message from the executive director

February 2009 marks the twentieth year since the founding of Children's Craniofacial Association. As I begin my twentieth year with CCA, I reflect on all of the people who played a role in getting us where we are. I am grateful for each of you.

Over the years, CCA has been blessed with the donation of time, professional expertise, and monetary support of thousands of individuals.

meet lily ray walker

By TOSHA WALKER

Lily Ray Walker blessed our family on December 21, 2005. We waited through several years and one traumatic miscarriage for her arrival. She tops the charts as being our family’s all-time best Christmas gift ever! If you have ever seen the movie “Yours, Mine and Ours,” she is the “Ours” and is certainly the glue that cements our beautiful family together.

Lily has two older brothers (Tanner, 9, and Nick, 10) and one older sister (Josey, 14) who are so protective of her she thinks — correction, she knows — she is the
Eight-year-old Kaylee Santiago is a third grader from Pennsylvania who loves being with her family, going to school, making friends and enjoying life. She’s also very caring of others and willing to help whenever she can. Maybe that’s why she wants to be a nurse when she grows up.

At school, Kaylee has lots of friends and likes going to her reading and swimming classes. She’s really into the Junie B. Jones series of books and reads them at home and at school.

Purple is her favorite color, so naturally her room has lots of purple, and she wears a lot of purple clothes. She even has a purple backpack she takes to school.

Kaylee has a sister, Maddie, who is six years old. (Read more about Maddie on page 4.) They often play together and share some of the same hobbies, including reading, dancing and swimming.

During the week, Kaylee attends CCD classes. Twice a week, she attends tap and ballet classes, which she began last year. She’s really looking forward to her first recital this spring.

In May (her birthday month), Kaylee will play baseball for the Miracle League. She’s so excited about it! In fact, she had a chance to meet some Pittsburgh Pirates team members, who helped raise money to build the field. She has even appeared on Fox Sports Network and local news websites to support the league.

Like a lot of young girls, Kaylee loves the Disney princesses and enjoys watching each of their movies. As for her favorites, she rates the princesses in this order: 1) Cinderella 2) Sleeping Beauty and 3) Snow White. She likes the Disney movie, “Camp Rock” (Mitzi’s her favorite performer), and she watches Disney shows, “Zack and Cody” as well as “Hannah Montana.” Plus she tunes in to a variety of shows on Animal Planet.

Kaylee is quite a tech-savvy kid. She has a laptop and likes to go to the Webkinz and Pogo Internet sites to play games. She frequents the Noggin, High School Musical and Disney sites as well. Kaylee also has a Nintendo DS text messenger. Her neighborhood friend, Mallory, has one too, and they have fun playing games and chatting with each other.

Kaylee has Apert syndrome and has had four surgeries so far, with none planned in the near future. Doctors are checking her development and will make decisions on what kind of surgeries or procedures she needs when she gets older.

She went to last year’s CCA retreat in Myrtle Beach, SC, and had a blast! She made new friends and has kept up with them through letters. Kaylee may go to this year’s retreat in Grapevine, TX. Hopefully she’ll catch up with her friends there and will, no doubt, make new ones, too.

Meet Kaylee Santiago

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I was born on April 14, 1984, with a bilateral facial cleft involving my palate and upper lip. The cleft extended mid-face, affecting my eyes and nose, which caused my eyes to be disfigured. This condition left me totally blind.

I lost track of how many surgeries I’ve had, but I’ll just say I’ve had enough of them to keep me going. From what my dad has told me, I had my left eye removed due to an infection. I wear a full prosthetic left eye and a shell eye as my right. My eyes were abnormally small, and the doctors had to reconstruct them so that it looks like I have normal eyes. To this day I still have to take care of my eyes. I suffer eye infections now and then, for which I take daily medicaiton.

I had water on my brain; I have a scar where doctors placed a shunt.

Doctors had to build my nose because it was too small and misshapen.

All in all, I really was a miracle child and a survivor. Doctors suggested to my parents that I be given up for adoption because of all the medical issues. They thought my parents wouldn’t be able to take care of me along with my four siblings. They even said I’d die if I didn’t have the necessary operations.

My mom threw a fit and refused to give me away. She felt like if she had me that she should keep me. She didn’t care how many surgeries I would undergo. What mattered to her was that I was alive and crying like any other baby.

So I stayed in the hospital for about a month or two and underwent all the major operations needed to help me survive. The doctors tried to fix my eyes, but there was already too much damage for me to ever see.

I never let my blindness stand in my way. My favorite things are reading Braille books, listening to music, meeting friends on the Internet, watching medical programs on TV and chatting on the phone.

My advice to anyone out there facing a craniofacial challenge is to keep your head held high and never give up.

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cca mugshots

Meeting facilitators from Association Works, John & Sheryl Paul

This issue’s “mugs” were taken of some of CCA’s board members and our meeting facilitators during our directors’ once-a-year, face-to-face strategic planning meeting in October 2008. You can purchase your mug from our webstore and then send us YOUR mugshots!
meet madelyn santiago
By Tanya Thorpe

Madie is six years old and is in the first grade. When she is at home she loves to read. Her favorite books right now are from the Junie B. Jones series. After reading one, she asks me to read it so we can talk about it. Recently, she read one 60-page book in less than a day! Her teacher was shocked that she’s only in first grade and doing so well.

Madelyn takes ballet, jazz and gym classes. Her favorite part of dancing is when she gets to do her handstands. She makes me count how many seconds she can keep her feet straight.

