

ccanetwork



newsletter of the children's craniofacial association

Cher — honorary chairperson

winter 2010

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andrew's story

By George Davis

When Dammy and I had found out we were having a son, I felt that overwhelming sense of pride and joy I can only assume all fathers have. I remember saying those words during that revealing ultrasound: "That's my boy." Our daughter Zoe was two at the time and was so excited when we told her she was going to have a little brother.

The pregnancy was uneventful for the most part, and because of complications during Zoe's birth, we opted for a cesarean birth for Andrew. He wasn't Andrew at the time as we were totally unsettled on a first name; however, his two middle names George (for his father) and Scot (his grandfather) had already been staked in the ground.



message from the executive director

2010 marks the beginning of CCA's third decade of serving families affected by facial differences. In preparation, the board of directors and staff met for the annual strategic planning meeting. We reviewed last year's activities and updated our strategic plan to ensure we're on track with programs and services that meet the needs of our families. And we developed strategies to provide the resources necessary to fund our plans for the future.



see **andrew**, page 10

see **executive director**, page 14

meet matthew young

Matthew Young is nine years old and is from Mullica Hill, NJ. He's in the fourth grade and likes going to school, where he's met some new friends. Math is his favorite subject, and he participates in his school choir. He also attends a social club one day a month, where he learns social skills and talks about how to make friends.

Recently, Matthew finished an animal studies class at school. At the end of the class, he had the chance to adopt a month-old African bullfrog. He

calls him Daddy Junior, feeds him every day before school and loves to watch him swim.

Matthew really likes journaling and writing stories. He wrote a story about his younger cousin, **Mary**, as well as a story about a teacher he had last year. This past Thanksgiving, he spent time listening to people and interpreted what they said in even more stories.

When he's not writing, Matthew likes to play Mario on Wii and other games with his dad and

younger sister, **Lauren**. (He and sis get along great, by the way.) He has a handheld DSi that he likes to play racecar games on, too. Incidentally, Matthew likes to go-cart — the real deal, not the game — and he's a pretty good driver.

Matthew spent the holidays at home with his mom's family and his dad's parents, who came in town from Florida for Christmas. He was mainly happy to have his dad home. He's a helicopter pilot in the Marines and has been in Afghanistan for seven

months. He's home for good as far as they know. Matthew wrote a story about his dad called "American Hero."

Matthew was born with Frontonasal Dysplasia and has had seven corrective surgeries so far. Right now he's doing great.

He's been to two CCA retreats, one in Dallas and the other in Myrtle Beach. He's had a fantastic time at both and had the chance to make new friends. He's looking forward to the next retreat in Boston. He says he "can't wait!"



ccateen

meet kaylee kramer



hi, my name is **Kaylee Kramer**. I am 14 years old and I am in the 8th grade. I live in Somonauk, IL, with my parents, my brother and my sister.

First, a little about my family. My dad, **Dan**, works as a welder. I like to spend a lot of time with him. My mom, **Dena**, runs a daycare at home, and I help her out

whenever she needs it. I like to go shopping and go for walks with my dog Duke and with my mom.

My sister, **Amber**, and I love to go shopping, get our nails done and dance in the car like rock stars. She is 17 years old and really awesome. My brother **Brandon** is 15, and he plays baseball, videogames and eats — a lot! We sometimes have a fun time drawing together.

Now, let me tell you a little about me. I like to draw, watch TV and laugh with my friends. I also play soccer for the Somonauk Bobcats. My favorite positions are goalie and forward.

Now, a little about my animals. My dog Duke is the newest member of the family. He is a yellow lab and is almost a year old. He's very



playful and loves to take up the whole bed at night. I also have two ferrets: Skylar, who is three, and Allie, who is one. They are wild and full of energy, and they love to play in the cage that my dad and I built. We also have two cats, Carmel and Callie, who are playful at times.

When I grow up I want to become an animal rescue cop, because I love animals. Animal cops rescue all sorts of animals, and I just think that would be a really fun job.

I was born with Craniosynostosis with a cleft eye, and I have had five surgeries to correct this. Even normal things like going to the grocery store are

sometimes difficult. People will ask me if my brother has punched me in the face, and I simply look at them and reply, "I was born this way." I also get a lot of stares, and I just ignore them, but sometimes I stare back or go up to them and ask them what they're looking at.

It has been difficult being different all my life. It is the hardest thing anyone could go through, and I just want to be like everybody else. But, the coolest thing is I may be the only one in the United States who has Craniosynostosis with a cleft eye.



ccasupersib

meet
lauren
young



my name is **Lauren**, and I am eight years old. I am currently in the third grade at Saint Margaret's School. I live with my mom, dad and older brother **Matthew** in Mullica Hill, NJ.

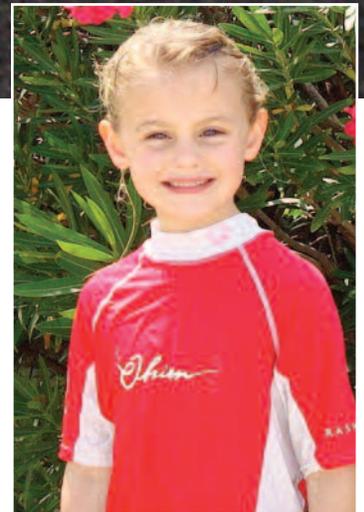
My favorite sport is basketball. I also play softball and have taken dance lessons since I was two years old. In my free time, I love to play the Wii (Yoshi is my favorite character), swim in my pool, read books, ride bikes and surf the waves down at the beach in the summer.

I also like to listen to music. I just went to my first concert and saw Kelly Clarkson. I had a great time, and hope to see her again.

Dolphins are my favorite animal, and when I grow up I hope to become a dolphin trainer.

In 2008, I went with my family to the CCA retreat in Myrtle Beach, SC. I sang "Take Me Out to the Ballgame" with my brother for the talent show. This past summer, I went to the retreat at the Great Wolf Lodge with my brother and mom. (My dad is a helicopter pilot in the Marine Corps and was deployed to Afghanistan for seven months, so he could not come with us.) I had a fun time in the water park and enjoyed meeting new friends.

