ccanetwork

newsletter of the children's craniofacial association   Cher — honorary chairperson   winter 2009

inside

cca kind

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

see **Lily,** page 8

message from the executive director

Twenty Years of Service!

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.

see **executive director,** page 12

Mallory, Kaylee, and her sister, Maddie

meet kaylee santiago

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.

ccaadult

meet christina mitchell

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 medication.

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!

Outgoing board chair, Rose Seitz

Chair-elect, George Dale

Erica Crabtree-Mossholder

Robin Williamson

Paula Guzzo

Dr. Tony Davis

Bill Mecklenburg

meet madelyn santiago

By Tanya Thorpe

maddie 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.

Maddie 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, Maddie 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! Maddie 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 Maddie 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 Maddie to be on the other side of things. All in all though, she was a trooper.

ccasupersib

IRA charitable rollover extension

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

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.

calendar of events

date	event	contact
Mar 8, 2009	**Smiling Thru the Mask – A dinner to benefit CCA** Restaurant 1620 Little Rock, AR	wendelynyvonne@hotmail.com
Mar 22, 2009	**Henry's March for CCA** 5k Fun Run CSU, Stanislaus Turlock, CA	laurynhenry@sbcglobal.net myspace.com/henrysmarch 209.664.0500
Jun 24, 2009	**Craniofacial Symposium** Great Wolf Lodge Grapevine, TX	AReeves@ccakids.com www.ccakids.org 800.535.3643
Jun 25-28, 2009	**19th Annual Family Retreat** Great Wolf Lodge Grapevine, TX	AReeves@ccakids.com www.ccakids.org 800.535.3643
Jul 18, 2009	**Jaci's Country Bash (Dance)** Morrisville, PA	JSamhammer@gmail.com
Jul 23, 2009	**Heroes for Hope Gala** Jorge Posada Foundation New York, NY	JGorecki@ccakids.com www.ccakids.org 800.535.3643
Aug 22, 2009	**4th Annual Wendelyn's Course of Dreams Golf Tournament** Country Club of Arkansas Maumelle, AR	wendelynyvonne@hotmail.com
Sep 12, 2009	**Alexa's Appeal** Dinner/Auction, 5-10 PM Modesto, CA	deniserast@sbcglobal.net
Sep 2009	**Jylian's Links of Love** Golf Tournament Location TBA (Texas)	JGorecki@ccakids.com www.ccakids.org 800.535.3643
Oct 3, 2009	**5th Annual Friends of Jeremy Golf Tournament** Corning Country Club Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com

PERMISSION™
Skincare for Men

Giving Back

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

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

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

www.permissionskincare.com

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

holiday parties

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 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

The 4th Annual Friends of Jeremy Golf Tournament was held on Saturday, October 4, 2008, at the Corning Country Club in Corning, NY. The new venue this year provided a beautiful setting and course for our golfers.

CCA kids, left to right: Ryan Gulich, Andrew Perry and Jeremy 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 co-workers, 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**.

The Dale Family, George, Kristine, Tommy, Jeremy and Cody

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.

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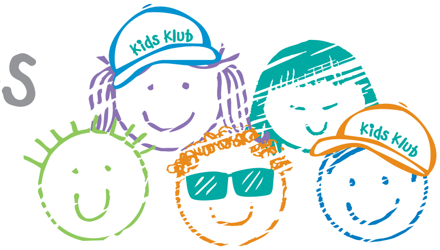
Lily also loves to play with her "babies" and, if we would let her, she'd play outside all day with her brothers and sister. She loves all the snow this year and had her first sledding day. She had a ball!

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!

Kids Klubs



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

Contact Annie Reeves for a Kids Klub application today!

donors in the spotlight

Memorial donations were given in the name of George E. Shephard, shown here with Great-granddaughter, Megan Cronin

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.

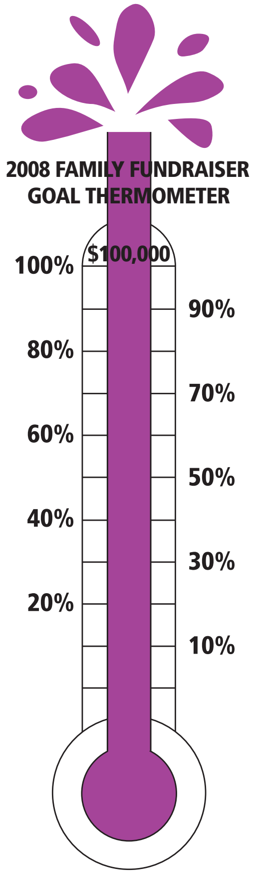
Angela recounted for us how her grandfather always put family first. He was there when Megan was born and two years ago, at 84 years old, traveled over five hours with them for one of her surgeries, sat through the eight-hour ordeal with the family, and was there to comfort Megan when she woke up. The 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!

