

ccanetwork

newsletter of the children's craniofacial association

Cher — honorary chairperson

fall 2008

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juliana's story

By Tami Whetmore

Juliana with her mom, Tami, and her sister, Kendra

Way back in high school I told my friends “one of us will have a child with differences.” Little did I know that I would be the blessed one of the group.

Very early in our pregnancy with **Juliana** we found out that something was special about her. After several ultrasounds which could not locate her stomach, the doctor told us that she was not developing normally. I remember looking at her on the ultrasound screen and thinking, “Wow, her tongue is really pronounced, but isn't she beautiful?”

The next several months were filled with fear of what was going to happen to our angel. There were many sleepless nights between that day at the doctor and March 5, 2003, when she finally arrived. Her delivery had been in the planning stages for months. Nobody knew what to expect, so everyone had to prepare for the unknown.

Her delivery was traumatic, however the hospital staff was prepared for any scenario. Juliana was a fighter from the very instant that she came into the world. The

see **juliana**, page 10



message from the development director

Season's Greetings All!

During this busy time of year, celebrate with CCA as we approach 2009 –our 20th Anniversary! Celebrate with us also, our many wonderful, busy families, who give back and enable us to care for all CCA kids through their “Family Fundraisers.”

Throughout the year, and especially during September's observance of Craniofacial Acceptance month, these families held golf tournaments, walks, runs, picnics, dinners,

see **development director**, page 7



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



ccakid

meet josh keeton

three-year-old **Josh Keeton** from Tennessee is a sunny little fellow who loves to laugh and loves life. He enjoys going to school (a mother's day out program at a local church), where he plays and plays with about 15 other kids his age. He's learning his letters right now, and one of his favorite parts of the day is story time.

Josh is very creative and into anything artistic, whether it's drawing, making crafts or singing songs. He's also a member of his church choir and has already proven to be not only a great singer but a quick study. His teacher has remarked that he has a great musical memory.

Josh likes to play *Star Wars* and "superheroes" with this older brother **Jacob**. He also likes to play hide-and-seek and other fun games with older sister **Caitlin**. When it comes to TV programs, he watches "Dora the Explorer," "Go, Diego, Go!" and "Backyardigans." He also enjoys Little Einstein DVDs. Regardless of the show, he always gravitates toward the songs.

As any typical toddler, Josh loves sweets, especially chocolate. Apart from that, he's a little bit of a picky eater. (Well, maybe more than a little!) His favorite food at the moment is a peanut butter and jelly sandwich, but only if it's

made a certain way. His mom, **Amanda**, uses a special tool that cuts the sandwich into a round shape and crimps the edges at the same time.

Josh has a mild form of hemifacial microsomia; the left side of his face is smaller. He underwent his first surgery when he was just three months old to repair a cleft lip. He's also



had some skin tags removed. When he gets older, around the time he hits puberty, Josh will have his next surgery, a jaw distraction. Hopefully Josh will only have to have one of those performed, but that depends on the rate of his growth.

He and his family went to their first CCA retreat this past summer in Myrtle Beach, SC. Josh, his brother and his sister had a great time meeting new friends and sharing fun times. In fact, he had so much fun Saturday night he was seen breakdancing on the dance floor! And there was a pretty good chance he was singing along to every song.



meet lili smith

hi, my name is **Lili Smith**. I live in San Francisco, CA, with my parents and older brother, **Abram**, who is 18 years old and a senior in high school. For fun, I like to work out at the gym, surf the Internet, sing, watch TV and hang out with friends.

One day, my tutor (I'm home schooled) showed me an article in our local paper that said you could apply to be a member of the Youth Leadership Commission for my county. When I heard the word "youth" I was really nervous. I didn't know how

the other kids would treat me. At first I was hesitant and said "no thank you," but my tutor did the right thing when she pushed me to do it. I filled out the application with her, wrote the essay and went by myself to the interview.

This August, when I came back from sleep-away camp for a month, one of the first things my mom told me when she saw me was that I had been accepted onto the Marin Youth Leadership Commission! I was really excited but at the same time nervous because I didn't know how I would

do with the other kids. Now that I'm on the commission, I'm having a great time. A year ago I never believed this could have been possible.

All of my life I've grown up with Apert syndrome, which has affected the way people think of me and the way they treat me. My years in our local middle school were some of the hardest and worst I can remember. My peers really didn't accept me for who I was, and my teachers didn't believe I could learn. I never thought it would be possible to do the work that I am doing today in my home school. I now know that I am equal to my peers. My teacher taught me to believe in myself, and I'm working as hard as I can at school.

This summer was the first time I came to a CCA retreat, and I had a great time. I found kids who felt exactly the way I did about life — they didn't feel equal to kids who had no differences. I talked with the other families and realized that all of us kids have so much in common; they go through exactly the same things as I do.

One other thing: I hope that by being a member of the Marin County Youth Commission I can be an advocate for special-needs kids in our school district. It's important to me to bring some of our concerns and challenges to the table.

And one final thing: Do not ever let someone tell you that you can't do something — not even yourself!



ccateen



meet caitlin and jacob keeton

By Amanda Keeton



Caitlin is eight years old and in the second grade. She loves choir and church activities. She also enjoys playing outside and spending time with her friends. As most girls her age, she likes Hannah Montana. She likes to read and is a good student at school. Caitlin is a very sweet girl and a great big sister.

She also loves playing with her brother **Josh**. Caitlin will sometimes dress him up in a costume and plays "pretend" with him. They love to play kitchen and "cook" food together. Then they bring Mommy a sampling of their "food."

Caitlin is very protective of her little brother. You can sometimes catch them cuddled together on the couch watching a movie.