I also enjoy going to the Sib Shop at the Children's Hospital in Philadelphia.



At the Sib Shop, I get to meet other kids who have special brothers or sisters. I have made many friends through the Sib Shop and CCA retreats, and I can't wait to go to Boston this summer.



calendar of events

date	event	contact
Mar 7, 2010	3rd Annual Henry's March for CCA 5k Fun Run CSU, Stanislaus Turlock, CA	lauryhenry@sbcglobal.net myspace.com/henrysmarch 209.664.0500
Jun 24, 2010	Craniofacial Symposium Hyatt Regency Cambridge Cambridge, MA (overlooking Boston)	AReesves@ccakids.com 214.570.9099 800.535.3643
Jun 24-27, 2010	20th Annual Cher's Family Retreat Hyatt Regency Cambridge Cambridge, MA (overlooking Boston)	AReesves@ccakids.com 214.570.9099 800.535.3643
Jul 25-30, 2010	Camp Courage Atlanta, GA	www.choa.org/campcourage
Jul 30-Aug 1	Moebius Syndrome Conference Moving Mountains for Moebius Bloomfield, CO	Coloradomoebius2010@q.com Vicki@moebiusysyndrome.com www.moebiusysyndrome.com 303.814.2144 or 660.834.3406
Aug 28, 2010	5th Annual Wendelyn's Course of Dreams Golf Tournament Country Club of Arkansas Maumelle, AR	wendelynyvonne@hotmail.com
Sep 11, 2010	4th Annual Seth's Stride for CCA Canton, OH	mythreekids@neo.rr.com Stacy Swihart www.firstgiving.com/sethsstride
Sep 2010	Jylian's Links of Love Golf Tournament Location TBA (Texas)	JPatterson@ccakids.com www.ccakids.org 800.535.3643
Sep 19, 2010	Smiling Through the Mask – A dinner to benefit CCA Restaurant 1620 Little Rock, AR	wendelynyvonne@hotmail.com
Sep 25, 2010	Little Fire, Big Heart Dinner/Auction Melwood Art Center Louisville, KY	TarynSkees@gmail.com www.littlefirebigheart.com
Oct 2, 2010	6th Annual Friends of Jeremy Golf Tournament Corning Country Club Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com



▲ CCA Kid Henry Johnson of Turlock, CA with his CCA mug

h&r block

If you're not already a customer of the H&R Block folks for your taxes, having your return done for 2009 with their help will also help CCA!

H&R Block will donate \$25 to Children's Craniofacial Association if you designate CCA as your charity when you have your taxes done there! Call Jill at CCA for a form.

bracelet sales continue!



"Beyond the Face is a Heart" wristbands

The great response to our CCA bracelets has prompted us to sell them throughout the year!

Bracelets are \$1 each

Available in the 5 colors of CCA's logo faces:

royal, orange, teal, purple, lime

Sizes: 8" (universal/adult) and 7" (small/child)

To purchase and/or sell, email or call Jill
JPatterson@ccakids.com • 800.535.3643

become cca's "friend"
on facebook!



CA now has its own facebook page and cause!
You can look us up by simply searching for
Children's Craniofacial Association!

5th annual friends of jeremy golf tournament

By Kristine Dale

The 5th Annual Friends of Jeremy Golf Tournament was held on Saturday, October 3, at the Corning Country Club in Corning, NY. As always, we had an incredible turnout and overwhelming support from the community, our co-workers, friends and family.

One hundred sixteen golfers came out to have fun and show their support for the kids of CCA. We had a record number of tournament and hole sponsors and tremendous help from local businesses and national organizations who donated prizes and silent auction items.

The tournament included a raffle, silent auction, closest to the pin 50/50, closest to the line prize and a skins game. Our local car dealership, **Simmons-Rockwell**, sponsored a new car prize for a hole-in-one contest. Unfortunately, no one won the car, but everyone had fun trying! The event was a huge success — we netted **\$28,000** for CCA!

This year we celebrated our fifth anniversary of the tournament by recognizing the individuals and businesses that have supported the event each of our five years.

Individuals were given a Friends of Jeremy blanket, and businesses were presented with a recognition plaque.

The tournament continued to be advertised through local newspaper and TV stations. Jeremy was again joined this year by a few of his CCA friends, **Andrew Perry** from Massachusetts and **Ryan Gulich** and **Sophia Lorenz** from Big Flats, NY. Their participation in the tournament helped raise awareness of craniofacial conditions. The final highlight of the event was when CCA kid Andrew Perry, won the 37-inch Sharp LCD TV donated by Corning Incorporated.

We are so grateful to everyone who supported this event and the kids from CCA. For more information and to see photos from the tournament, visit www.friendsofjeremy.com.



cca 20th anniversary t-shirts

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



We still have the following sizes available: Adult sizes, S, M, 2XL, and 3XL. **And we're happy to announce youth sizes are still available:** XS (2-4), S (6-8), M (10-12), (L youth, order S adult).

goodsearch & goodshop

Every time you shop online at your favorite stores you could be saving money and earning a donation for Children's Craniofacial Association.

Our new toolbar, developed by **GoodSearch & GoodShop** takes just a few seconds to download. More than 1,300 top stores including **Apple, Best Buy, Gap, PetSmart, and Staples** are pitching in and will donate a percentage of each sale to our organization. There's no extra cost to you and you may even save money as the merchants are providing us thousands of money-saving coupons!

The GoodSearch toolbar also includes a search box which is powered by Yahoo! Each time you search the web, about a penny is donated to us!

There's no easier way to help CCA. Please spread the word! Here's a link to the toolbar for more information: <http://www.goodsearch.com/toolbar/childrens-craniofacial-association-cca>

motorcycle raffle winner!



CCA is pleased to announce our bike winner: **Tucker Woods**, of Lindon, Utah!

