donated was sincerely appreciated. Please visit our websites to view race results, additional photos and sponsors: warriorathletics.com/henrysmarch or myspace.com/henrysmarch.



2009 FAMILY FUNDRAISER
GOAL THERMOMETER



smiling through the mask

CCA Volunteer fundraiser, **Wendelyn Osborne**, held her inaugural event, a five-course dinner / presentation she called, "Smiling Through the Mask," which she dedicated to the memory of **Dr. Paul Tessier**, the father of craniofacial surgery who was one of her own surgeons.

Held at **Restaurant 1620** in Little Rock, Arkansas, the evening began with Wendelyn talking about CCA and its vision that everyone be accepted for who they are, not how they look. She sang, accompanied by **Steve Struthers** on the ukulele, "Somewhere Over the Rainbow/It's a Wonderful World," during a slide show of the Myrtle Beach Retreat.

Dr. Kirt Simmons, a craniofacial orthodontist at Arkansas Children's Hospital, shared the dental complexities of craniofacial patients. Three-year old CCA kid, **Ryan Holliday**,

who was born with Pfeiffer syndrome, traveled with his family from the Dallas/Fort Worth area to share their story with guests. There was a humorous monologue by **Jana McKnight**. Other presenters during the evening were **Dr. Michael Spann**, reconstructive and plastic surgeon with **Arkansas Plastic Surgery**, **Dr. James Suen**, Chairman/Professor at **University of Arkansas for Medical Sciences** in Otolaryngology-Head and Neck Surgery.

Special thanks to Restaurant 1620 chef/general manager, **Tim Morton** and chef/owner, **Evette Brady**, for making the event possible. (Tim also caters Wendelyn's annual golf scramble for CCA!) Thanks also to **Steve Copley, Roberta Long, Cindy Ford, Annette Hamby, and Ebony Blevins** for their help at the event. Wendelyn would like to thank local media outlets for promoting the event including **Evan Hoffmeyer, Melinda Mayo, Katrina Dupins, Casey Stokes, and Pamela Smith** from ABC affiliate **KATV**; **Cheesa Parham** from **Arkansas**

AR LT. Governor, **Bill Halter**, **Michelle Holliday** and her two children, **Kathryn and Ryan**

Democrat Gazette; **Donna Terrell**, **FOX16 News**, and **Trey Mallott** with the NBC affiliate, **KARK**.

Ryan's parents, **David** and **Michelle Holliday** said they were glad to attend and honored to meet special dinner guest, **Arkansas Lt. Governor Bill Halter**. The family has dedicated themselves to helping others with craniofacial conditions and

believes Wendelyn's dinner event helped foster the awareness and education of the challenges faced by these individuals. They told, Wendelyn, "We really appreciate what you have done and continue to do!" Children's Craniofacial Association agrees!



Evette Braden, Wendelyn Osborne and 1620 Chef, Tim Morton



2009 motorcycle raffle for cca



Johnny Pag (J.R. Pagnini) has given away bikes to a number of charities he supports, CCA included! Last year he donated a motorcycle to the Heroes4Hope Gala in New York City which was then autographed by the entire New York Yankees team! It auctioned for more than **\$27,000!** This year CCA is happy to be holding a raffle for one of the Johnny Pag bikes and the winner gets to choose the color!

CCA volunteers, **Rob Gorecki**, the **Seitz family**, **Emerald** and dad, **Al Demor** and members and friends of the **O'Brien family** all helped sell raffle tickets at trade shows attended by **Johnny Pag Motorcycles**. **Tickets are \$5 each, or 5 for \$20**, and the drawing isn't until August, 2009 so there's still plenty of time to get involved! Call our office if you'd like to sell tickets in your area.

See www.johnnypag.com.



yoli, from page 1

Apert syndrome, I began to search the Internet for information. This is when I found Teeter's page (www.apert.org). What wonderful information we found.