Jacob is five years old and in kindergarten. He really enjoys school and likes to play with his friends. He loves *Star Wars*

and all superheroes. Playing outside and riding his bike are some of Jacob's favorite things to do. He is a very loving little boy and still loves to give hugs.

Jacob and Josh are all "boy" when they're together. They love to play *Star Wars* and play with their light sabers. They also play with their little action figures together. They get along very well. I'll often catch Jacob talking about

how much he loves Josh and he will actually say that Josh is so cute. They are very fun to watch together.

Neither of the kids has ever made a big deal of Josh's facial differences. He is mildly affected, but they rarely mention it. They love him very much and treat him wonderfully. They really enjoyed going to the retreat and meeting so many new people. I will never forget the three of them being on the dance floor that last night, dancing and laughing the night away. It was a wonderful time for them, and they had so much fun.

ccasupersibs

craniofacial acceptance month

Beyond the Face is a Heart

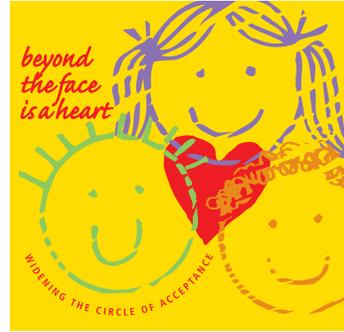


This year marked the fourth year CCA observed September as Craniofacial Acceptance Month across the nation. CCA families, friends, volunteers and related support groups widened the circle of acceptance for individuals with facial differences. The goal is to create awareness that beyond the face is a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

Many of our CCA families were able to get their local newspapers to

feature them in the paper. Radio stations also ran PSAs throughout the month of September. And this year, the **governors of Maine, Texas and Vermont** each declared September Craniofacial Acceptance Month!

New in 2008, CCA held **National Picnic Day** in September as part of Craniofacial Acceptance Month. CCA families held picnics in **Alabama, Colorado, Connecticut, Nebraska, North**



Carolina, Ohio, Texas and Washington! In fact, we already have several picnics lined up for next year!



CCA thanks everyone for all of their hard work in making Craniofacial Acceptance Month such a great success!



good news – stepping up to spread awareness

Cher Convention

ovingly dedicated to the memory of **Harry “Sonny” Smith**, the fifth Biennial **Cher Convention**, a gathering of Cher fans to benefit CCA, was held at Caesar’s Palace on August 11th and 12th.

Convention-goers were treated to numerous new impersonators. In addition to regulars, **Wayne Smith** (Cher, Dallas, TX), **Chad Michaels** (Cher, Los Angeles, CA), **Mark Parry** and **Catherine Marie Carter** (Sonny & Cher, England), and **Amy Hohimer** (Cher, Chicago, IL), the ensemble cast of Chers as well as Billboard



dance-chart topper, **Pepper Mashay** (CA), guitar aficionado, **Frank D. Wright** (CA), **Steven Crews** as Rod Stewart (Jasper, Indiana), and another Sonny, **Billy Scadlock** (Las Vegas, NV), included **Betty Atchison** (Orlando, FL) **Helene Masiko** (Woodbury, NJ), **Andrew Raymer** (Tucson,

AZ), and **Saffire Trinity** (Austin, TX).

A Monday evening cocktail party and the talented impersonators started off the event. Tuesday was the all-day “convention” with an evening break for Cher’s show at the Palace Colosseum, followed by another party and entertainment afterward. Cher’s Caesar’s contract had her visiting with dozens of folks backstage, so it got too late for her to join the fun but she gave a shout out to the gang during her concert, *“The*

Cher Convention is in town! I love you guys!”

Needless to say, an audience of her most

devoted fans definitely pumped her up! CCA staffers were invited backstage along with CCA kid, **Robbie Gorecki**, for a brief visit. She also graciously posed with convention items to send kudos to everyone.



Five decades of Cher

Volunteers for the extravaganza include event organizers **Judy Didelot** and **Kim Werdman** along with **Linda Vala**, **Linda Alamprese**, **Mike Werdman**, and **Brad Wright**. Also regular helpers are **Dave Didelot**, **Robbie Gorecki**, **CCA**, **Darla**, **Mike**, & **Ashley Kramer**, **Javier Ozuna**, **Charles Carlson**, **Mary Anne Cassata**, **Scott Clark**, **Sandie Deyo**, **Kathy Vysoky**, **Fred & Judi Freeman**, **Kathy Dewilde**, and **Mike Didelot** (& canine mascot, **Velvet**), joined this year by **Glenn Wright**, **P’Or & Mark Long**, **Jim Duncan**, **Bruce Landry**, **Teresa Black**, **Arva Godwin**, **Allan Umitten**, **Matt Giberti**, **Rita & Brandon Hammond**.



Cher and Rob Gorecki, one of her first CCA kids, all grown up!

Sponsors, including friends like **Mary Ann Budnick** and a number of **Wal-Mart** stores, helped with expense funds for the event. Media coverage was donated by many



sources including **Andy & Angelica Bertrem's** donated ads on Google, **Directed Technologies**, **CCA**, **Steve Leary** on **Broadway World**, and **PNN Radio**.

Items were donated for auction by **Cher** herself, **Bob Mackie**, **CCA**, **Linda Vala**, **Katie Mercado**, **Andrew Bernard**, **John Hoelester**, **Mary Ann Cassata**, **Robert Bollinger** and **Star Wares**. Regular attendees **Scott Clark**, **Robyn Fisher** and her family, **Bruce Gelly** and **Javier Ozuna** were among the big bidders.

CCA is extremely grateful to all who helped put together the celebration as well as all who participated in any way.

Good News continued next page ⇨



Denise and Alexa with Tanner and his mom

Alexa's Appeal for CCA

Reported by mom/event coordinator, Denise Rast

I hosted a dinner and presentation recently called Alexa's Appeal for CCA, and I had a single goal in mind — to reach out to our community and spread awareness and acceptance for craniofacial conditions. And my goal was met.