In December, CCA held a drawing for a **Johnny Pag Motorcycles ProStreet**

and Tucker's name was drawn by **John**, a member of the **Italian Club of Dallas**. Club members were volunteering at our CCA office that day, helping with our newsletter mailing. Tucker purchased his raffle tickets at "**Lily's Dinner**" (see page 15). The lucky winner chose the black edition of the bike and we'll be sure to publish a photo of him with the bike in an upcoming newsletter issue. Special thanks to Johnny Pag, to CCA families and friends who helped sell tickets, and to all who purchased them.

Congratulations Tucker!



donors in the spotlight

This issue we feature donors, **Fred and Judi Freeman** of Tucson, Arizona. Fred and Judi have been supporters of Children's Craniofacial Association for many years. Their grandson, **Robbie**, has grown up with CCA and they see the value of our programs and services first hand.

The Freemans give through their local United Way. CCA receives quarterly checks from the **United Way of Tucson and Southern Arizona**, gifts from "The Fred and Judi Freeman Charitable Fund." They tell us they give this same way to their church and all the causes they support.

We're extremely grateful to these folks for their kindness and for their ongoing contributions. Thank you so much!



girls' night out

The Richmond, Virginia, Center for Cleft and Craniofacial Care knows girls just want to have fun.

The music was pulsing, the lights of the salon sparkled and stylists chatted with their clients as their scissors flashed and snips of hair fell to the floor. Upstairs, the mood was completely different, as soothing tunes and aromas of flowers filled the air. Dim lights and candles provided just enough light to allow the clinicians to concentrate on applying soothing ointments as they

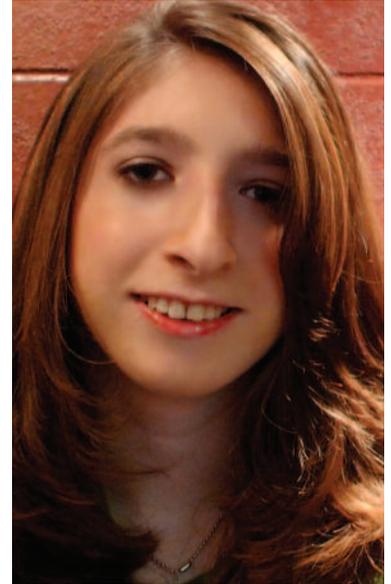
and Craniofacial Care in Richmond, Virginia.

For the girls, it was an extraordinary evening. They were the first participants in "Girls Night Out," a new program created for girls with facial differences. The girls were treated to an evening of pampering, including new hairstyles, manicures, facials and makeovers at the Nesbitt Salon in Richmond.

making important decisions about a potential new "look," they were understandably a bit uneasy.

The evening started with a fun and noisy pizza party, hosted by Alycia Roland, a former patient of the center, now a successful businesswoman. Everyone had a chance to get acquainted and unwind. The girls had a chance to look through style magazines for inspiration and talk with some older girls from Sigma Sigma Sigma sorority, who volunteered both their time and their fashion savvy.

Greg and Carol Nestor, the owners of Nesbitt Salon, opened the doors of the fashionable salon for the event. Along with an incredible group of staff volunteers, the Nesbitt team donated their services for the evening. After dinner, the girls were whisked away to begin their individualized treatments. It was difficult to tell who was having a better time — the girls, their families as they watched the transformations, or the salon staff who worked so hard to make the evening perfect for each girl. "The evening surpassed



"I feel so beautiful," says Carleigh, born with Treacher-Collins syndrome.



Destiny, born with hemifacial microsomia, chats with her stylist while her family looks on.

massaged the faces of their clients.

Not an unusual scene for a high-end salon, but this night was special. The salon was hosting an exclusive party for teenage girls who are patients at the VCU Center for Cleft

As the girls entered the salon with their families, their excitement was visible, but so was a certain amount of nervousness. Some of the girls had traveled hours to participate. Faced with meeting new peers and

everyone's expectations," said the center's director, craniofacial surgeon Dr. Jennifer Rhodes.

The program, funded by a grant from the MCVH Auxiliary of VCU Health System, takes place each quarter for a different group of patients. "Growing up is hard to do, but when you have a facial difference, the teenage years can be especially harsh," said Dr. Rhodes. "We want to support our patients' emotional needs by doing what we can to help boost their self esteem. Getting together with peers who have had similar life experiences really helped our girls feel

comfortable and accepted.”

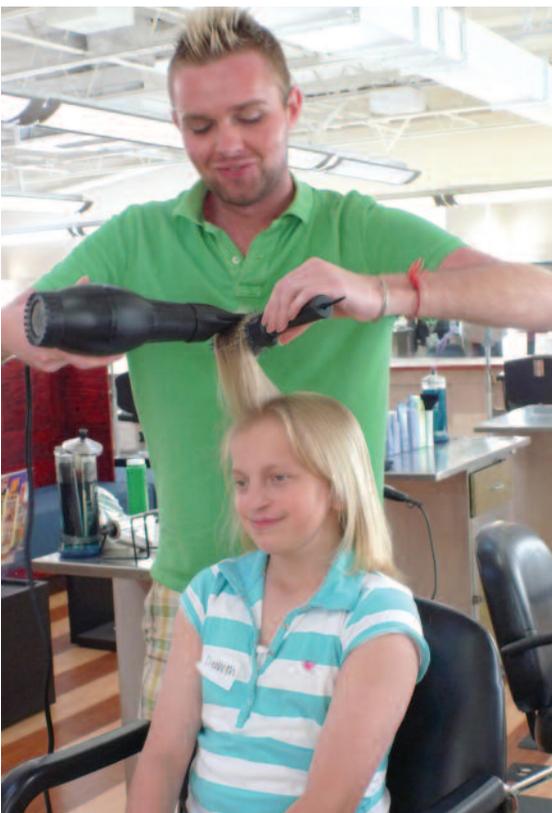
The “Girl’s Night Out” program was designed to foster self-esteem in preteen and teenage girls who are followed by the VCU Center for Cleft and Craniofacial Care. Teenagers with facial differences often feel isolated, not realizing there are other teens facing the same problems. The program provides girls with facial differences the opportunity to be a part of a peer network, an important aspect of normal adolescence. “It let a

bunch of girls with similar problems relate and relax!” stated Carleigh Dahmen, age 14, who was born with Treacher-Collins syndrome.