We made plans to go make our first visit to see Jolene in August 2005. We arrived at our hotel and met with her CASA worker, **Paul**, who took us over to **Momma Mary's** house to visit with Jolene. During this visit we found out that she also had shaken baby syndrome. She suffered a stroke because of the shaking, which affects her right side. She also has a shunt, suffers with seizures and has multiple allergies. Her right arm and leg both draw up. She had just undergone cleft palate repair and would need more surgeries in her future. Needless to say, we were overwhelmed with all this new information about her and were really scared.

We made plans to come back to visit and play with Jolene while Mary went out for a little bit. She loved to pick up blocks and stack them. She and Mike had a blast. We took her out to breakfast and she had many stares. We didn't care as she was so happy. We were there for about five days, but we didn't make a decision to adopt her until we knew we had all her resources available where we lived.

I called Children's Mercy Hospital and found that they had several children with Aperts. I was so relieved. I called our school to see if all her needs could be met and they could. They could provide her with physical, occupational and speech therapies while she attends school.

I called the local hospital to see about having physical and occupational therapy done for Jolene over the summer. Not only did the therapist work at the hospital but also at the school she would attend. After all the research, I felt we had all we needed and contacted some friends and family and talked about our decision. We knew that this little girl would need a lot of support.

We got her home that December, and she went right to sleep in her new bed. She never cried for being homesick and has never shown any kind of separation anxiety.

Jolene is our only girl. We have three sons, **Keith**, 26, **Joshua**, 21, and **Stephen**, 16. I have two sisters and they all have boys. She is the first granddaughter on my side, and my mom adores her.

Momma Mary had Jolene since she was 3-and-a-half months old and had seen her through some of her most difficult surgeries. We feel that Jolene's personality came from Mary. Because of her, Jolene has turned



Adoption day: Judge Robin Crouch, Paula, Michael and Yoli Flores

out to be the most beautiful little girl, with such happiness, personality and strength. We all love Momma Mary! She has become family to us.

Jolene is now 6. She has had all her fingers separated and her toes separated to help her balance as she walks. She's had her hamstring and Achilles tendon feathered on her right leg, so she can stand flat footed. She has one more major surgery pending, her mid-face, to help create a deeper eye socket, better sinus cavity and a bit of an overbite.

Jolene attends kindergarten, and the children are wonderful to her. She goes to regular class part of the day and special education for the rest of the day. She has physical, occupational and speech therapy several times a week. Her vocabulary is always expanding, and she's learning her ABCs,

numbers, colors and basic sign language.

She also loves being in school plays and has so much fun. For the Christmas play last year, Jolene did not have to have someone stand with her or hold her; she stood on her own. It was awesome to see the happiness on her face as she sang the songs all the other children sang.

Jolene attends First Baptist Church with us, where she goes to her worship class and Sunday school. She enjoys it so much and has become quite well known. I cannot believe the number of people who come up to



continued next page ➡

her and say, "Well there's Jolene. How are you?" And she'll say "Fine." (She's been working on saying the word "fine" for awhile and is doing very well. Although Daddy has been teaching her to say "groovy," I'm trying to discourage that for now. When we watch church services on TV she will put her hands in the air and praise as well. It's so touching to see her do this.

She loves to go shopping — she's a girl's girl for sure! She also enjoys being outdoors, and if she had her way, she'd be there all the time. She loves our cats, with "Kitty" being the only one that tolerates her loving hugs. Jolene is also a big help in the kitchen and anywhere else around the house. She enjoys being read to, and



likes to read by herself, whether it is a newspaper or a book. We don't know if she understands what she's reading, but when asked, will tell you in her "Yolese" what she has read.

Sometimes I wish we could have gotten Jolene

when she was that little one year old I saw in Adopt Us Kids, but I am so thankful that we finally did get her. It has turned out to be a wonderful journey with her. She keeps us busy, and she keeps us laughing. She shows so much love to us and to others.