There were posters of CCA kids all over the walls. I put together a presentation, which was filled with information and photos of children living with craniofacial conditions. When I was finished, there wasn't a dry eye left in the house. No one left that night without approaching my family; most of them were in tears and filled with emotion because of what they saw.

We had an amazing group of people attend this event. Dinner was fabulous and everyone had a great time, but it was the photos of the kids that made it an evening to remember. Thank you to all the parents who gave me photos. It made their kids a very special part of the night.

I was overwhelmed with the number of people asking me to do this event next year and make it an annual event. People were handing me business cards to call them for sponsorship next year. The event has even made the local news!

Thank you, CCA, for letting me put on this event in my daughter's name. Next year, our goal, along with raising awareness and acceptance, is to raise lots of money for CCA!

Look for Alexa's story in CCA's Annual Fund Appeal letter!



Alexa with mom Denise, Tanner and Lisa

save the date

June 24-28, 2009

CCA's 19th Annual Family Retreat Grapevine, TX

The 19th Annual Family Retreat will be in Grapevine, TX (10 minutes from DFW airport) June 24 – 28, 2009. **CCA will also hold a craniofacial symposium starting at 1 p.m. on Wednesday, June 24, resuming at 9 a.m. on Thursday, the 25th.** See you next year in Texas! (www.greatwolf.com)

development director, from page 1

auctions and more. Funds were raised and awareness and understanding spread, fostering our vision – acceptance for “who we are, not how we look.”

This holiday, all will memorialize leading philanthropist, actor, Paul Newman. He put his own image on his ‘Newman's Own’ line of products and gave all profits to charity. They say he felt funny at first about having his famous face on the packaging. His company's motto is “Shameless Exploitation in Pursuit of the Common Good.” The motto on our acceptance-month posters is “Beyond the Face is a Heart.” CCA is very grateful for those hearts—“CCA's Own.” Just think of the courage and heart it takes a CCA kid and their family to promote our cause by stepping out of their

comfort zone “in pursuit of the common good.” They “face” the public for the good of others who will go through similar heartache, enduring a lifetime of reconstructive procedures. Bigger hearts there are none. We are extremely grateful for these selfless hearts and brave faces that may someday indeed, be famous as well!

And, of course, we are grateful for everyone who supports our mission and celebrates with us when strides are made. We could not have reached CCA's 20th “birthday” without each of you!

Thank you for sharing your blessings and all good wishes for many more in the coming year!

Jill Gorecki
CCA Development Director

3 cheers for volunteers!

CCA would like to thank all of the area restaurants who have supported us by donating lunch for our newsletter volunteers, as well as the local radio stations who have supported us!

Restaurants:

Cantina Laredo
Dickey's BBQ
Honeybaked Ham
Jason's Deli
La Madeleine
Pappasito's Cantina

Radio Stations:

100.3 Jack FM
Mix 102.9

**Thank you for your support,
we truly appreciate everything!**

new 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



NEW! cca's Kids Klubs

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

Contact Annie Reeves for a Kids Klub application today!

cca mugshots



IRA charitable rollover extension

Good News! The IRA Charitable Rollover has been extended for 2008 and 2009 tax years! Donors 70½ years or older may make a charitable gift of up to \$100,000 to CCA (or any charity) from an IRA or Rollover IRA without having to take a taxable distribution as long as the gift is transferred directly to one or more public charities. Please consult your tax professional to ensure your overall financial objectives are being met and you may contact Children's Craniofacial Association if you have further questions.

got questions? who you gonna call...?

By Tracy Romano, Pediatric Craniofacial Program Coordinator, Medical City Children's Hospital, Dallas, TX

Your craniofacial program coordinator. That's who!

As a pediatric craniofacial program coordinator, I am responsible for ensuring all pediatric craniofacial patients receive quality care and comprehensive services. My days are filled with ensuring that amazing kids with amazing families are well informed and best prepared for all aspects of their surgeries. I answer questions regarding what to expect while at the hospital. I initiate child life, social work and dietary consulting sessions. I also oversee the care delivered to assure the best outcome, plus I help prepare families for discharge.

My other duties include providing and coordinating educational activities for our staff. And, as part of a major craniofacial center, I am integrally involved with international charity cases. I am also involved in the marketing and promotion of services we provide.

As a "seasoned" nurse (27 years), I have experienced many special moments, but none has defined my career as much as watching a child experience for the first time the realization that she now has fingers that move on her precious little hands.

The emotion that followed was unforgettable, and I feel blessed to have been able to witness and be a part of that very special

moment for that child and her dad. It was life-altering for the child — and for me!

I get as much satisfaction of knowing I have helped a

family through a difficult time as I do learning something new each day. And you know, our kids can be the best teachers!

firstgiving fundraising proposal to cca families

...or how to get a free hotel stay at the next 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 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 (either 2009 or 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!

Join these CCA families who've already been awarded their hotel stay at the next retreat:

Gulich Family
Wendelyn Osborne
Dale Family
Swihart Family

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 face-to-face asking.

Thanks to all who've started Firstgiving pages to raise funds for CCA!

Becky Carlisle-White, Wade's Page
Lisa Crawford
George Dale, Friends of Jeremy
John Dalton
Dede and Pete Dankelson, Pete's Scramble
Casey Deakins
Tamara Gavin-Freeman, Austin's Luau of Love
Beverly Grimm
Gulich Family, Ryan's Road
Melissa Jurek
Jennifer Lucas, Be Brody's Angel
Denise Rast, Alexa's Appeal
Rose Seitz
Francis Smith
Stacy Swihart, Seth's Stride

Juliana, from page 1

neonatologist intubated her and she immediately reached up and pulled the tube out. Not once, but twice. We knew that we were going to have our hands full!