Dr. Rhodes and Ruth Trivelpiece, the center’s clinic coordinator, also recognized that teens can “burn out” while going through their lengthy and complicated treatment plans. This treatment fatigue, along with the normal adolescent struggle to assert independence, can contribute to less than ideal patient compliance. Dr. Rhodes and Ms.

Trivelpiece hope the program will allow the teens to realize the team is working with them to achieve their potential in many different areas.

“We had the opportunity to interact with the girls and their families on another level. They saw us as people, not just health care providers. It was a very fulfilling experience,” said Dr. Rhodes.



Finishing touches bring a smile to Elizabeth, born with bilateral cleft lip and palate.



Katherine, born with Pfeiffer syndrome, gets a new look just in time for her high school graduation.

As the evening came to a close, it was remarkable to see the girls’ transformations. Each girl posed for a glamour portrait, exhibiting a sense of self confidence and an inner ease that was more than just a result of their spa treatments. There was a new sense of confidence and an ease that was apparent, not just with other participants, but within the girls themselves.

As each girl posed for her final portrait, the families, salon and center staff gathered around excitedly to share their stories and say goodbye. Hugs and high fives abounded. As one of the girls stated, “I can’t believe I have to go home now. I

feel so beautiful—I’m ready to go out and show off the new me!”

Based upon comments and suggestions from the attendees of the first “Girls Night Out,” along with input from the volunteers, the next “Girls Night Out” will only get better. And Dr. Rhodes is not ignoring the boys—plans are underway for a fun-filled event that will appeal to teenage boys for their own special “Boy’s Night Out.”

Call 804-828-3042 or visit us at www.craniofacial.vcu.edu for more information about the “Girl’s Night Out” program or the VCU Center for Cleft and Craniofacial Care.

andrew, from page 1

We arrived at the hospital confident that this was going to be a much smoother experience than the emergency c-section we went through with Zoe. How quickly we would be proven wrong.

I still remember those first few moments like it was yesterday. When Andrew first saw the light of this world and I that red hair it was evident we would have two little red heads on our hands.

As I kissed Dammy and walked over to the weighing station, the nurse started to clean him up. She then said the first words that indicated that something wasn't normal. "His ears are a little low set" she said. My response was a confused and sarcastic, "A little?"

As the doctors tended to Dammy, and my mother kept the camera rolling for another minute, I got the weird sensation that she felt Dammy shouldn't see Andrew now. Then the tape stopped as a new world for us was beginning. He was cute as a bug with curly red hair.

I carried our son over to my wife and laid him on her chest and we cried with joy for the birth of our son.

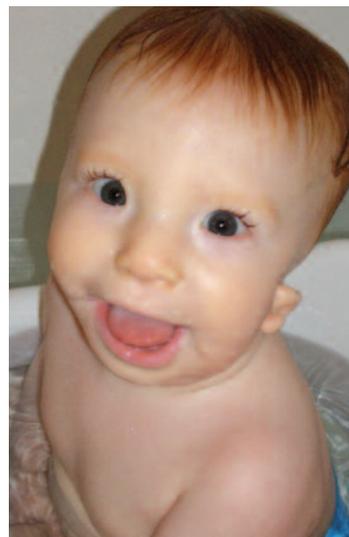
Within the hour, he was nursing despite the fact that he was born with a Tessier type 7 cleft, which essentially is a defect in the corner of the mouth that

never closed, giving him an omnipresent smile.

Also, within the hour, I had the laptop in hand and was searching the Internet for "facial malformations," which was absolutely the worst thing I could have ever done, but what it did was prepare us for the worst.

In addition to the cleft, it appeared (and was later confirmed) that he had bilateral microtia with atresia and bifacial microsomia. Medically speaking, microtia means "small ear," and atresia means "no ear canal." Microsomia means "small face." Some of his characteristics were very similar to Treacher Collins and other syndromes. We feared the worst and simply needed help, answers and education.

I also searched on the Internet for specialists and surgeons who helped correct some of these differences. I even sent a photo of Andrew to Dr. Jeffrey Fearon before



Andrew was 24 hours old. When I realized that he was in Dallas, about a one-hour drive, we were very excited to get a chance to see him.

Andrew didn't cry, and he couldn't hear more than you or I could if we plugged our ears with our fingers. He failed the hearing test at the hospital and was classified as a deaf baby.

There was concern with Andrew gaining weight because of his cleft and losing as much milk as he was swallowing, so we had multiple swallow studies done. Watching your young, helpless infant son struggle to swallow anything thicker than milk was quite sad, and Mom and I shed more than a few tears during the discussions with doctors and nurses.

We decided against inserting a "g-tube" or "button," and we were told quite frankly that if we took Andrew home without inserting a feeding tube that he would die and the hospital wouldn't be held responsible. Andrew continued to nurse for two years and never fell below the normal weight for his age, nor did he have one upper respiratory infection. He learned to adapt to his environment very well.

We visited many doctors and specialists during Andrew's first year — from

audiologists and anthropologists to dieticians and so on.

We met Brooke, Andrew's first audiologist, who performed detailed hearing and response tests on Andrew and ultimately determined that his hearing could be corrected with the use of a conductive hearing aid. Since his inner ear was present and functioning normally, he simply needed to get the sound from the outside world to his inner ear since it could not travel normally through the ear canal. He was fitted with for a BAHA (Bone Anchored Hearing Aid).

When we went in to see Brooke and try on the hearing aid, it was a glorious day. You could see Andrew's face light up when he heard for the first time with his BAHA. Technology is a great (and expensive) thing.

As I worked full time, Dammy played the roles of mother and super orchestrator. She got involved with ECI (Early Childhood Intervention), who visited the house at least once a week and provided a great service for her and our family. We had sign language instructors, occupational therapists and speech therapists who played major roles in Andrew's advanced learning and development.

continued next page →



In fact, some of them have continued to be a part of our extended family. I want to mention Mrs. Lauren Roe with Jumpstart Center. She is one of the major reasons Andrew is at the level he is today with his speech.

