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.

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.

see andrew, page 10
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!”
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.
M y 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**

<table>
<thead>
<tr>
<th>date</th>
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<tr>
<td>Mar 7, 2010</td>
<td>3rd Annual Henry’s March for CCA 5k Fun Run</td>
<td><a href="mailto:laurynhenry@sbcglobal.net">laurynhenry@sbcglobal.net</a></td>
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<tr>
<td></td>
<td>CSU, Stanislaus</td>
<td>myspace.com/henrysmarch</td>
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<td></td>
<td>Turlock, CA</td>
<td>209.664.0500</td>
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<td>Jun 24, 2010</td>
<td>Craniofacial Symposium</td>
<td><a href="mailto:AReeves@ccakids.com">AReeves@ccakids.com</a></td>
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<tr>
<td></td>
<td>Hyatt Regency Cambridge, MA (overlooking Boston)</td>
<td>214.570.9099</td>
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<tr>
<td></td>
<td>20th Annual Cher’s Family Retreat</td>
<td>800.535.3643</td>
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<tr>
<td></td>
<td>Atlanta, GA</td>
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<tr>
<td>Jul 30-Aug 1</td>
<td>Moebius Syndrome Conference</td>
<td><a href="mailto:ColoradoMoebius2010@q.com">ColoradoMoebius2010@q.com</a></td>
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<td></td>
<td>Moving Mountains for Moebius</td>
<td><a href="mailto:Vicki@moebiussyndrome.com">Vicki@moebiussyndrome.com</a></td>
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<td></td>
<td>Bloomfield, CO</td>
<td><a href="http://www.moebiussyndrome.com">www.moebiussyndrome.com</a></td>
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<td></td>
<td></td>
<td>303.814.2144 or 660.834.3406</td>
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<td>Aug 28, 2010</td>
<td>5th Annual Wendelyn’s Course of Dreams Golf Tournament</td>
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<td></td>
<td>Country Club of Arkansas Maumelle, AR</td>
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<td>Sep 11, 2010</td>
<td>4th Annual Seth’s Stride for CCA</td>
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<td>Stacy Swihart</td>
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<td><a href="http://www.firstgiving.com/">www.firstgiving.com/</a> Sethsstride</td>
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<tr>
<td>Sep 2010</td>
<td>Jylian’s Links of Love Golf Tournament</td>
<td><a href="mailto:JPatterson@ccakids.com">JPatterson@ccakids.com</a></td>
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<tr>
<td></td>
<td>Location TBA (Texas)</td>
<td><a href="http://www.cca.org">www.cca.org</a></td>
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<tr>
<td></td>
<td></td>
<td>800.535.3643</td>
</tr>
<tr>
<td>Sep 19, 2010</td>
<td>Smiling Through the Mask – A dinner to benefit CCA</td>
<td><a href="mailto:wendelynyvonne@hotmail.com">wendelynyvonne@hotmail.com</a></td>
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<td></td>
<td>Restaurant 1620 Little Rock, AR</td>
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<td><a href="mailto:TarynSkees@gmail.com">TarynSkees@gmail.com</a></td>
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<td></td>
<td>Melwood Art Center</td>
<td><a href="http://www.littlefirebigheart.com">www.littlefirebigheart.com</a></td>
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<td>Oct 2, 2010</td>
<td>6th Annual Friends of Jeremy Golf Tournament</td>
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<td></td>
<td>Corning Country Club</td>
<td><a href="http://www.friendsofjeremy.com">www.friendsofjeremy.com</a></td>
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<tr>
<td></td>
<td>Corning, NY</td>
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**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!**

CCA now has its own facebook page and cause!

You can look us up by simply searching for Children’s Craniofacial Association!

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

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

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!
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 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 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.

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 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 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.

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

“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.

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 was 24 hours old.

When I realized that he was in Dallas, 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 multipleswallow studies done. Watching your young, helpless infantson 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 ears since it could not travel normally through the ear canal. He was fitted with 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.
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.

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 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
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.
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 fundraiser, 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!!!

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.

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!
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 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.
Ily'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!

HELPFUL TIP!
SafeLink
Submitted by Darnell Menard

SafeLink Wireless is a government supported program that provides a free cell phone and airtime each month for income-eligible customers. For information, please visit www.safelink.com.
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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C CA 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
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!