She had her first surgery at five days old. This first procedure was placing her trach and g-tube. After spending the first 16 days



of her life in the NICU, we were finally able to bring her home. Her older sister **Kendra** was eagerly awaiting her arrival at home.

We had prepared Kendra by slowly introducing pictures of Juliana to her. At first the pictures didn't really show her face, only that she really did exist. Then we started showing Kendra more up-close pictures. Kendra was so amazing for only being two at the time. I will never forget the first thing that she said when she actually saw Juliana. She said "That's my baby sister and I love her." I could not have been more proud of

both of my girls at that moment.

We traveled from our home in northeast Florida to Miami in late March 2003 and began Juliana's craniofacial surgeries with **Dr. Anthony Wolfe** at **Miami Children's Hospital**.

The first 18 months of her life were very difficult on all of us. We got to know the hospital staff very well between **Wolfson Children's Hospital** in Jacksonville and Miami Children's Hospital. We spent more time at both of them than we did at home. In

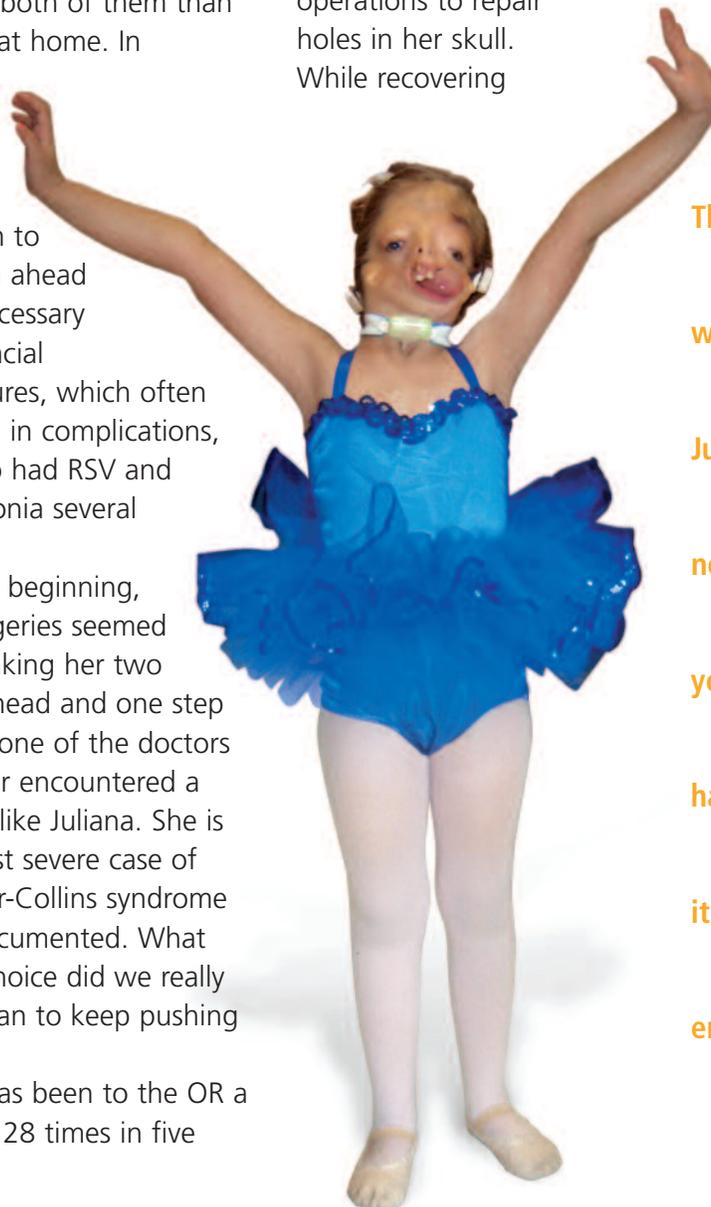
addition to pushing ahead with necessary craniofacial procedures, which often resulted in complications, she also had RSV and pneumonia several times.

In the beginning, her surgeries seemed to be taking her two steps ahead and one step back. None of the doctors had ever encountered a patient like Juliana. She is the most severe case of Treacher-Collins syndrome ever documented. What other choice did we really have than to keep pushing ahead?

She has been to the OR a total of 28 times in five



years, some of them more major than others. She has had simpler procedures and major intracranial operations to repair holes in her skull. While recovering



from these major operations, **Thom** and I heard some of the most terrifying words that a parent can hear: "She may not survive this." We were told this more than one time, and each time we went to our knees and prayed. God had bigger plans for Juliana.

Juliana began kindergarten this year at our local elementary school. Our school district started a hearing impaired and visually impaired program there this year. What a blessing it has been! She is learning so fast that I am having a hard time keeping up

The greatest lesson that we have learned from Juliana is that God does not give you more than you can handle; you just have to choose to handle it in a positive and enlightening way.

continued next page ⇨



with her signing abilities. It is so overwhelming to see her learning and interacting with her peers. The kids in her class have accepted her and care for her. If she is out of class for a doctor appointment or surgery, they are concerned about her and asking how she is doing.

There will be nothing in this world that will hold Juliana back from achieving her dreams. She is extremely intelligent and always finds a way to communicate with those who do not speak her language (sign language). We don't know what the

future holds for Juliana, but we will certainly continue to be her biggest supporters as she reaches for the stars.

The greatest lesson that we have learned from Juliana is that God does not give you more than you can handle; you just have to choose to handle it in a positive and enlightening way.