Andrew underwent his first surgery when he was a year old to repair the cleft in his lip. This was a very sad time for all of us. We were going to be forever changing Andrew, and he would never look the same. Although this was a very tough decision, we knew that it was in his best interest. The hardest part for us was to know Andrew would be under anesthesia, but the hardest part for Andrew was going to be nursing with this medical super tape holding the two sides of his lip together. He healed

beautifully and only has minor scarring.

Andrew is one of the most amazing kids I know. He has never allowed his hearing impairment to hold him back. He is a go-getter, loves attention and just wants to be loved all the time. He has his sister Zoe there to "mother" him, and he loves it (although he likes to fight with her from time to time). He started a Pre-K for 3-year-olds this year as well as a deaf-ed program within our local ISD, and he is doing fabulously. He has an incredible support system at home and school. I see a very bright and vibrant future for my son.

Kids Klubs



children's craniofacial association

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 take part in discussions. Sign up for one of four age groups: Kindergarten through third grade, fourth and fifth grades, sixth through 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'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

For a complete list of our programs and services, visit:
www.ccakids.org/prg.asp

fundraising news

second annual chocolate festival for cca



held on October 18, 2009 at the **Aventura Mall** Center Court in Aventura, Florida, the 2009 Chocolate Festival was another sweet adventure for

shoppers! **Chef Rick Chiavari**, executive chef of **Porto Vita** restaurant and Aventura Mall's **Laura Nichols** teamed up again along with many local "chocolatiers" and chefs, to create incredible desserts all made of chocolate! In addition to Aventura Mall, sponsors of the event included **Porto Vita**

Property Owners

Association, Joe & Trina Cayre, DP

Property Holding LLC, Combined Resources, LLC, Mark J. Gordon

Foundation, Sapoznik Insurance, Spotmaster Cleaners, Epic Residences and Hotels, Gym Kidz, Cailis

Mechanical Corporation and Pro-Tech International.

Chef Rick is the uncle of CCA kid, **Seth Swihart** of Canton, Ohio. He and Seth's aunt, **Laurie**, cousins, **Kelsey** and **Brett**, Laurie's dad, **Leo**, and many friends including **Elaine, Janet, Jamie, Renée, Harley, Dylan, Mishelle** and **Eileen** all volunteered to make the day run as smoothly as Chef Rick's chocolate fountain! Chocolate lovers purchased tickets for \$1 each or \$10 for 13 tickets and traded 1-3 tickets for a taste of each full-sized treat.

This year folks were also enjoyed chocolate-themed fashions, raffle drawings, music, auctions, a super bowl trophy created in chocolate and a giant CCA logo



chocolate bar! Many thanks to all who participated with donating, creating and buying the yummy delights raising over **\$23,000** for Children's Craniofacial Association!



tamale fundraiser

the **Community Relations Team (CRT)** from the **Booz Allen Hamilton** firm (Houston) and the **Aldine Church Ladies Group** have teamed up again in support of Craniofacial Awareness Month and in honor of CCA Kid, **Natalie Wardlaw** by making, selling and buying tamales!

The CRT at Booz Allen donated all the items required to make the tamales. Aldine Church Ladies – **Rosie Martinez, Norma Navarro, Margarita Cortez, Esmeralda Garcia, Juanita Veliz Yadira Rivas, Nereida Hernandez, Abigail De Los Reyes,** and **Graciela Guzman** made at least 1,440 tamales which were purchased by Booz Allen employees, NASA civil servants and other contractors. Former lead of the CRT, **Lorna Wallace** and current leads, **Angela Cason** and **Alexa Ramby** helped **Abigail De Los Reyes** – friend of Natalie's mom, Jennifer – coordinate another successful effort. Along with additional donations from the Booz Allen Hamilton firm, the group brought in over **\$1,000** in the process! That's a hot tamale!



snowman auction

ms **Tracy Tidwell's Gifted and Talented students** of the **Barbers Hill ISD** crafted snow people and auctioned them off online. Over **\$500** in proceeds came to Children's Craniofacial Association in honor of CCA kid, **Wade White**, whose sister, **Antasia**, is one of the GT students in the Primary school.



fundraising news

denim day

At the suggestion of one of their employees, **Alcan Cable**, in Atlanta, Georgia, held a casual-dress day at their company and collected **\$600** for CCA. Thanks to everyone there!

penny drive

Angela Marcum and **Lincoln Heights Elementary** school held another Penny Drive among students and sent in over **\$500** dollars for Children's Craniofacial Association. Thank you!

chili cook-off

PetroCasa Energy in Fort Worth, Texas, held a Chili Cook-off for employees to enjoy and to help raise funds for Children's Craniofacial Association. Coordinator, **Dan Cherkassky** notified CCA and over **\$400** was delivered to our office following the effort. Thanks!

pampered chef

Jessica Dornier held a Pampered Chef funder, raising **\$300** to benefit Children's Craniofacial Association, in honor of her son, **Rick**. Half of the proceeds came from Pampered Chef for Jessica's efforts getting orders and half came from **Bobby Mayo**, her Pampered Chef consultant! Many thanks to both Jessica and Bobby, and to all who participated.

Watch for a recap of some notable 2009 Firstgiving fundraising pages for CCA in our next issue!

merry microwave!

Merry Christmas wishes came to the CCA office in the form of a new microwave oven for our "kitchen"! **Jim** and **Beverly Butera**, long-time supporters/volunteers of Children's Craniofacial Association (and parents of CCA staffer, Jana Peace) replaced a dangerously old one for us. THANKS SO MUCH!!!