Madie loves to swim. Her latest accomplishment was jumping in the deep end and swimming across to the other side! Needless to say, her favorite class at school is swimming. Her class has pool parties, which are a lot of fun.

Madelyn is also a girly girl. She loves her pink stuff and her jewelry, and she loves to have her hair done up “pretty.” In the summer she refuses to wear anything but sundresses.

Although she may be girly, Madie likes going to Pittsburgh Pirate games and really enjoys the fireworks afterward. She also loves going to the zoo as well as camping. Most recently we went ice skating and had a blast! Madie is also proud of losing five teeth. (That’s mainly because she loves finding money under her pillow!)

This past summer, she amazed me at the CCA retreat. She made friends with lots of the kids, and a few parents even thanked me because they said that Madie brought their kids out of their shells.

Madelyn actually had her own bout with surgery. She had an operation on her bladder and kidneys. After watching Kaylee be in and out of hospitals, I think it was hard for Madie to be on the other side of things. All in all though, she was a trooper.

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

2009 marks the 20th anniversary of Children’s Craniofacial Association! This will be a year-long commemoration of 20 years of giving hope and a celebration of CCA’s “birthday”!

Watch for our limited edition 20th Anniversary Logo T-shirts which will be available for purchase or with a minimum donation.

Giving Back

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

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

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

www.permissionskincare.com

Calendar of Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event</th>
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<tr>
<td>Mar 8, 2009</td>
<td>Smiling Thru the Mask – A dinner to benefit CCA</td>
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<td>Mar 22, 2009</td>
<td>Henry’s March for CCA 5k Fun Run</td>
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<tr>
<td>Oct 3, 2009</td>
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<td><a href="mailto:gdale@stny.rr.com">gdale@stny.rr.com</a></td>
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<td></td>
<td>Corning Country Club Corning, NY</td>
<td><a href="http://www.friendsofjeremy.com">www.friendsofjeremy.com</a></td>
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</table>

Save the date

June 24-28, 2009

CCA’s 19th Annual Family Retreat

Great Wolf Lodge | Grapevine, TX

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

www.greatwolf.com
Dallas

CCA, together with Drs. Jeffrey Fearon, David Genecove and Carlos Barcelo, hosted its 19th annual holiday party at Southfork Ranch, in Parker, TX, on Saturday, December 13th. Around 500 attendees joined us for a morning full of fun!

Radio Disney was the entertainment once again, and everyone 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 made their own cookies, snowflakes, Christmas trees and made picture frames.

The firefighters of nearby Plano joined us, bringing a real fire truck for the children to see. And, the Dallas Stars Ice Girls were there and gave autographs. There were even real snakes! Yikes!

Families went home with lots of door prizes, which were donated by several local businesses. Prizes included passes to Six Flags, a luxury suite for 10 at the Mesquite Rodeo, paintball passes from Celebration Station, a gift certificate to the Magic Time Machine, passes to the Fort Worth Zoo and the Dallas Zoo, and autographed items from the Texas Rangers and Dallas Mavericks!

Advanced Neuromodulation Systems, Inc., donated toys for door prizes as well!

And, a big THANK YOU goes out to the following businesses and individuals for donating money for our party: Professional Flooring Supply, Ortho America, Medical Modeling, KLS Martin, and Bill and Liz Mulholland.

As always, the highlight of the party was Santa Claus.

Children had pictures taken with Santa, and everyone went home with a keepsake photo and toy.

CCA would like to thank Southfork Ranch and their wonderful staff for hosting! A huge thank you goes out to our wonderful volunteers from the Italian Club of Dallas as well as CCA friends Richie Cook and Adam Golden!

Midwest

Santa also stopped by at the Parkway Chateau in Kenosha, Wisconsin to visit with CCA kids and families there who gathered for a pizza lunch, crafts and visiting. Mom Marla Verdone of Janesville, Wisconsin, planned the festivities with the help of her daughters Lara and Lexandra manning the craft table and distributing, then drawing, door-prize tickets. Regulars joined with new families and lots of networking and sharing made the afternoon successful and fun.

Kids sat on Santa’s knee for photos and to tell him what they wanted for Christmas. A good time was had by all. See you next year!

Santa Claus chats with 16-month-old Sydney Garcia as new friends, Brittany Borg and Marie Sanchez (standing) look on.

CCA Moms, Altrina Shorts, Jill Gorecki, Marla Verdone at the Midwest Holiday party.
4th annual friends of jeremy golf tournament
By Kristine Dale

We were extremely fortunate to have a beautiful blue sky and breathtaking views of the fall foliage. We had an incredible turn-out and overwhelming support from the community, our coworkers, friends and family. A total of 138 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 support 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 prizes and a skins game. The event was a huge success, raising $27,200 for CCA!

The tournament continued to be advertised through local newspaper and TV stations. We were very fortunate this year to have news coverage the day of the tournament and a recap the day after. Jeremy was again joined this year by two of his CCA friends. Andrew Perry from Massachusetts and Ryan Gulich from Big Flats, NY, who participated in the tournament, helped raise awareness of craniofacial conditions among the participants and the community.

We are so grateful to everyone who supported this event and the kids from CCA. The 5th Annual Friends of Jeremy Golf Tournament will be held at the Corning Country Club on October 3, 2009. For more information and to see photos from the tournament, visit friendsofjeremy.com.

firstgiving fundraising proposal to cca families
There's still time to get a free hotel stay for the 2010 retreat

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

Beginning right after this year’s retreat and through 2009, any family raising more than $5,000 for CCA will be awarded one hotel room at the next retreat they attend (either 2009 or 2010) for the three-day retreat period! This invitation is extended to everyone already holding events throughout the year and includes any type of effort, not just Firstgiving.