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.

donors in the spotlight



This issue we shine the spotlight on individuals, now angels, who've given to CCA upon their passing.

leave a legacy

We enjoy expressing special thanks to our contributors through our Donor List which is published in each newsletter, in our Annual Report, and here, highlighting all of the different ways folks give to Children's Craniofacial Association (CCA).

You might imagine we are extremely grateful when an unexpected donation comes our way upon the passing of an individual who has bequeathed a portion of their estate to help our organization. However, as much as we love surprises, we always bemoan the fact that it's too late to say a proper, "Thank you," and in these instances, although we know, "who," we have no way of knowing why or how this cause was chosen.

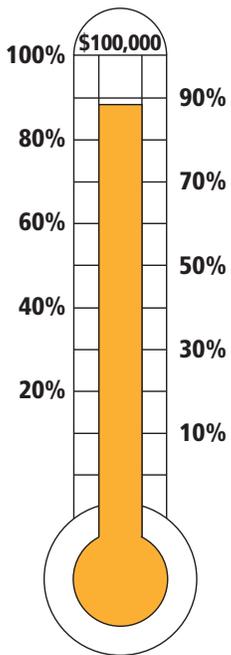
We wish we could thank those who thought ahead, arranging planned giving according to their wishes, and who made the decision to champion CCA posthumously.

To that end, we have initiated the CCA Legacy Society, for those who wish to name Children's Craniofacial Association as a beneficiary. Through this effort, we will chronicle information about those who endow our future and the future wellbeing of our CCA kids.

If you wish to fill out a declaration form and legacy history for our society archive, please contact us. If you have already set up a bequest in CCA's name, please allow us to include your intentions in our records, describing your gift of security, for the future of Children's Craniofacial Association.

fundraising news

2008 FAMILY FUNDRAISER GOAL THERMOMETER



CCA's family fundraising goal for 2008 is \$100,000. By the end of the first quarter our families had raised **\$13,363.50**. By the end of the second quarter you had raised a total of **\$37,631.66**. At the end of the 3rd quarter, families have pushed the totals up to **\$88,214.79!** We're almost there! Thanks so much for all you do! We have a lot of exciting fundraising stories to share this quarter...

Steinagel Family



Kathie and Mark Steinagel held a yard sale benefiting CCA. Also, CCA program director **Annie Reeves** hosted the **Second Annual White Buffalo BikeFest** raffle, which was held in her west Texas hometown of Snyder.

Highland Elementary School held its annual Denim Day in honor of former student and CCA kid **Justin Prince**. And **Kim Rogers**, mom to CCA kid **Kate**, continues to collect cans for cash to raise money for CCA.



Justin Prince



Kate Rogers



Brittany (pictured here with brother, Quinn, and mom, Harlena) gave the money she received for her 18th birthday to CCA.

For her 18th birthday, **Brittany Stevens** collected cash for CCA in lieu of gifts. Also, the **Fourth Annual Friends of Jeremy Golf Tournament** was held. (Check out the results in next edition of the newsletter!)

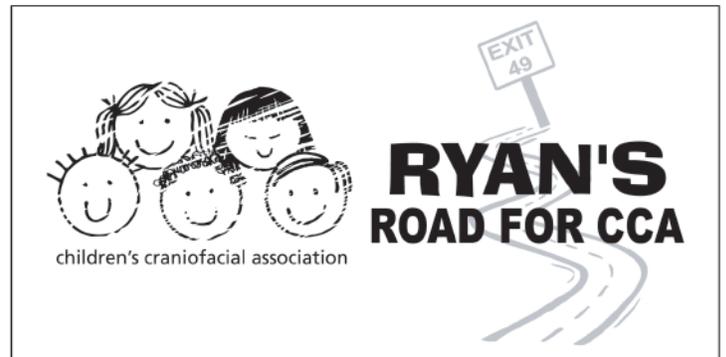
Bob's 60th Birthday



Birthdays benefactor, Bob Blake, and "Claire"

Our hats are off to **Robert Blake's** partner, **Lou**, who surprised him with a 60th birthday bash like no other. Bob's a big Cher fan, so the party had a Cher theme — invitations forged by "Cher," a cake that read,

"If Bob Could Turn Back Time" — even Cher-twin "Claire." Donations were made to CCA in lieu of gifts, **\$1,500** total, which Bob suggested be used for a party at our annual Cher's Family Retreat next June. Believe! Happy 60th, Bob, and thanks to all!



Ryan's Road

Reported by mom/event coordinator, Nicole Gulich

Our son, **Ryan Gulich Jr.**, was born December 1, 2001, with Apert syndrome. Since his birth, we have spent a lot of time traveling back and forth to Children's Hospital in Boston, MA. We have met other families with Apert kids and have had great conversations but no long-term friendships.

Last year, **Ryan Sr.** and I first heard about CCA in our hometown through the **Dale** family's annual Friends of Jeremy Golf Tournament. We have really enjoyed getting to know the Dales. They encouraged us to go to the retreat in Myrtle Beach this year. We went and loved every minute of it. We were so excited about the CCA community and wanted to become involved. After talking with **Stacy Swihart** at the retreat about the **Seth's**

Stride, we decided that we too could organize a walk to benefit CCA.

On September 13, we held a walk called **Ryan's Road for CCA**, which raised **\$6,711** and counting! We had about 85 walkers, including children, who collected over **\$3,000** in pledges. Our top team, led by **Kelly DeGuire**, collected over **\$1,100** alone. Our other top team leaders were **Jessica Drake** and **Danielle Peters**. Our top individual collectors were the **Blier family**, the **Sweet family** and **Judy Hillman**.

We also received corporate sponsorships to add to our total. **Fourtuna Energy**, our presenting sponsor, donated **\$1,000!** **Gas Field Specialist**, **Emery Industrial Supply** and **Dr. Castellana** were other leading sponsors for our walk.