Jolene has learned to say "I love you!" Sometimes it's hard to understand, but we know what she's saying. She gives great big hugs, but most of the time they come with several tight hugs and pats on the back. We do so enjoy this from our girl.

In 2006, we went to the CCA retreat in Salt Lake City, Utah, and had the best time. We met so many wonderful children and their families. We made friends with another Flores family there. Their little girl, Shara, has Apert's, and she and Jolene hit it off. I hope to see them again in Texas this year. It will be great to catch up with the rest of the families when we get there.

What a blessing CCA has been for our kids. We just love Annie Reeves. She's so caring and so concerned for all of us.

Find out more about our story on the Adopt Us Kids website: <http://www.adoptuskids.org/resourceCenter/parentSupport/familyStories/flores.aspx>

Here's our Teeter's page, too:

<http://www.apert.org/flores2/index.html>

God bless you all!



Two winning cups: A CCA mug and The Stanley Cup!

Kids Klubs

Want to stay in touch with your CCA friends throughout the year? Join one of CCA's Kids Klubs. You'll talk with other "kids" your age, make new

friends, play games, and join discussions. Join one of four age group levels: Kindergarten thru third grade, fourth and fifth grades, sixth thru eighth grades, and ninth through twelfth. Each level has age-appropriate activities that will keep you connected. So join your CCA friends now and let the fun begin!

Contact Annie Reeves for a Kids Klub application today!



children's craniofacial association

two-stage palatoplasty

A Utah Protocol

By Dr. Louis Morales

Over the past 20 years, a palatal prosthesis has been utilized in the care of cleft palate children. Initially, it was used as an adjunct in presurgical orthopedics, but it soon became part of the treatment of both unilateral and bilateral clefts.

Over the past 18 years, more than 700 children underwent staged palate repairs. We performed a retrospective study reviewing patients undergoing the two-stage closure with emphasis on speech, growth and rate of pharyngeal flaps. Here's how our protocol has evolved:

- 1 Presurgical orthopedics at 6 weeks of age.
- 2 Cleft lip repair after 6-8 weeks of orthopedics.
- 3 Soft palate cleft repair with Z-plasty at 9 months of age with prosthesis.
- 4 Definitive repair of hard palate cleft at 4 years.
- 5 Alveolar cleft bone grafting at 6 years.

Our Utah protocol has shown the two-stage palatoplasty to be an excellent approach to cleft palate repair over the past 18 years — with minimal morbidity, good facial growth and good speech outcomes.

We obtained our data by reviewing patient charts and then following up with our cleft palate and craniofacial team as well as our speech pathologist and orthodontist. We reviewed a total of 450 patients, of which 329 patients were unilateral clefts and 121 bilateral clefts. We had an additional 35 patients that were cleft palates only that underwent a two-stage closure.

The two-stage closure has been controversial as there have been concerns with speech. Our initial results revealed a technically easier lip repair with better alveolar alignment with presurgical orthopedics. The residual

hard palate cleft became smaller with an average size of 3 mm at 4 years of age, making it very easy to close the cleft. There were 25 patients where the cleft margins were so closely approximated that there was no functional cleft. (See photos below.)

Fistula rate was less than one percent as the residual hard palate cleft was relatively simple to close. The speech concerns were initially the most worrisome aspect of this protocol, but despite initial articulation concerns, the speech pattern approached normalcy with ongoing speech therapy.

The pharyngeal flap rate has been less than one percent. With delayed hard palate repair and with an easier technical repair, the amount of resultant scar tissue was much less, allowing for better maxillary growth.

The incidence of Le Fort osteotomies has been less than 10 percent. As an added aspect of using palatal prosthesis, palatal adhesions have been performed to assist in closures of very wide cleft palates (i.e. Pierre Robin).