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

Giving Back with Firstgiving
We’re pleased to provide a free CCA-customized “firstgiving” site for anyone who wants to help raise funds for CCA. Log onto firstgiving.com/ccakids and tell your personal story of why you support CCA or post an event you’re having. You can set a goal and track success. Folks will respond with contributions because they know you! This is an especially easy way to “ask” for donations if you’re uncomfortable with the face-to-face approach.
Lily, from page 1

princess of the house and expects to be treated as such. She has been a special kid from the get-go, and we couldn’t imagine not having this adventurous addition to our wonderful family.

Before Lily was born, we knew she had a feisty personality. In the womb, she strongly protested to impingements of her “space,” food and loud noises. However, we weren’t prepared for exactly how “feisty” this little girl could be.

The day she was born, the pediatrician told us she had some kind of a syndrome and that she would likely have kidney and heart problems. We were shocked. We just thought she had spent too much time in the birth canal and then having to use suction to get her out, she had a large hematoma on her head.

Now we understand why her birth was so difficult: Her right coronal suture was fused, and her head wouldn’t collapse to come out. We were lucky she was so small, or we would have had an emergency C-section, according to the doctors.

We didn’t know what to do or where to turn for support. (I hadn’t found CCA at this point). We shed many tears not knowing if our sweet baby girl would be ok and not knowing what her future might hold.

They told us her heart and kidneys were fine but that she was missing part of her brain (the corpus collosum), and she had some kind of syndrome that included craniosynostosis. The corpus collosum is a structure in the center of the brain that houses more than 250 million nerve cells and does most of the communication between the right and left brain.

The doctors told us that the degree of developmental delay is variable and depends on the individual. It could range from none to severe. One doctor told us that Rain Man had the same diagnosis. This only added to our frustration because we didn’t really have any real answers yet. I asked what I could do to stimulate more communication pathways and they said nothing. I tried anyway. I did all I could think of to stimulate her brain. I tried music, dance, touch, massage, reading, exercises and a whole lot of love.

We didn’t have a definitive diagnosis until she was six months old. That’s when Dr. Morales told us that Lily has Craniofrontonasal Dysplasia syndrome. (Say that 10 times fast.)

At seven months old, she had surgery to release her right coronal suture and also had her right orbit advanced two centimeters. One of the hardest things for parents to do is to hand over their precious, innocent child to the anesthesiologist right before surgery, knowing your baby will never look the same again.

She came out more swollen than we ever could have imagined. She was also overdosed on morphine in the PICU and had a code blue moment in her daddy’s arms. I think that was our scariest moment thus far. After the first few scary days, her eyes were swollen shut for a total of seven days! She was miserable!

Four days after her discharge, she was readmitted for meningitis and bacteremia. She had to have a PICC line for six weeks at home, which she tried to pull out along with her feeding tube. She just wanted to be free!

I finally found CCA after Lily’s first surgery. What a great support and network they have. I only wish I had found them earlier.

Lily has also had eye-muscle repair on her eyes, and tubes placed in her ears, as well as having her tonsils and adenoids removed. The next stage of surgery is to bring her orbits closer together and build a bridge to her nose. This will be at age four, and Dr. Morales told us it is one of the hardest craniofacial surgeries you can have. We are very nervous already.

Through all of this Lily has continued to touch the hearts of nearly everyone she meets. She is very social and loves to talk to anyone and everyone. Lily is also very smart and has a great memory!

She is the pride and joy of our family. With just one conversation or hug from her you can feel her beautiful, strong spirit shining through. Lily has our family and entire neighborhood all wrapped around her little finger. Her big blue eyes and beautiful blond, curly hair attracts people everywhere we go.

She says “hi” to all the “grandmas and grandpas” at the grocery store. They love it. She has a tender heart for the elderly and always wants to come to the hospital with me when I work so she can see the patients.

She also loves to “clean” her teeth and checked my braces when I had them. At the tender age of two, she already aspires to be a dentist.

She has known her ABC’s since she was 18 months old and learned the Pledge of Allegiance a couple months ago. Lily enjoys going to pre-school and her gymnastics class. Other moms tell me that all their kids talk about is playing with Lily at school.

continued next page ⇨
Lily also loves to play with her “babies” and, if we would let her, she’d play outside all day with her brothers and sister. She loves all the snow this year and had her first sledding day. She had a ball!

She also loves reading, riding her scooter, boating, swimming and singing. She has so much energy and instantly makes new friends wherever she goes. She speaks very well and is mature for her age.

We know that no matter what comes her way, Lily will face it head on and come out even better than she was before. We are so grateful to have her in our home and have truly been blessed to have her in our family. We love you, Lily!

We open 2009 shedding light on a special family who chose to donate to Children’s Craniofacial Association in memory of George E. Shephard, who passed away in September and at 86, was a father of five, grandfather of 12 and great-grandfather of 16. One of George's granddaughters is Angela Cronin, a devoted CCA volunteer and mom to 3½ year-old Megan, who was born with a craniofacial condition.

Angela recounted for us how her grandfather always put family first. He was there when Megan was born and two years ago, at 84 years old, traveled over five hours with them for one of her surgeries, sat through the eight-hour ordeal with the family, and was there to comfort Megan when she woke up. The entire family has followed his lead and in that spirit, chose to honor him with memorial donations to CCA.