Jake Henson, Stephen Orban, Joel Evans, Joe Henson and Robert West

mr. mistletoe and the elves in training

Stephen Orban and fellow 8th graders, **Joel Evans, Bob West,**

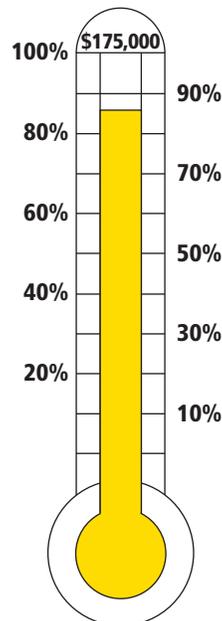
Jake Henson and **Joe Henson** from **Troy Jr. High** in Troy, Ohio put together a horn ensemble and performed over the holidays at several events. One was a luncheon at **Emerson Climate Technologies, Inc.** The company offered to make a contribution to a worthy cause to thank the group, "Mr. Mistletoe and the Elves In Training," for their entertainment. The five horn players chose Children's Craniofacial Association to honor Stephen's cousin, **Avery Lytle** of Pennington, New Jersey "for all she's been through." CCA is extremely grateful for a **\$150** donation because of these generous, talented and caring kids and we wish them much success!

holiday giving

Angela Cronin, mom of CCA Kid **Megan Cronin**, tells us she got a call from one of the employees of her mother-in-law, **Fran Cronin**. Fran is the Activities Director for **Wesley Health Care Center**, a nursing home in Saratoga Springs, New York. Her employees wanted to get her something for Christmas and decided to make a donation to CCA in her name!

Thank you to Fran for inspiring such meaningful giving and to her gift makers, **Cheryl, John, Wanda, Sandra, Kathy, Lynn, Bridget, Colleen, Cathy, Sarah** and **Pat!**

2009 FAMILY FUNDRAISER GOAL THERMOMETER



funds for cca

Employees at the headquarters of the **Solis Women's Health Centers** collected funds for charity at Christmas and this year, chose Children's Craniofacial Association to receive their gifts as **Margaret Jenna**, mom of CCA Kid **Elizabeth Ivy Dalton**, is an accountant there and put in a good word. Thank you to all for this generous contribution.

executive director,
from page 1

Increasing the number of families we serve remains our most important goal. We want to be sure there aren't families out there making this difficult journey alone. To reach more families, we are continuing to spread awareness through CCA's National Outreach Program.

This year, we'll continue to publish educational materials. Two syndrome booklets, discussing vascular malformations and frontonasaldysplasia, will round out our series of guides. We also plan to publish articles addressing sleep apnea as well as foot problems associated with Apert syndrome. We'll finish translating our booklets into Spanish and begin work on translating the website. In addition, we'll continue to enhance CCAKids.org, publish quarterly newsletters and hold four webinars.

Also, we will hold the 20th Annual Family Retreat in Boston and, in conjunction with it, the Second Annual Craniofacial Symposium.

CCA board and staff want to thank all our families for joining the efforts on so many levels. Together we're meeting our goals and objectives toward serving all individuals and families affected by facial differences.

Charlene Smith
Executive Director

girls' night out, from page 9

About Dr. Rhodes and the VCU Center for Cleft and Craniofacial Care

The creation and success of "Girls Night Out" is a direct reflection of the vision of **Dr. Jennifer Rhodes**, Virginia's only dedicated craniofacial and pediatric plastic surgeon. Dr. Rhodes attended medical school at the University of Pennsylvania and completed residencies in general surgery and plastic surgery in New York City at St. Vincent's Hospital and Montefiore Medical Center respectively. She completed her craniofacial fellowship at The Craniofacial Center in Dallas, Texas, under the direction of **Dr. Jeffrey A. Fearon**. In 2008, Dr. Rhodes became the Director of the VCU Center for Cleft and Craniofacial Care at the VCU Medical Center in downtown Richmond.

The medical center is on the forefront of health care, providing patients with some of the most progressive treatments and technology available. In addition, it has received several national honors for leadership in human resources, including becoming one of the nation's top 100 best companies for working mothers by Working Mother magazine.

Dr. Rhodes strongly believes in providing coordinated

interdisciplinary care for children with complex and unusual craniofacial anomalies. Her team consists of pediatric specialists from craniofacial surgery, neurosurgery, ophthalmology, dermatology, interventional radiology, audiology, otolaryngology, genetics, speech pathology, psychology, dentistry, orthodontics, oral and maxillofacial surgery, occupational therapy, clinical anthropology, nursing and a clinic coordinator. This interdisciplinary team meets several times a month to evaluate patients and develop an individualized, coordinated and integrated treatment plan for each patient.

"We're here to help our patients and their families with all aspects of care related to their conditions. During new patient evaluations, we spend as much time as needed with families. No family leaves with any questions unanswered," said Dr. Rhodes. "We pride ourselves on being a resource center for both families and community health care providers. We let our families know that we will be there with them as their children grow from prenatal and pre-adoption needs to psychological

counseling during the turbulent teenage years."

The center also provides a variety of services, including prenatal consultation for expectant parents. The discovery of a craniofacial condition on prenatal ultrasound can create a stressful situation for expectant parents. Understanding the diagnosis, and the type of care their baby will need, helps put families at ease.

Knowing that the center is there for support and advice, as well as comprehensive treatment, is a real help for families. During the prenatal consultation, clinic coordinator **Ruth Trivelpiece**, talks to parents about their emotional needs as they prepare for the birth. She also provides support and education to the families, including instruction in specialized feeding techniques for babies born with craniofacial anomalies including cleft lip and palate.

Despite Dr. Rhodes' busy surgery schedule, she and Ms. Trivelpiece continuously work to improve care for the center's patients. Gathering feedback from families has helped Dr. Rhodes focus on ways to make clinic visits and hospital stays a more positive experience.

fundraising news

dinner and silent auction held for craniofacial awareness

Lily's First Annual Craniofacial Awareness Dinner and Silent Auction was held on Saturday, September 26, 2009, at **Noah's** in Lindon, UT. We had an amazing turnout. More than 100 guests attended.

We also received more than 100 great items for the silent auction. Everywhere I went to ask for sponsorship or donations, it always went better if Lily was with me. She would politely smile and thank them, without being asked. It was so adorable!

I feel like we reached a new level of awareness in



our community, and from the comments I received, we touched many people. Lily was the princess of the evening and was thrilled to have a dinner named after her.

Our evening started with a delicious dinner catered by **Tucano's Brazilian**

Grill. I put together a short presentation, introducing CCA, Lily and a few of her CCA friends. We had a special presentation by Lily's wonderful surgeon, **Dr. Louis Morales**. We were so fortunate to have him come and spend his time and educate our

family and friends on craniofacial conditions.