The final soft palate Z-plasty repair was not

performed until 16-18 months of age. There have been 48 patients in this category, of which one has necessitated a pharyngeal flap. All have had good speech outcomes.



good news

Wendelyn Osborne of Little Rock, Arkansas was featured on her local ABC affiliate, **KATV** as Arkansan of the Week in January. She credits producer, **Patrick Green**, anchorman, **Scott Inman**, and the crew there with getting her story out. Wendelyn is a CCA adult whose condition is called CMD, craniometaphyseal dysplasia. She is an active volunteer for CCA, spreading awareness and helping to raise funds for our cause. Congrats Wendy!



austin Freeman received his first promotion, on March 21, 2009, in the Civil Air Patrol! Congratulations Austin!



elizabeth Hubbard recently received some "Good News." She has been accepted into Landmark College in Putney, Vermont! Congratulations, Elizabeth!

the Grathoff family are pictured here with the Stanley Cup! They even brought their CCA Mug and took a picture of the "Two Winning Cups." (See Mugshots on page 9.)



feeling good about your decision to give

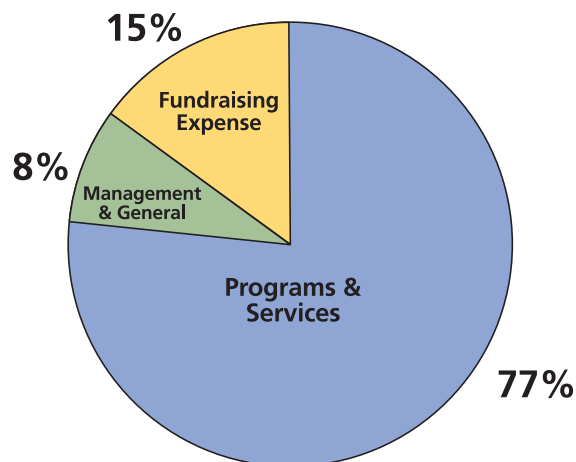
I recently got a fundraising communication that said, "When Sam Walton, founder of Wal-Mart, was asked how he would cope with a recession, he simply stated, 'I decline to participate.' Not a bad answer. People are tired of hearing gloom and doom. Donors want assurance your mission is alive and well and continues to benefit others."

Children's Craniofacial Association believes this to be true and we want to assure all CCA stakeholders that we continue to persevere during this economic downturn. Through good times as well as during struggles, our programs and services remain in place. We are frugal with operating dollars in order to maintain education and assistance to help our ever-growing number of families in need.

One example is that, for now, our newsletter is 16 pages instead of 20; as appropriate, we condense content in order to cut costs in less painful ways, rather than cutting programs. The pie chart illustrates for donors where contributions are used. I am committed to making sure all of you know how important your gifts are to this cause and to maintaining your confidence in our stewardship of the resources you provide. We want you to feel you've made the best possible decision about giving; and as you conduct your due diligence, feel free to call on us for any information you may seek. Your support is critical and extremely appreciated.

Sincere thanks,
Jill Gorecki
CCA Development

2008 Distribution of Funds



chair, from page 1

Quality

CCA strives to provide quality programs and services and to continuously improve the ways we provide support. We have expanded our use of technology by providing webinars and online support groups. We have also provided customized Care Pages to help families keep their loved ones up to date on their child's progress, and we have provided customized Firstgiving pages for our volunteers to promote their fundraising events and collect donations online.

All of these quality services enhance the support that we offer our families. As we move forward, we will continue to seek out the best ways to provide quality support and services to our families.

Commitment

Dedicated staff and hundreds of volunteers

have consistently used their talents and contacts to help grow CCA and spread awareness of individuals living with facial differences. Children who have had an incredible experience at the family retreats have gone back to their schools and held special awareness events.

Now, and in the future, we are committed to reaching more individuals and families, to providing excellent service based on feedback from you and to raising the level of acceptance of those living with facial differences.