George was loved and remembered by his family, relatives and many friends and we are extremely grateful and honored to benefit in his name. Thank you!

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

Contact Annie Reeves for a Kids Klub application today!

**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.
fundraising news

CCA’s family fundraising goal for 2008 was $100,000. By the end of the first quarter our families had raised almost $13,500. By the end of the second quarter you had raised more than $37,500. At the end of the 3rd quarter, families pushed the totals up to more than $88,000! At year end you had raised around $147,000! Thanks so much for all you do!

Special thanks go to families who sent donations for the holidays in lieu of exchanging gifts, and to all who responded to our annual fund appeal. We appreciate those who gave in any way throughout the year as well as everyone mentioned here. All of you brought CCA to a successful close for 2008!

I organized a social awareness event and fundraiser at Borders Bookstore in Montgomeryville, PA, last December. My friends, volunteers and I wrapped gifts for free while also passing out pamphlets I created with more information on facial disfigurement.

Because of everyone's generosity, I raised $165 for CCA in Quentin’s honor. I hope my project spread more awareness for this cause, so that CCA’s vision of “a world where all people are accepted for who they are, not how they look,” can come true.

Arbonne Hostess Giving

For the second year, CCA mom Cheryl Swearingen, along with her family, Clint, Matt, and Amy, held a holiday fundraiser for CCA. With the help of her Arbonne representative, Trisha Goodale, Cheryl sent 35 percent of the sales to CCA.

"The Gift” Holiday Concert

CCA mom Angela Cronin (center) with daughters, Megan (held) and Emma (in front), and Angela’s cousin, vocalist Mallory O’Donnell.

On December 13th we hosted “The Gift,” a holiday concert to benefit CCA. Thanks to the generosity of vocalists Mallory O’Donnell and Jeanne O’Connor accompanied by musicians Matthias Donnelly and Matt Donnelly, we were able to raise more than $2,700 for CCA. In addition to the wonderful holiday music, we had a very successful raffle and enjoyed coffee and cookies from Something’s Brewing in Greenwich, NY. I would like to extend a special thank you to my sister Jessica Schwerd for her help in planning the event. Along with all of our family and friends, the event could not have happened without charitable donations from the community, including Jane Schwerd, Mae Communications, G. Lane Construction, Country Power Products, Linda Corazza and Barb Sartell.

Lemonade Sale for CCA

Wade White’s sisters, Antasia Hart and Destiny Carlisle help CCA in their brother’s name.

Antasia and Destiny love raising money for CCA and “wanted to

Fundraising in Honor of Quentin Zaengle

I’m Bridget Cardell and I currently attend Mount Saint Joseph Academy in Pennsylvania. This year I enrolled in a class called Senior Seminar, where the students become active in a cause or organization.

For my project, I was an activist for Children’s Craniofacial Association. I became interested in this organization because I have a family friend, Quentin Zaengle, who has Apert syndrome. After hearing of the work CCA does to help children with craniofacial differences, I immediately wanted to become involved.
help other families the same way CCA has helped ours. Because of generous donors, our family was able to attend the CCA retreat in Myrtle Beach this last year.” It meant so much to the girls, and they were encouraged to give back. Take a look at the photo!

More follow-up news from fundraising efforts held last fall to benefit CCA.

**Girl Scout Troop 1369**

Dear Children’s Craniofacial Association:

We are Girl Scout Troop 1369, first year juniors in Tampa, Florida. Each year we choose a children’s Charity to donate 10% of our cookie money to. Last year we choose CCA and would like to present you with a check for $178.00. This amount represents cookie money and donations from a Girl Scout S.W.A.P day event that we ran.

We learned about your organization through one of our troop members, Katie Moore, who has Pfieffer’s Syndrome. She told us about the work you do to support families that need to travel to get to good doctors and how you organize an annual retreat for families who have a member with a craniofacial issue.

Katie is 10 years old and travels to Dallas, Texas to have her evaluations, surgeries and orthodontic work. Originally, she had a surgery in Tampa at the age of 16 months. Unfortunately, she experienced a very negative outcome that caused her to loose her forehead from a surgical/post-surgical infection. Katie has required several surgeries to correct the damage done by the previous surgery/infection and in addition needed surgeries to deal with other issues that some people with Pfieffer’s syndrome require. Katie’s family is lucky to be able to travel to Dallas and they are also lucky to have family in Dallas. They know the importance of seeking out an experienced doctor to handle such a rare issue. They also understand the hardships that families may face in traveling a long distance for important care. They are glad to recognize and help the CCA who helps families like them to get the care they need.

Your Friends from Girl Scout Troop 1369

Tampa, Florida

**“Be Brody’s Angel”**

Mom **Jennifer Lucas** and family, friends and acquaintances helped garner funds for CCA in **Brody’s name**. Donations from those who would “Be Brody’s Angel” totaled more than $2,000!

**Austin’s Luau of Love**

**Austin Freeman** and family applied to their local Walmart for their Luau of Love campaign and were granted $1,000 for CCA! Thank you!

**Carnival of Caring**

Eight-year-old **Avery Lytle**

Avery Lytle ran a booth at her school’s Carnival of Caring, educating folks about CCA and craniofacial issues and recruited a balloon man to make animal balloons as she collected $250 for CCA kids!!! Wow, Avery! Thanks!