The night closed with the final bids on the silent auction items. It got a little competitive in the final seconds, but everyone had a great time. We raised more than **\$8,000** total in just one night of fun, food and good times. All the hard work and preparation definitely paid off! I already have ideas for next year, and we will need to expand to a bigger place! Lily can hardly wait.

I want to give a special thanks to everyone who was willing to lend a helping hand. This was not easy to do, and with everyone's help, we made a very successful and fun night of it! Thanks to our family, friends, neighbors and supporters. We would like to thank those who donated items for the auction, money, time or both. Our family felt so much love and support that it was absolutely incredible. Thank you!



My Favorite Holiday - Valentines Day



by: Miranda Larkin

CCA Kid Miranda Larkin's artwork for the CCA Kids' Klub "Favorite Holiday Challenge"

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Submitted by Darnell Menard

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holiday parties



Dallas

CCA, together with **Dr. Jeffrey Fearon**, hosted its 20th annual holiday party at **Southfork Ranch**, in Parker, TX, on Saturday, December 12th. Around 500 attendees joined us for a morning full of fun!



Radio Disney was once again the entertainment, and everyone really participated in the fun, music and games. The parents had just as much fun as the kids, especially during the hula hoop and dance contests! Everyone enjoyed cake and punch as well as arts and crafts. The kiddos decorated their own cookies and picture frames.

The **firefighters of Parker County** joined us, bringing a real fire truck for

the children to see. And the **Dallas Stars Ice Girls** were there and gave autographs. The snakes made their second appearance and were a hit—even Santa held one!

Families went home with lots of door prizes, which were donated by several local businesses. Prizes

included gift cards to the **Great Wolf Lodge**, a gift certificate to the **Magic Time Machine**, passes to the **Fort Worth Zoo** and

the **Dallas Zoo**, passes to **AMC theaters**, a **Frisco RoughRiders** merchandise packet and autographed items from the **Texas Rangers** and gymnasts, **Carly Patterson** and **Nastia Lukin!**



As always, the highlight of the party was the big man himself, Santa Claus. Children had their pictures taken with Santa, and everyone went home with a keepsake photo and toy.

CCA would like to thank Southfork Ranch for hosting, as well as their wonderful staff! A huge thank you goes out to our wonderful volunteers from the **Italian Club of Dallas**, CCA Parent, **April Gorman** and all of her friends who came out to help as well as CCA friends **Richie Cook** and **Adam Golden**.



Midwest

Mr. and Mrs. Santa and an elf stopped at the **Parkway Chateau** in Kenosha, Wisconsin to

visit with CCA kids and families who got together for a pizza lunch, crafts and



visiting. Mom **Marla Verdone** of Janesville, Wisconsin, helped plan the gathering and her daughter, **Lara** passed out drawing paper and manned the craft table. Regulars joined a few new families and lots of visiting made the afternoon successful and fun. Kids sat on Santa's knee for photos and to tell him what they wanted for Christmas, raffle tickets were distributed for door prizes, and a good time was had by all. See you next year!



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Corporate / Foundation Gifts

CCA Corporate / Foundation Friends

(up to \$1,000)

AT&T (Employee Giving)
American Express (Employee Giving)
American Express Charitable Fund
(Matched Gifts of Janell Nelson)

Anonymous
 Aptus Partners, LP (John Romero)
 Attachemate/NetIQ (Matched gifts of employees)
 Baby Hands Down by Erin Scott
 Baker Roofing Company
 Bank of America (United Way Campaign Employee Giving)
 Charity Motors (CARS-Charitable Auto Resources)
 Children's Medical Charities (CFC)
 Cleveland Bakers Local No. 19
 Creative Growth Counseling & Coaching, Inc.
 Danze & Blood Architects
 DFWBID
 Dominion Foundation (matched gift of John Charles Larson)
 Dorroh & Kendrick
 Deutsche Bank Americas Foundation (Matched Gift of Kent Penwell)
 Epic Systems, Inc.
 Five Star Quality Care, Inc. (recommended by Robert Sharrett)
 Frugal Flower, Inc. (purchases percentage)
 Funding Factory (Ink/cell recycle rebates)
 GoodSearch/GoodShop
 Home Depot (Matched Gifts of Doug Hopkinson)
 JackTheDonkey.com by David Katz
 Jefferson Lumber and Millwork by Mary Lytle
 Johnny Pag Creations
 Justgive (donors listed separately)
 Katie's Clothes Bin (by John & Laurie Bovenkamp family)
 Katsafourous Bequest
 Legacy Global Foundation directed by the Mitchell family
 A grant from Kraft Foods Global, Inc.
 Kroger (purchases percentage incentives)
 Neal Oral & Maxillofacial Surgery, PLLC
 Network for Good (donors listed separately)
 One Cause (purchases incentives)
 PASCO (Personal Assistance Services of Colorado)
 Pfizer (United Way Campaign Employee Giving)
 Prudential Foundation (Employee/Matching Gifts)
 Prudential Foundation (Matched Gift of Diana Critchlaw)
 Random House, Inc. (Matched Gift of Heather Miller)
 Redwoods Group (Matched Gift of Bill Mecklenburg)
 Safeway, Inc. (purchases percentage incentives)
 Saidman & Associates, Inc.
 Sarah Hall Productions by Sarah Hall
 Schoolpop, now One Cause (online purchases percentage program)
 Steam Clean Pressure Wash by Todd Rademacher
 Schwab Charitable Fund (Donor Advised)
 A grant from Starlight Foundation, Inc.
 A grant from Tektronix Foundation (Larry Bolton)
 Truist for Qwest (Employee Giving)
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 United Way of Central Maryland (Donor-Directed Donations)
 United Way of Greater Milwaukee (Donor-Directed Donations)
 United Way, Heart of Illinois (Donor-Directed Donations)
 United Way Mile High (Donor-Directed Donations)
 United Way New York (Donor-Directed Donations)
 United Way of Southeastern Pennsylvania (Donor-Directed Donations)

United Way of Southern Tier-Corning, NY (Donor-Directed Donations)
 United Way of Tucson and Southern Arizona (Donor-Directed Donations)
 WJH Investments
 Wesley Healthcare (employees of Fran Cronin)
 Wellpoint Foundation Funds Management (Employee Giving)
 Wellpoint Foundation (Matched Gifts)
 Wells Fargo (Employee Giving)

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

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

CCA Corporate / Foundation Partners (\$5,000-\$10,000)

A grant from the Max & Victoria Dreyfus Foundation
 A grant from the Jorge Posada Foundation
 A grant from May & Stanley Smith Charitable Trust
 Triangle Foundation (Donor-Advised Grants)
 A grant from Martin Woodall Foundation, Inc.