To raise additional funds, we sold candy bars and CCA hangers. We also held a Wii raffle at our local **Sam's Club**, which brought in nearly **\$500**. The lucky winner was **Angela White** from Elmira, NY.

We would like to thank all of our volunteers, especially **Dorie Hughson** and **Tanya Mattison**, who helped organize and collect donations. Tanya went above and beyond her aunt-like duties to make Ryan's Road such a success!

We would also like to thank **Ron, Patty** and **Darek Gulich, Ken Mattison, Jessica Drake, Vickie Smith,** and **Jeanie Smith** for all you efforts selling candy bars to your coworkers and friends!

We had such a great time raising money for CCA, and we look forward to doing it again next year!

Raising funds, and awareness.

We're extremely grateful for all CCA families and friends who helped observe the **Fourth Annual Craniofacial Acceptance Month** this September. They helped widen the circle of acceptance and remind everyone that beyond the face is a heart. Plus their efforts resulted in contributions that surpassed expectations for the month, helping us pay for 2008 programs and service costs. Thank you all!



Josie Dowd

Scrapbook "Crop" for CCA

Reported by mom/event coordinator Kellie Dowd

The first annual **"Heart beyond the Face" scrapbook crop fundraiser** took place October 4. The event was hosted by **Jamie**



Croppers for CCA observing "Beyond the face is a heart"



Jamie Lewis & Kellie Dowd

Lewis and Kellie Dowd, mother to two-and-a-half-year-old **Josie Dowd**, who has Apert syndrome.

We were fortunate to receive several

raffle items and free dinner from **Jets Pizza**. Each cropper paid \$35 to crop for the day, which included lunch and

dinner. We had 14 croppers, and all had so much fun getting projects done as well as browsing everyone's books and getting lots of new ideas. We look forward to holding this crop on an annual or bi-annual basis to benefit CCA!

I also held a **Pampered Chef Party**, raising about **\$300** from my show profits. Plus the Pampered Chef consultant's husband owns a tattoo shop, **Deep Image Art**, in South Lyon, MI, that donated **\$100**. How generous! Thank you, all! And thank YOU, Kellie!

CCA "Hanger" Sales for September



CCA families and friends across the nation got on board for this year's observance of **Craniofacial Acceptance Month** by

raising funds in creative ways with our support "hangers." These hangers are similar to other hang tags sold for charities at grocery store checkouts and elsewhere. Donors are asked to support by paying \$1 or more per hanger, and the donor may write their own name or someone to be honored.

Many donors kept their hangers or posted them at events or at schools. Others opted to return them to CCA to be hung at our Dallas headquarters. We have numerous hangers strung from the ceiling, sent to us by individuals and families, including the **Menard** and **Roncicka** families.

Thanks to all who joined in the effort!

more fundraising news

wendelyn's 'course of dreams' golf challenge

The 3rd Annual Wendelyn's "Course of Dreams" Golf Challenge, a lead-in to September's National Craniofacial Acceptance Month, was held Saturday, August 23rd, netting over **\$9,000** for CCA! Fourteen teams (56 golfers) participated in this year's scramble, enjoying beautiful weather, pleasant temperatures and a nice lunch, catered by **Restaurant 1620**. Drinks were donated by **Arkansas Coca-Cola Bottling Co.** and **Rainwater, Holt & Sexton Law Firm**, novelties by **Blue Bell Creameries** and apples by **Ben E. Keith Distributors**.



The Wal-Mart team enjoys ice cream sandwiches from event sponsor, Blue Bell

This event helped heighten awareness of facial disfigurements with eighteen photos surrounding the scoreboard, doubling as a teaching tool with each photo representing an individual hole while highlighting a particular anomaly. Wendelyn also shared **Jeremy Dale's** story on hole signs placed at each green and in addition, each green was marked with a craniofacial fact. The golfers were given a multiple choice test with questions to be answered at each hole. The winner, which was drawn from a hopper containing tests with all the correct answers, received a \$50 gift card to **Academy Sports**. This was a fun exercise in which the golfers enjoyed learning about Goldenhar syndrome, Jeremy's anomaly. The golfers also participated in several competitions to win prizes including a Taylor Made Driver, donated by **Academy Sports**, a Cleveland Wedge donated by **Edwin Watts**, and cash!

Wendelyn knows first-hand about facial disfigurements. At 10 months, she was diagnosed with craniometaphyseal dysplasia (CMD) in which her parents were told she would not live to be 10 nor would she ever walk! Yet, she's beating the odds at 42 and believes it's important for everyone to understand the need for CCA. Wendelyn stated, "Even though our looks may improve with various



Winning team, Angel Law Firm, received 4 rounds of golf to Pleasant Valley Country Club.

reconstructive procedures, all the challenges one faces do not go away."

Wendelyn would like to extend her heartfelt gratitude to the wonderful people who made this event possible: Volunteers include **Jan Smith, Roberta Long, Toni Thrash, Jana McKnight, George & Linda Dicus, Cindy Ford, and Sharon Anderson**. Other generous supporters include **Lindy Blackstone** and her associates at the **BUZZ** all sports radio **103.7 FM** promoting the event, the local ABC affiliate, **KATV's Melinda Mayo**, host of "**Good Morning Arkansas**" who interviewed Wendelyn on their live broadcast, **Bale Honda, Sam's Club, Tara Eggers at Fast Signs, Tammy Tasky at Academy Sports, Andy Southern with Arkansas Coca-Cola Bottling Co., Mike Rainwater with Rainwater, Holt & Sexton Law Firm, Doug Hutchins with Blue Bell Creameries, Rusty Mathis with Ben E. Keith Distributors and Tim Morton**, owner and chef of **Restaurant 1620**.