**Penny Drive**

CCA mom, **Angela Marcum**, whose daughter, Lillian was born with Goldenhar syndrome, is also a third-grade teacher at Lincoln Heights Elementary in Greenville, Michigan. Her students and former students were touched by CCA’s cause and Marcum’s resolve to spread awareness that “Beyond the face is a heart.” Her class involved the entire student body and together they were widening the circle of acceptance and helping to support CCA with a penny drive that alone raised almost $1,000. That’s 100,000 pennies!!!

Add to that donations from Angela’s husband’s employer, **Betz Industries**, and her sister’s employer, **Lynnette Rhodes**, and Angela’s fundraiser totaled almost $1,500! Thanks to ALL!

**Evening of Giving**

For the third year, the **Seitz family** participated in their local **Simons Mall “Evening of Giving,”** selling tickets to shop at the mall on a night designated especially to help charities. The donated portion of ticket sales provided almost $200 for CCA.
The number of pro-bono services CCA has received has been, and continues to be, invaluable. There have been so many individuals and groups willing to give their expertise to make it possible for CCA to use financial resources in the most efficient manner. And there have been so many individuals willing to give of their valuable time to volunteer at CCA’s office. We’ve also seen countless people at events, spreading awareness across the country. And we’ve had so many dedicated donors recognizing the value in these programs that change the lives of the individuals and families we serve.

CCA is literally the product of each and every one of these individuals. There are entirely too many to list here, but as you read this you know who you are, and please know how much we appreciate every single thing you do!

Although we wish there weren’t a need for CCA to exist, there is, so we’re glad we have been able to serve families affected by facial differences for the past 20 years. Thousands of families have taken and continue to take active roles in ensuring the delivery of programs and services.

Today, our families are involved in every facet of the organization. Some families are active in spreading awareness throughout the country through the National Awareness Program. Some offer emotional support to other families in need of a shoulder on which to lean or just someone to talk with through the Family Networking and Internet Support Programs. Others find their niches in fundraising. Yet all are enthusiastic about their roles and all are vital to the effectiveness of CCA and its mission.

Over the past 20 years, the economy has ebbed and waned, and so have the resources available to nonprofits. Through all of the good times and difficult times, CCA has managed to “be there” when a family was in need of support.

Did we have lean years? You bet. But because of the dedication of board members, volunteers, our families and the support of the community, we survived and thrived. There were times when CCA relied on the donation of pro-bono goods and services and even the donation of office supplies to keep the doors open — even when “the doors” were to my garage. But keep them open we did, and as a result of the dedication of generous volunteers and donors, CCA has “been there” to support individuals and families affected by facial differences for 20 years. We’ve “been there” providing emotional support, educational materials and information, financial assistance, public awareness and acceptance, advocacy and much more.

Through fiscal responsibility, CCA has been able to ensure adequate financial resources necessary to deliver current programs and services. Through responsible stewardship we have been able to build a modest reserve, ensuring these important programs and services won’t go away during a downturn in the economy.

CCA periodically surveys our families to be sure we are serving our community in the most effective manner. Our programs and services are a direct reflection of these surveys. As a result, we are providing programs that, regardless of the effort, expertise and resources required, are most important to the members of the community we serve. These programs make a positive impact on the lives of these individuals and families — programs that help affected individuals and family members live happier, more productive lives.

So, as we begin our twentieth year of service, the hard work and dedication of individuals, families, volunteers, donors and staff have collectively brought CCA — the premier craniofacial family support organization — this far and will take the organization well into the future.

Charlene Smith
CCA Executive Director

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
Grateful for these and all other donations, fees, purchases, fundraisers and in-kind donations not recorded here.

Monetary Donations of $25 or more

Note: For space consideration, 2009 donations under $100 will only through 4th quarter, 2008. We are extremely grateful for these and all other donations, fees, purchases, fundraisers and in-kind donations not recorded here.

We do our best to accurately recognize donors. If you notice an error, please let us know.

CFC (Combined Federal Campaign, federal-employee giving)
Dan & Denise Paulson
John & Charlene Smith
Larisa Speetzen (auto donor)
Courtney Vincent

CCA Benefactor
($5,000 +)
Mark Hagen
Greg Luettelkemeyer
Margaret Patterson, IRA Rollover
John & Sheryl Paul
Magdalene Rose Berken, IRA Rollover

CCA Guardian
($10,000 +)
Marie Florence Desrosiers Trust Bequest
John and Patricia Dyer