CCA Corporate / Foundation Partners (\$10,000 or more)

Cher Charitable Foundation

Fundraising Events

Up to \$1,000

Alcan Cable Denim Day for CCA / ARA (Alcan Recreation Association, Employee Group)
 Aptus Partners LP
 Baltimore Marathon / Firstgiving Page / Pamela Mishra, CCA Supporter
 Brookhall School Staff Collection in name of Janice Stegmann
 Carnival of Caring / Avery Lytle, CCA kid
 Cash Can / Freeman Insurance, CCA Supporter
 Cash Can / Kim Rogers, CCA Volunteer
 Janis Cazare's Firstgiving Page
 Charity Big Top Show / Erica Mossholder, CCA Volunteer
 Hopkinson Family, Donation through Awareness Effort
 Ink / Cell Recycle for CCA / CCA Families & Friends
 Jewelry Sale / Peggy McDannel
 Jewelry Sale / Robyn Johnston
 Little Fire, Big Hearts Dinner Auction for CCA / Taryn Skees, CCA Volunteer
 Tamara Mantlo's Firstgiving Page
 Jana Peace Email Fund Appeal

Orland Park Village Denim Day / in honor of Kate Rogers, CCA kid
 Pampered Chef / Jessica Dornier / Bobby Mayo, in honor of Rick Dornier
 Penny Drive / Angela Marcum / Lincoln Heights Elementary
 Permission Men's Skin Care Line
 PetroCasa Energy Chili Cookoff
 Solis Women's Health Holiday Collection
 Timber Ridge Elementary School Collection in honor of Cale Morris
 Hannah Steinagel's Firstgiving Page / Kathie Steinagel, CCA Volunteer
 Sammi Wayne's Lemonade Sale for CCA / Samantha & Jennifer Wayne
 Snowman Auction / Barbers Hill ISD Gifted & Talented classes / Tracy Tidwell, organizer in honor of Wade White

\$1,000-\$5,000

Be Brody's Angel / Jennifer Lucas & Family, CCA Volunteers
 CCA Family Retreat Chance Raffle
 Cher Convention / Kim Werdman, Judy Didelot, Coordinators
 Family Fun Stimulus Package Raffle / Matthew Abernathy, CCA Volunteer w/Jana Peace
 Friends of Freddie Firstgiving Page / Rose Seitz, CCA Volunteer
 Jaci's Country Dance Bash / Jaci Samhammer, CCA Volunteer
 Johnny Pag Motorcycle Raffle
 Dawn Page Firstgiving Page
 Smiling Through The Mask Dinner / Wendelyn Osborne, CCA Volunteer
 Starbucks Community Clean-Up / Emily Tipton, Organizer w/Jana Peace, CCA Volunteer
 Tamale Sale / Booz Allen Hamilton, Houston & Aldine Church Ladies Group- Abigail De Los Reyes, Organizer in honor of Natalie Wardlaw

\$5,000 or more

Alexa's Appeal for CCA / Denise Rast, CCA Volunteer
 Lily's Dinner for CCA / Tosha Walker, CCA Volunteer
 Ryan's Road / Gulich Family; Nicole, Ryan, Ryan Jr., Lauren, Madalynn
 Seth's Stride / Swihart Family; Stacy, Mitch, Seth, Gabe, Sydney

\$10,000 or more

Jylian's Links of Love Golf Tournament / CCA & Bilbow Family; Kendall, John, Jylian, Mikey, Ivy
 Wendelyn's Course of Dreams Golf Tournament / Wendelyn Osborne, CCA Volunteer

\$20,000 or more

Chocolate Festival / Rick Chiavari / Aventura Mall
 Friends of Jeremy Golf Tournament / Dale Family; Kristine, George, Jeremy, Tommy, Cody
 Henry's March / Johnson Family; Rachel, TJ, Lauren, Henry
 Heroes 4 Hope Gala / Jorge Posada Foundation / beneficiary, CCA

testimonial

Makena at 3 years old ▶

Christmas 2009 ▼



CCA is such a wonderful organization! Their willingness to help financially decreases the strain for our family. We travel to Mayo Clinic in Rochester, Minnesota for our daughter's facial palsy appointments. Since Rochester is eight hours away from our home, it is time consuming, and can take a toll on your finances as well. CCA's assistance is very much appreciated! The compassion, caring and professional manner that the organization's [employees] display are positive attributes! Keep up the great work!

Brad, Antoinette, Makena and Kaden Heier Steele, North Dakota

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.



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3 cheers for volunteers!

For several years now, **Lisa Vernon** has been a volunteer, cheerfully donating her time and expertise to Children's Craniofacial Association. Lisa is a graphics designer with her own firm, **Vernon Creative**, and has collaborated on many projects for CCA, both in design and marketing. She may be best known at CCA for designing our Craniofacial Acceptance Month poster and she helped with marketing to launch the effort over five years ago. The design is used each year and also graces CCA's "hangers," cards which families distribute during the month of September to spread awareness that "Beyond the Face is a Heart" and to foster "widening the circle of acceptance."



Currently, Lisa does the graphics work for our fund appeal packages. These are the mailings that arrive between newsletters in spring for our Retreat Fund Appeal and in fall for our Annual Year-End Campaign, asking folks to donate. This is no small task and she works with us from beginning to end, transforming a story, photos and a request letter into an attractive and effective package which inspires the giving that supports CCA's programs and services.

Thanks Lisa, for all you do. Three cheers from all of us at CCA!