Impact

Anyone who has received medical travel assistance or attended the family retreat on scholarship has felt the impact CCA can make.

Anyone who has watched their child grow up in the CCA family and go on to college or a career has felt the impact that CCA can make. Anyone who has seen a group of CCA kids building the groundwork

of lifelong friendships at the dinner/dance on the last night of the family retreat has felt the impact CCA can make. And you must admit you've felt CCA's impact by reading the quarterly newsletter.

This impact has been growing over the last 20 years and will continue to grow. As many of the "original" CCA kids engage with the organization now as CCA adults, the next generation of CCA kids will be growing, learning, making friends, building confidence and getting proper medical care because of the impact that CCA will make.

Sustainability

By far, this is the most important trait, because without sustainability, CCA would not have been able to achieve all it has. You have all made a significant impact on CCA's ability to provide the programs and services. We have been able to last for 20 years thanks to your donations and fundraising events, as well as donations from your family and friends. With your continued support, thousands of children and adults impacted by facial difference will benefit from the programs and services that we offer.

My 9-year-old son, **Jeremy**, was born with Goldenhar syndrome. We found CCA and attended our first family retreat in 2003 when he was 2 and a

half. We knew before we left that first retreat that we would be back for more.

Not only has Jeremy benefited from being part of CCA, but so has his younger brother **Tommy**. He sees differences in individuals but recognizes them for being unique people who have something to offer him, such as fun, laughs or friendship.

Twenty years ago, people living in circumstances similar to ours had no support such as CCA. It makes me realize how lucky we are to have Jeremy grow up during a time when he can benefit from all CCA has to offer.

As we celebrate CCA's 20th anniversary, I think of all the accomplishments and memories that have been created through the hard work and generosity of many individuals.

Now, I ask you to take a moment to consider what you can do to **sustain** this great organization so CCA kids in the future will benefit from the many **quality** programs and services. Take a moment and consider how you can help to maintain the **commitment** to raise awareness for people living with craniofacial difference. Together, we can make an **impact** now and in the future.

George Dale
CCA Board Chair

cca's yahoo support groups

CCA is now offering support groups for 3 ages!

Middle School Age:

http://health.groups.yahoo.com/group/ccateens_middleschool/

High School Age:

http://health.groups.yahoo.com/group/ccateens_highschool/

Adults:

<http://health.groups.yahoo.com/group/ccakids/>

If you would like to join one of our online support groups, please visit the links above or contact CCA's Program Director, Annie Reeves, areeves@ccakids.com

Eighth Annual heroes4hope gala

Children's Craniofacial Association is proud to announce we have again been invited to join the **Beneficiaries Circle** of the **Jorge Posada Foundation Eighth Annual Heroes4Hope Gala**. The Gala will take place on **Thursday, September 10, 2009**, at the Sheraton New York Hotel and Towers in New York City.

Joining other organizations such as Montefiore Medical Center and the National Foundation for Facial Reconstruction, CCA will raise funds and awareness for programs and services. As a member of the Beneficiary Circle, the Jorge Posada Foundation grants 100% of the proceeds from our efforts.

The Jorge Posada Foundation is a nonprofit organization founded by the New York Yankees' All Star Catcher, **Jorge Posada** and his wife, **Laura**. Their son, **Jorge, Jr.** was diagnosed with Craniosynostosis when he was just 10 days old and had to undergo seven major surgeries to correct the condition.

Heroes of Hope Gala is attended by many of Jorge's friends from the New York Yankees team, both past

and present, including **Derek Jeter, Bernie Williams, Jason Giambi, Alex Rodriguez, Tino Martinez, Mariano Rivera, Robinson Cano, Bobby Abreu, Willie Randolph** and **Joe Torre** as well as many other celebrities and close friends. Last year's emcees were **Kelly Ripa** and **Mark Consuelos**. This year, actor **Paul Rudd** will help host the festivities and the event will honor the living past New York Yankees catchers!