Memorials / In-Honor Gifts
Lillian Albergo, in memory of George E. Shephard
James & Michelle Alheim, in memory of George E. Shephard
Kevin Allibuse, in honor of Aaron Nocum’s 1st Birthday, by Caroline Mingojo
American Society of Plastic Surgeons, in honor of Erin Williams
Ms. Billie Andrews, in memory of Anne T. Hawk
Aware Consulting, in memory of Seth Sturman
Trevor Bartley, in honor of Rocky, with love in our hearts
Renee & Wayne Basmann, in honor of Robbie Gorecki
Be Brody’s Angel giving, in honor of Brody Lucas
Borders Giftwrap Funder / Bridget Cardell, in honor of Quentin Zaengle
Deborah Breslove, in honor of Baby Samuel Grossman
Mark Bronson, in honor of Duncan Hopkins
Angelic Bruns, in honor of Cher’s Birthday
Edward Bruns, in memory of George E. Shephard
Richard & Bruce Bulloss, in memory of George E. Shephard
Doug & Ann Burgin, in honor of Rick Dornier
Larry Carpenter, in honor of Cher’s Birthday
Larry Carpenter, in honor of Cher at Christmas
Dorothea & George Casey, in memory of George E. Shephard
Alexandra Chambers, in memory of John Michael Chambers
Maureen Cleary, in memory of George E. Shephard
Patricia Concelica, in honor of Anne T. Hawk
Michael & Frances Cronin, in memory of George E. Shephard
Angela Cronin & family, in memory of George E. Shephard
Harvey & Venita Crowson, in memory of George E. Shephard
Gerald & Ruth Dankelson, in memory of Arthur Bertsch
Gerald & Ruth Dankelson, in memory of Gordon Nielsen
Eileen Dankelson, in memory of Elaine Petsche
Grace & Gary Deily, in honor of Jeremy Dale
J. & C. Belmonte, in memory of Betty Smith
Felicia Derosa, in memory of George E. Shephard
Patricia Despres, in memory of George E. Shephard
Camilla Hawk Diaz-Peraz, in memory of Anne T. Hawk
Melanie & Cosimo Dilbari, in memory of George E. Shephard
Mr. and Mrs. Gary Donohoo, in memory of Anne T. Hawk
Eileen Donovan, in memory of George E. Shephard
Kathleen M. Dunn, in memory of Bill Dunn
Mr. and Mrs. John Dyer, in honor of granddaughter, Florence Horn
Gary & Karen Evans, in memory of George E. Shephard
Ben & Patricia Farmer, in memory of George E. Shephard
Dr. Jeffrey Fearn, in honor of colleagues
Thomas & Shelley Flores, in honor of Brixton Flores
Frieda & Jeremy giving, in honor of Jeremy Dale
Nellagene & Leigh Gilbert, in memory of George E. Shephard
Greenwich BPO Elks, in memory of George E. Shephard
Garrick & Jennifer Groves, in honor of Ella
Alfred Harf, in honor of Chase Ingram
Hearts and Hands O.C.C.L., in honor of Kathryn Hopkins
Jim & Arleen Heirty, in memory of Margaret Lux
Jim & Arleen Heirty, in memory of Lois Witkowski
Jim & Arleen Heirty, in memory of Dave Cody, Sr.
Jim & Arleen Heirty, in memory of Thomas Wachholz
Jim & Arleen Heirty, in memory of Thomasina Mastralucco
Jim & Arleen Heirty, in memory of Carol Steinmetz
Highland Elementary Denim Day, in honor of Justin Prince
Angela Houllihan, in honor of Megan Cronin

Law Offices of Steve Howen, in honor of Brian Scott Cook
Edward Howland, in memory of George E. Shephard
Ingram Family Holiday Giving, in honor of Chase Ingram
Donald & Mary Jones, in honor of the Gossett Family
Nancy Judy, in memory of Pauline Burzio
Vasiliki Karagianis, in memory of Anne Hawk by Dr. & Mrs. M. Karagianis
Sarah Ehr & Andrew Kelley, in honor of Olivia Sanborn
Joan Kiesendahl, in memory of George E. Shephard
Arthur & Alison Kontaxis, in memory of George E. Shephard
Alison & John Larson, in honor of Chase Ingram
Claudia Lozano, in honor of Seth Aaron Nocos
Donald & Ann Lucas, in honor of Brody
Donald & Ann Lucas, in honor of Brody Lucas on our 43rd Anniversary
Ryanbrook Fire Department, in memory of George E. Shephard
Debra Macut, in honor of the Macut Family at Christmas
Doug & Janis Macut, in honor of Dr. Sava & Dottie Macut at Christmas
Melissa Manos c/o BPI, in memory of Anne T. Hawk
Donald & Charlene MacGregor, in memory of Anne T. Hawk
Thomas & Madeline McAdam, in memory of George E. Shephard
Denise & Shawn McCormick, in memory of George E. Shephard
Candice Renee McLaren, in memory of Xavier Mack
Ellen McPadden, in honor of Jeremy Dale, from Aunt Ellen
Bill & Christine Mecklenburg, in honor of Morgan
Deborah Mecklenburg, in honor of Morgan from her grandparents
Laurie Monnier, in honor of Jeremy Dale
Jim & Maryjo Montalbano, in honor of their daughter, Jennifer’s 33rd birthday
Jessie & Theodore Morgan, in honor of Morgan Baldwin from Nana
Phyllis & Lee Morris, in memory of George E. Shephard
Alison Morrissey, in memory of Rachel Morrissey
Lori Naseef, in memory of Howard & Suzanne Pann
Ann Nesbitt, in memory of George E. Shephard
Hope & George Nohejl, in honor of Maggie Berger
Ralph Nuckols, in honor of Jeremy Dale