In addition to enjoying the beautiful weather, the golfers made their bids on numerous silent auction items at the "turn-a-round" as well as after the game while enjoying their lunch and anxiously awaiting for their names to be called for door prizes which were donated by various businesses.

Next year's foursome promises to be even better than before, so mark your calendar and tell your friends about the **4th Annual Wendelyn's Course of Dreams**, which will be held **Saturday, August 22, 2009** at Country Club of Arkansas in Maumelle.



Wendelyn (center) with volunteer helpers, Toni (left) and Jana (right) Thank you Ladies!

more fundraising news

second annual seth's stride



On September 20th, the **Swihart family** and lots of folks in Canton, OH, and parts beyond came out in support of **Seth's Stride for CCA**. In its second year, the walk raised about **\$7,000** while spreading awareness for all kids dealing with craniofacial challenges.

It was a gorgeous day for the walk, and attendees were treated to all kinds of activities in addition to great exercise! There was a funfest following the walk that



included a bounce house for the kids, a magician, a rock-climbing wall, face painting, a caricature artist, singing and musical entertainment,

raffles, food and drink, and lots of fellowship all in support of Seth and his cause!

Other CCA kids and their families also attended. Special thanks to **"The Granted Wish Foundation"** for providing lodging for the families of **Samantha Klinger** and **Josie Dowd**. Seth's mom, **Stacy**, hopes more families will attend each year.

Thanks to all who volunteered and participated, and to event sponsors:

Marathon Petroleum, M&J Bitzel Car Wash, E&M Liberty Welding, JMW Trucking, Ohio Retina

Assoc., Sanders Funeral Home, Inc., KEYES Computer Services, Vasco Asphalt, Sparta Steel & Equipment Corp., Stein, Inc., Bikers for Jesus, Remember Me Jewelry, Jim and Barb Marracinni, and Chiavari's Antique Bricks.



more fundraising news

first annual chocolate festival for cca

Stacy's brother **Rick** got on board again this year down in South Florida. This time **Chef Rick Chiavari**, executive chef of **Porto Vita** restaurant, together with the folks at **Aventura Mall**, put together a **Chocolate Festival for CCA** — and raised about **\$24,000!**

Held just after Seth's Stride on October 5, the irresistible chocolate tasting lured everyone at the mall that day. You'd think they would have samples but they were full-sized chocolate goodies, including cupcakes, cookies and much more. Chef Rick even had a chocolate fountain at his booth!



So, how'd they do it? Chef Rick got all of his chef friends together, who donated their chocolate desserts, and **Aventura Mall** covered the expenses for all of the signage and tickets. The mall-going public heard about it through extensive media coverage — TV, radio, print, mall and Internet ads — which really helped increase attendance.

Everything was purchased with tickets, \$1 each or \$10 for 13 tickets, and all items cost from 1 to 3 tickets. They also raffled donated items every half hour. There was also a silent auction for dinners/lunches at the participating restaurants.

see **chocolate**, page 16

calendar of events

date	event	contact
Dec 13, 2008 10 a.m.-Noon	CCA Holiday Party Southfork Ranch Parker, TX	AReeves@ccakids.com 214.570.9099 800.535.3643
Feb 22, 2009	Smiling Thru the Mask – A dinner to benefit CCA Restaurant 1620 Little Rock, AR	wendelynnvonne@hotmail.com
Mar 22, 2009	Henry's March for CCA 5k Fun Run CSU, Stanislaus Turlock, CA	laurynhenry@sbcglobal.net myspace.com/henrysmarch 209.664.0500
Jun 24, 2009	Craniofacial Symposium Great Wolf Lodge Grapevine, TX	AReeves@ccakids.com www.ccakids.org 800.535.3643
Jun 25-28, 2009	19th Annual Family Retreat Great Wolf Lodge Grapevine, TX	AReeves@ccakids.com www.ccakids.org 800.535.3643
Aug 22, 2009	4th Annual Wendylyn's Course of Dreams Golf Tournament Country Club of Arkansas Maumelle, AR	wendelynnvonne@hotmail.com
Oct 3, 2009	5th Annual Friends of Jeremy Golf Tournament Corning Country Club Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com

more fundraising news chocolate, from page 15

A special thank you goes out to our corporate sponsors **Aventura Mall, Turnberry Associates, Spotmaster Cleaners, Epic Hotel & Residences, Southern Wine and Spirits** plus participating local bakeries, restaurants, marketplaces and hotels.



And we are truly grateful for the many volunteers who helped make this event a delicious success: **Seth's Aunt Laurie and Uncle (Chef) Rick, Kelsey, Amy, Mishelle, Poppy Leo, Elaine, Janet, Ken, Andrea, Tonia, Mirtia,**



Renee, Sarah, Bruno, Nicola, Nicolina, Ivan, Mark, Juan, Mustaffa, Hans, Raul and Mike.
Thank you!

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
- Kids Klub
- Yahoo support groups
- Webinars



children's craniofacial association
20 Years of Giving Hope
1989-2009

join cca in celebrating its
20th anniversary in 2009

more fundraising news

Jylian's Links of Love Celebrity Golf Tournament



CCA Volunteers stand ready for registration.

daughter of **John** and **Kendall Bilbow** from Arlington, TX, and she was the perfect representative for the event, visiting and posing with golfers and drawing some of the winning tickets on special raffles. Her dad, John, led our committee and introduced CCA to **Whitestone Golf Club** in Benbrook, just southeast of Fort Worth. They graciously hosted the event at this beautiful course with the help of



Jylian Bilbow



Mark Hagen

Worth, **What-A-Burger**, **Charles Schwab**, **Dallas Labs**, **Direct Strategies**, and many other supporters throughout the DFW Metroplex.

The first annual **Jylian's Links of Love** golf tournament was held September 22, grossing more than **\$10,000** for CCA!