Tickets are on sale at \$750 per ticket or a table of 10 for \$7,500.

Families are encouraged to spread the word to businesses or others who may wish to attend or sponsor a table for the cause. **The table sponsorships do count toward our 20th anniversary promotion for CCA families to get their 2010 Retreat hotel stay free!**

For more information on tickets and corporate sponsorships, please call CCA Development Director, **Jill Gorecki** at 1.800.535.3643, or email her at jgorecki@ccakids.com.

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 to lean on. 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
- Kids Klub
- Yahoo support groups
- Webinars

save the date

Monday, September 21, 2009
Jylian's Links of Love
Whitestone Golf Club | Benbrook, TX



On Monday, September 21, 2009 Children's Craniofacial Association will hold its second annual "Jylian's Links of Love" benefit golf tournament at Whitestone Golf Club in Benbrook, Texas. The tournament will begin with a shotgun start at 1:00, (registration begins at noon with lunch) and will end with a dinner and silent auction.

Visit www.jylianslinksoflove.com for registration and sponsorship details.

Craniofacial Acceptance Month

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

As part of the 5th Annual Craniofacial Acceptance



Month, CCA will hold its 2nd Annual National Picnic Day on September 12th (or other date in September of your choice). CCA families across the nation will hold picnics giving them a chance to get together with other families in their areas, while promoting awareness in the communities.

It's not too late, if you would like to hold a picnic contact CCA Program Director Annie Reeves. CCA will invite all of the families in your area and help you organize your picnic.

In addition to raising awareness and acceptance, CCA is raising funds to support programs and services available to all individuals with facial differences and their



families. Contact CCA Development Director, Jill Gorecki for materials about this year's fundraising events.

We hope you will join this important effort! Please call 800.535.3643.