Margaret & Kenneth O’Gara, in memory of George E. Shephard
William & Jane O’Hara, in memory of George E. Shephard
Glenn & Diane Otto, in honor of Sarah Eicher
Norma Peace, in honor of Beverly & Jim Butera
Pfeifer Support Group, in memory of Seth Sturman
Family of Ava Beeler
Family of Ashley Bock
Family of Caroline Dale
Family of Ryan Holliday
Family of Olivia Sanborn
Family of Wade White
Carol Quarnato, in memory of George E. Shephard
Andrea Richard, D.O., in memory of Ram Nath Pathak
Jere Robertson, in honor of Jane Morell
Cynthia Robideau, in memory of George E. Shephard
Jessica Roche, in memory of all CCA kids
Joyce Ronzcka, in memory of Joe Ronzcky, for his family
Gail & Walter Rook, in memory of Scott Guzzo
William & Elizabeth Rooney, in memory of George E. Shephard
Jennifer Rosenberg, in memory of Suzanne Chiaison
Carolyn & Thoms Russett, in memory of George E. Shephard
Thomas & Mary Ryan, in memory of George E. Shephard
Mr. & Mrs. Merle Sampson, in memory of Anne T. Hawk
Iris Schell, in honor of Caroline Dale
Mr. & Mrs. Leroy Schroeder, in memory of Anne T. Hawk
Jessica & Frederick Schwert, in honor of Megan Cronin
William Schwert, in honor of Megan Cronin
William Schwert, in memory of George E. Shephard
Helen Shannon, in memory of George E. Shephard
June & William Shea, in memory of George E. Shephard
Kelly & Josh Silverman, in honor of Zach’s Birthday
W. Wiesen Smith, in memory of George E. Shephard
Jane Stickey, in memory of Caroline Dale and in the names of Patricia Powell & Iris Schell
William & Nancy Suwalski, in memory of Marvin Mandel from Bill & Nancy
Swanam Subramanian, in memory of Anne T. Hawk
Robert Vanni, in honor of cher
Leona Vitolo, in honor of Zach
Bordonaro
Daniel Walker, in honor of Cher at Christmas
Karen Waring, in memory of George E. Shephard
Marie Waring, in memory of George E. Shephard
Diana Weber, in honor of Thompson B. Weber
Dennis Webster, in honor of Jack & Tom McCall's 12th Birthday
Jon Welles, in honor of Jason Welles
John & April Wharton, in honor of Amber & Brooke McKinney
Barbara J. Wiedenman, in memory of Jennifer Walker from Barbara & Anna
J.B. & Cynthia Wills, in honor of Reed Wills

**Corporate / Foundation Gifts**

**CCA Corporate / Foundation Friends**

(up to $1,000)

- AT&T United Way Employee Contributions
- America's Charities (Employee Giving Funds Management)
- American Express Charitable Fund (Matched Gifts of Janell Nelson)
- Aware Consulting by Denise Newbould & The friends of Seth Sturman
- Banco Popular
- Bank of America (United Way Campaign Employee Giving)
- Century Lodge No 492, Order of Odd Fellows
- Cleveland Bakers Local No.19
- CFC Baltimore
- CFC Central Florida Area
- CFC Central Texas
- CFC Chicago Area
- CFC Coachella Valley Twenty-nine Palms Area
- CFC Eastern Massachusetts
- CFC, Fresno County
- CFC Global Impact, Overseas
- CFC LA Area
- CFC Maricopa County
- CFC Middle Tennessee / Nashville
- CFC New Orleans
- CFC New York City
- CFC Niagara Frontier
- CFC Philadelphia Area
- CFC Southeastern Connecticut
- CFC Southwestern Idaho
- CFC Yellowstone County
- Department of Social Services, Sisseton, SD
- Direct Strategies by Dana Heter
- Dream Kitchens, Inc. by Keven & Terri Schmidt
- Epic Systems, Inc.
- Financial Alternatives
- Funding Factory
- Gonser & Gonser by Cleo Gonser
- GoodSearch (search tool incentives)

Greenwich BPO Elks
Hearts and Hands O.C.C.L.
Home Depot Foundation (Matched gift of Doug Hopkinsin)
Italian Club of Dallas
Jim Wade Investments
John Ryden Construction
Justgiv (donors listed separately)
Kroger (purchases percentage incentives)
Law Offices of Steve Howen
Lynbrook Fire Department
Mission Fish (Ebay donations)
Nature’s Enterprises dba Euronat by Michael Carr
Network for Good (donors listed separately)
Office Depot (Rebate)
The Ochsman Foundation, Inc. by Ralph Ochsman
PASCO (Personal Assistance Services of Colorado)
Pfizer (United Way Campaign Employee Giving)
The Prudential Foundation (Employee/Matching Gifts)
The Prudential Foundation (Matched Gift of Diana Critchlaw)
SafeWay, Inc. (purchases percentage incentives)
Sarah Hall Productions by Sarah Hall
Schoolpop (online purchases percentage program)
Steam Clean Pressure Wash by Todd Rademacher
Triangle Foundation
United Way of Brevard (Donor-Directed Donations)
United Way CA Capital Region (Donor-Directed Donations)
United Way of Cedar Valley (Donor-Directed Donations)
United Way of Central Maryland (Donor-Directed Donations)
United Way of Fresno (Donor-Directed Donations)
United Way of metro Dallas (Donor-Directed Donations, CFC)
United Way of Long Island
United Way of southeastern Pennsylvania (Donor-Directed Donations)
United Way of the Southern Tier (Donor-Directed Donations)
Verizon (Matched gift of Robin Chuppurton)
A grant from the Gil & Dody Weaver Foundation
Wellpoint Foundation Funds Management
Wells Fargo (Employee Giving)
Zion United Church of Christ

**CCA Corporate / Foundation Sponsors**

($1,000-$5,000)

- Aptus Partners LP / John Romero
- A grant from The Alia Brotman Foundation
- A grant from Max & Victoria Dreyfus Foundation
- A grant from The Clappitt Foundation
- Glazo Smith Kline (Matched gift of Ginger Henshall)
- A grant from The Elena Melius Foundation
- The Redwoods Group (Matched Gift of Bill Mecklenburg)
- Charitable Auto Resources (CARS) vehicle sales incentive program
- KLS Martin LP
- Margaux & Associates / Jim Butera Matching Grant from Sam's Club
- Grants from Starbucks Corporation
- Recommended grants from Triangle Community Foundation
- United Way of Tucson and Southern Arizona (Donor-Directed Donations)
- Vivo Brothers, Inc.
- Wal-Mart Corporation Foundation
- Zelle Hofmann Voelbel & GLetty LLP / Tate Gorman