CCA kid **Jylian Bilbow** is the daughter of **John** and **Kendall Bilbow** from Arlington, TX, and she was the perfect representative for the event, visiting and posing with golfers and drawing some of the winning tickets on special raffles. Her dad, John, led our committee and introduced CCA to **Whitestone Golf Club** in Benbrook, just southeast of Fort Worth. They graciously hosted the event at this beautiful course with the help of

Josh Haynes and **Tabatha Forsythe**. Golfers were treated to a complimentary beverage cart throughout the day, provided by local distributors, **Coca Cola**, **Miller**, **Coors** and **Ben E. Keith**.

Local radio celebrity **Tony Zazza** from **Mix 102.9 FM** joined the festivities and promises to return each year with a team as we grow the event.

We are extremely grateful for the sponsorship, both in-kind and monetary, of numerous friends of CCA, including **Southwest Airlines**, **Avid Golfer** magazine, area **Marriott** hotels, golf courses, merchants, fine restaurants like **Ill Forks** and **Chamberlain's**, **Spring Creek Barbeque**, **Mike Janicek** at **Chik-Fil-A** on Bryant Irvin in Ft. Worth, **Jason's Deli** on Camp Bowie in Fort

John Bilbow welcomes the golfers to the tournament.



Thanks to volunteers who came out to help: **Judi Freeman**, **Rob Gorecki**, **Beverly Butera**, **Jana Peace**, **Schwab's Emily Harwood**, **Jylian**, **Mikey**, **Ivy**, **Kendall** and **John Bilbow**.



Tony Zazza and friends with Jylian and Mom, Kendall

And, of course, we could not hold a successful event without our wonderful golfers and all the companies who supported us by sending teams. Thank you so much for participating! We trust you had a great time, and we hope to see everyone again next year!

Start your engines!



Char Smith, CCA's Executive Director, says, "Thanks!" to all our hole sponsors.

donors, january 1 – september 30, 2008*

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Up to \$1,000

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 Austin's Luau of Love for CCA / Tamara Freeman, CCA Volunteer
 BeautiControl / Rose Seitz, CCA Volunteer
 Brittany Steven's 18th Birthday Appeal / Harlena Morton
 Cash Collection Cans placed for CCA / Kim Rogers, CCA Volunteer
 Craniofacial Acceptance Month "Hanger" Sales / Darnell Menard
 Crop for CCA / Kellie Dowd, CCA Volunteer
 "Current.com" Catalog Fundraiser / Mark & Laurel Sanborn, CCA Volunteers

Chase Ingram Birthday for CCA
 Denim Day / Taylor Bishop, CCA Volunteer
 Anne T. Hawk Memorial Giving
 Highland Elementary School Denim Day / in honor of Justin Prince
 Ink / Cell Recycle for CCA / CCA Families & Friends
 Italian Club of Dallas Collection for CCA
 Rock Sale for CCA / Antasia Hart, CCA Super Sib
 Sarah Orne Jewett Collection for CCA / Mary Zimmer, CCA Volunteer
 Smiley Face Campaign Collections / Peggy McDannel, CCA Volunteer
 Tony Orlando Concert Collection / Guzzo Family
 Yard Sale for CCA / Kathie & Mark Steinagel, CCA Volunteers

\$1,000-\$5,000

Beauty School Funder for CCA / Rebecca Lee, Coordinator in name of Suzanne Ronczka
 Robert Blake's 60th Birthday Event
 Border's Books Giftwrap for CCA / Margaret Jenna, Dalton Family, CCA Volunteers
 Moulton Family Fund Appeals
 Pete's Scramble event / Dankelson Family, CCA Volunteers

Retreat "Chance Raffle" held at CCA's Annual Family Retreat in Myrtle Beach, SC
 Saint Patrick's School Denim Day / Pete Dankelson, CCA kid
 Starbucks Community Clean-Up / Emily Tipton, Organizer w/Jana Peace, CCA Volunteer
 Starbucks/United Way Youth Day of Caring / Freddie Seitz, CCA Volunteer
 White Buffalo Bike Fest Raffle
 Yard Sale for CCA / Kathie & Mark Steinagel, CCA Volunteers
 Nick Wiese's High School Fund Appeal / Nick Wiese, CCA Volunteer

\$5,000 or more

Ryan's Road for CCA / Gulich Family, CCA Volunteers
 Seth's Stride / Swihart Family, Stacy Swihart, CCA Volunteer Coordinator

\$10,000 or more

Jylian's Links of Love Golf Tournament
 Wendelyn's 'Course of Dreams' Golf Challenge / Wendelyn Osborne, CCA Volunteer

\$25,000 or more

Cher Convention
 Chocolate Festival for CCA / in name of Seth Swihart, Rick Chiavari, CCA Volunteer Coordinator
 Friends of Jeremy Golf Tournament / Dale Family, George, Kristine, Jeremy, Tommy, Cody
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 Heroes 4 Hope Gala / Jorge Posada Foundation / CCA Donor, Families & Staff Contributions

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

third annual spooktacular contest winners



CCA is happy to announce the winners of our 3rd annual Halloween Costume Contest. Congratulations to all of our winners!

Two-year-old **Gabriella Ramsingh** was the winner of the 0-5 age group. She dressed up as Andy and her older sister was Raggedy Ann. So precious!

Ten-year-old **Sara Skarshaug** was the winner of the 6-12 age group. She dressed up as an Oompa Loompa from Willy Wonka and the Chocolate Factory! "Oompa-Loompa-Doompa-Dee-Do!"

Thirteen-year-old **Gracie Holland** was the winner of the 13-18 age group. She was a carhop. I'll take a chocolate milkshake, please.

children's craniofacial association

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