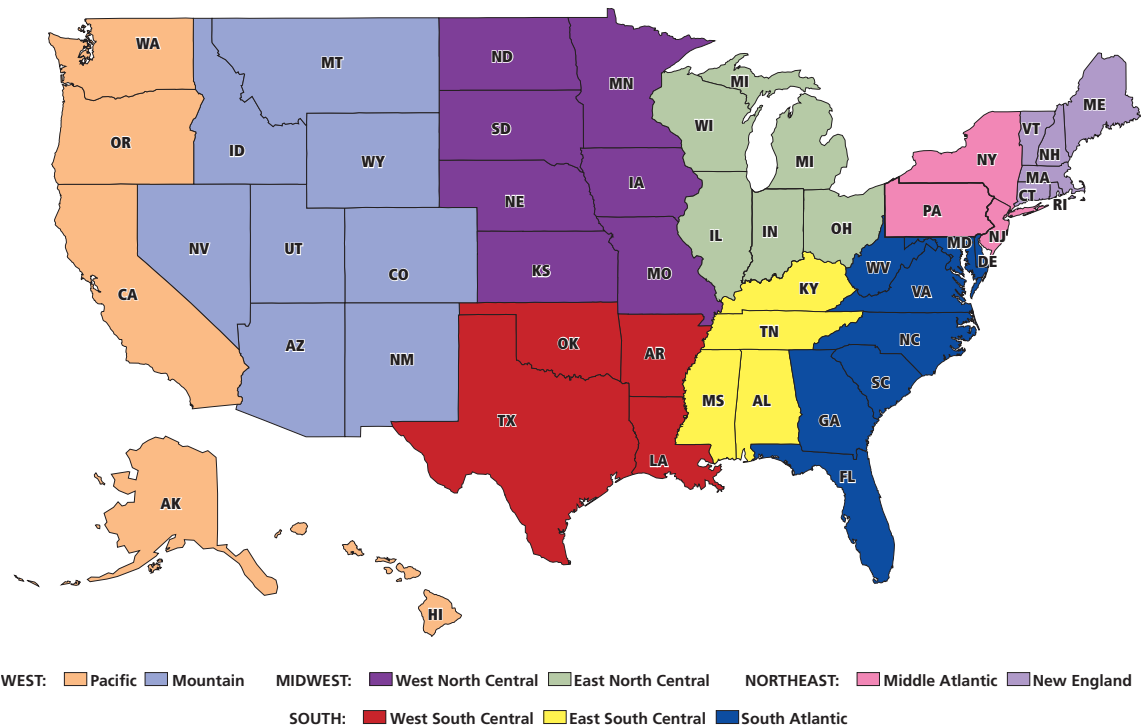
regional volunteers

Public awareness about craniofacial conditions is important on several levels.

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

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

CCA Regional Map



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

call or email CCA Program Director, Annie Reeves at 800.535.3643 or ARees@CCAKids.com.

donors, january 1 – march 31, 2009*

Gifts from Individuals

CCA Friends

(\$100 +)

Mario Adamo
Anonymous
Debra Breslow
Diana Critchlaw
Fred & Judi Freeman
Sarah Hall
Hugh & Joanne Jarvis
Roger & Carolyn Lamb
Robert Northness
Mary Reif
Andrea Richard, D.O.
Randolph Schaefer
Barry Scurran
Courtney Vincent
Kenneth Wilson

CCA Extended Family

(\$500 +)

CCA Sponsor

(\$1,000 +)

John & Sheryl Paul

CCA Benefactor

(\$5,000 +)

CCA Guardian

(\$10,000 +)

Marie Florence Desrosiers Trust
Bequest
John and Patricia Dyer

Memorials / In-Honor Gifts

Yolanda Baker, Austin, TX, in honor of Henry Johnson
Deborah Breslow, in honor of Mrs. Alice Kintisch, Edith Katzourin, Rabbi Elyse Frishman, Cantor Leon Sher, thanks for helping with Robbie's Bar Mitzvah preparation
Brookhall School Staff in name of Janice Stegmann
Christian Callens, in memory of Sidney Goldman
Judy Donaldson, in memory of Talin Robert Shaw

Jim & Arleen Heirty, in memory of Bill Hayes
Jim & Arleen Heirty, in memory of Bob Watier
Sylvia & John Loving, in honor of Ryan Holliday
Ann Lucas, in honor of Brody Lucas from grandparents
Jim & Maryjo Montalbano, in honor of their daughter, Jennifer's 34th birthday
Johnny Pag, in honor of Robbie Gorecki
Harold & Elvia Prange, in memory of Carolyn Muse
Mary & Megan Reif, in honor of JoAnn Kopshinsky & Robbie Gorecki
Fred & Rose Seitz, in honor of all CCA kids
Stephen & Lila Shain, in memory of Talin Robert Shaw
Jeffrey & Patricia Sharp, in honor of Rick Dornier
Doris & Ralph Teneyck, in honor of Tamara Mantlo
Timber Ridge Elementary School Collection in honor of Cale Morris
Mary Wilcox, in the name of Sarah Wilcox
J.B. & Cynthia Wills, in honor of Reed Wills

Corporate / Foundation Gifts

CCA Corporate / Foundation Friends

(up to \$1,000)

Bank of America (United Way Campaign Employee Giving)
Charity Motors (proceeds from a donated vehicle)
Creative Growth Counseling & Coaching, Inc.
Funding Factory
Justgive (donors listed separately)
Neal Oral & Maxillofacial Surgery, PLLC
Network for Good (donors listed separately)
Pfizer (United Way Campaign Employee Giving)
The Prudential Foundation (Employee/Matching Gifts)

The Prudential Foundation (Matched Gift of Diana Critchlaw)
Safeway, Inc. (purchases percentage incentives)
Sarah Hall Productions by Sarah Hall
Schoolpop (online purchases percentage program)
United Way Mile High
United Way New York
United Way of Tucson and Southern Arizona (Donor-Directed Donations)
Wellpoint Foundation Funds Management
Wells Fargo (Employee Giving)

CCA Corporate / Foundation Sponsors

(\$1,000-\$5,000)

Association Works by John & Sheryl Paul
A grant from Lifetime Fitness Foundation
The Redwoods Group (Matched Gift of Bill Mecklenburg)
Vivo Brothers, Inc.