**CCA Corporate / Foundation Partners**

($5,000-$10,000)

- A grant from the American Society of Plastic Surgeons, in honor of Erin Williams
- Association Works by John & Sheryl Paul
- A grant from Perot Foundation
- A grant from Stemmons Foundation

**CCA Corporate / Foundation Partners**

($10,000 or more)

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

**Fundraising Events**

**Up to $1,000**

- Alexa's Appeal for CCA / Denise Rast, CCA Volunteer

- Annual Arbonne Sales for CCA / Cheryl Swearingen, CCA Volunteer
- BeautiControl / Rose Seitz, CCA Volunteer
- Brittany Steven's 18th Birthday Appeal / Harlena Morton
- Borders Books Giftwrap for CCA / Bridget Cardell, CCA Volunteer
- Cash Collection Cans placed for CCA / Kim Rogers, CCA Volunteer
- Craniofacial Acceptance Month
- "Hanger" Sales / Carrie Ingram, CCA Volunteer
- Craniofacial Acceptance Month
- "Hanger" Sales / Darnell Menard, CCA Volunteer
- Craniofacial Acceptance Month
- "Hanger" Sales / Jaci Samshammer, CCA Volunteer
- Crop for CCA / Kellie Dowd, CCA Volunteer
- "Current.com" Catalog Fundraiser / Mark & Laurel Sanborn, CCA Volunteers
- Chase Ingram Birthday for CCA
- Denim Day / Taylor Bishoup, CCA Volunteer
- Evening of Giving / Seitz Family, CCA Volunteers
- Girls Scouts Suncoast Council 1369 Cookie Fund Giving / Katie Moore, CCA Kid
- Anne T. Hawk Memorial Giving
- Highland Elementary School Denim Day / Faculty
- Ingram Family Holiday Giving in lieu of Gift Exchange
- Ink / Cell Recycle for CCA / CCA Families & Friends
- Italian Club of Dallas Collection for CCA
- Lemonade Sale for CCA / CCA Kid Wade White's Super Sibs, Antasia & Destiny
- Rock Sale for CCA / Antasia Hart, CCA Super Sib
- Sarah Orne Jewett Collection for CCA / Mary Zimmer, CCA Volunteer
- Smiley Face Campaign Collections / Peggy McDannel, CCA Volunteer
- Tony Orlando Concert Collection / Guzzo Family
- Yard Sale for CCA / Katie & Mark Steinagel, CCA Volunteers

**$1,000-$5,000**

- Austin's Luau of Love for CCA / Tamara Freeman, CCA Volunteer
- Be Brody's Angel / Jennifer Lucas & Family, CCA Volunteers
- Beauty School Funder for CCA / Rebecca Lee, Coordinator in name of Suzanne Ronczka
- Robert Blake's 60th Birthday Event

**Border's Books Giftwrap for CCA / Margaret Jenna, Dalton Family, CCA Volunteers
- Moulton Family Fund Appeals
- Penny Drive for CCA / Lincoln Heights Elementary, MI
- Angela Marcum
- Pete's Scramble unevent / Dankelson Family, CCA Volunteers
- Retreat "Chance Raffle" held at CCA's Annual Family Retreat in Myrtle Beach, SC
- Saint Patrick's School Denim Day / Pete Dankelson, CCA kid
- George Shephard Memorial Donations / Crinon Family
- Starbucks Community Clean-Up / Emily Tipton, Organizer w/Jana Peace, CCA Volunteer
- Starbucks/United Way Youth Day of Caring / Freddie Seitz, CCA Volunteer
- "The Gift" Holiday Concert / Angela Cronin, CCA Volunteer
- White Buffalo Bike Fest Raffle / Annie Reeves, CCA Volunteer
- Yard Sale for CCA / Katie & Mark Steinagel, CCA Volunteers
- Nick Wie'sie's High School Fund Appeal / Nick Wie'sie, CCA Volunteer

**$5,000 or more**

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

**$10,000 or more**

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

**$25,000 or more**

- Cher Convention
- Chocolate Festival for CCA / in name of Seth Swihart, Rick Chiavari, CCA Volunteer Coordinator
- Friends of Jeremy Golf Tournament / Dale Family, George, Kristine, Jeremy, Tommy, Cody
- Henry's March / Johnson Family, Rachel, TJ, Lauren, Henry
- Heroes 4 Hope Gala / Jorge Posada Foundation / CCA DONor, Families & Staff Contributions
Special thanks to C.R. Conant, Josh Hurst, and Rod Zuniga, our friends at Dallas-based Liquid Logixx Studios (liquidlogixx.com), and composer Mark Menza (menzamusic.com), whose combined artistic expertise in design and production of a 30-second-spot PSA about Children’s Craniofacial Association, made for an in-kind donation to save CCA tens of thousands of dollars in prohibitive costs (i.e., we could never have done this without them!) The piece is duplicated for national distribution! See it soon!

Liquid Logixx President, Josh Hurst (L), lent creative “goodwill” and award-winning composer, Mark Menza, added the guitar score to our PSA.

CCA’s Jill Gorecki thanks C.R. Conant during his recent art show in Dallas. C.R. was instrumental in the development of our PSA project.

children’s craniofacial association
13140 Coit Road, Suite 517 • Dallas, TX 75240

RETURN SERVICE REQUESTED