CCA Corporate / Foundation Partners

(\$5,000-\$10,000)

CCA Corporate / Foundation Partners

(\$10,000 or more)

A grant from Horace Cabe Foundation
A grant from Elsie & Marvin Dekelbaum Family Foundation
A grant from Jorge Posada Foundation
Grants from May and Stanley Smith Charitable Foundation

Fundraising Events

Up to \$1,000

Alexa's Appeal for CCA / Denise Rast, CCA Volunteer
Brookhall School Staff Collection in name of Janice Stegmann

Carnival of Caring / Avery Lytle, CCA kid
Ink / Cell Recycle for CCA / CCA Families & Friends
Tamara Mantlo's Firstgiving Page
Johnny Pag Motorcycle Raffle
Timber Ridge Elementary School Collection in honor of Cale Morris
Hannah Steinagel's Firstgiving Page / Kathie Steinagel, CCA Volunteer

\$1,000-\$5,000

Be Brody's Angel / Jennifer Lucas & Family, CCA Volunteers
Friends of Freddie Firstgiving Page / Rose Seitz, CCA Volunteer
Seth's Stride / Swihart Family, Stacy Swihart, CCA Volunteer Coordinator

Smiling Through The Mask Dinner / Wendelyn Osborne, CCA Volunteer
Starbucks Community Clean-Up / Emily Tipton, Organizer w/Jana Peace, CCA Volunteer

\$5,000 or more

\$10,000 or more

\$20,000 or more

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

cca 20th anniversary t-shirts

Our limited edition 20th Anniversary Logo T-shirts are available for purchase at \$20 each plus \$5 priority shipping (more than 1 shirt, actual shipping-weight charges will be quoted). Or one T-shirt is free upon request with a single donation of \$100 or more.

Initial production of the special celebrative shirts comes in Adult sizes, S, M, L, XL, 2XL, and 3XL.



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 \$100 or more** through 1st quarter, 2009. We are extremely grateful for these and all other donations, fees, purchases, fundraisers and in-kind donations not recorded here. **Note: For space consideration, 2009 donations under \$100 will only be published in our year-end list. Cumulative \$100+ donations and In honor or In Memory dedications will continue to be published in each quarterly issue**

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

3 cheers for volunteers!

CCA is proud of our relationship with Store Manager & Coffee Master, **Emily Tipton** at the Starbucks located across from Medical City Hospital on the southwest corner of Forest Lane and Park Central (7718 Forest Lane).

For the past couple of years, Emily's store has participated in volunteer efforts through Starbucks "Make Your Mark" program which enables corporate "team members" to volunteer for causes that touch their hearts. In turn, Starbucks has granted \$10 for every volunteer hour up to \$1,000 for each approved project.

Emily's Starbucks store location is along the parkway bike path that follows the creek and goes behind the store. She helps CCA recruit volunteers who pick up litter and trash items strewn around the path area and then



Emily with CCA Kid, Brooklyn Nicholl

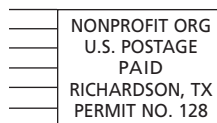
return to the store, after their community service, for refreshments, door prizes and fun. All efforts are later rewarded with grant funds from Starbucks for CCA (projects have been pre-approved by the corporation/foundation).

Emily enjoys volunteering for CCA whenever she can and loves to put smiles on our kids' faces. Thanks Emily. We feel the same about you!

children's craniofacial association

13140 Coit Road, Suite 517 • Dallas, TX 75240

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If you know of someone who would like to be placed on the mailing list please forward to us their name and address.