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



See our bursting thermometer! Your efforts helped surpass the family/friends fundraising goal!

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!

Fundraising in Honor of Quentin Zaengle

Bridget Cardell and Friends held a Borders Gift Wrap effort for CCA.

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.

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

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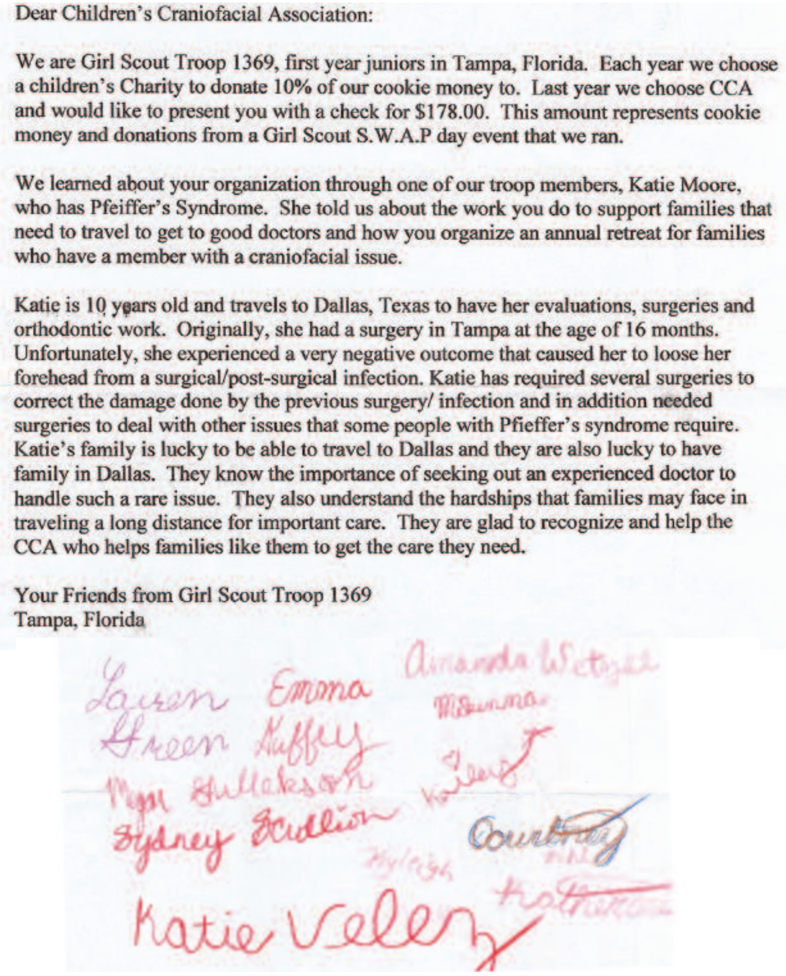
help other families the same way CCA has helped ours. Because of generous donors, our family was able to attend the CCA retreat in Myrtle Beach this last year." It meant so much to the girls, and they were encouraged to give back. Take a look at the photo!

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 chose 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 Pfeiffer'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 Pfeiffer'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

Lauren Green
Emma
Amanda
Sydney
Courtney
Katie Velez

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.

"Be Brody's Angel"

"Be Brody's Angel" logo, designed by his uncle, Keith Miks

Brody Lucas

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 accepts $1,000 in grant support from his local Walmart toward his Luau of Love effort for CCA

Along with helping raise funds for CCA kids through their Firstgiving page, **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!

executive director, from page 1

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

donors, january 1 – december 31, 2008*

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(up to $1,000)

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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
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Denim Day / Taylor Bishop, CCA Volunteer
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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 McDanel, CCA Volunteer
Tony Orlando Concert Collection / Guzzo Family
Yard Sale for CCA / Kathie & 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, Greenville, 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 / Cronin 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 / Kathie & Mark Steinagel, CCA Volunteers
Nick Wiese's High School Fund Appeal / Nick Wiese, CCA Volunteer

$5,000 or more

Ryan's Road for CCA / Gulich Family, CCA Volunteers
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Jylian's Links of Love Golf Tournament
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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

3cheers for volunteers!

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.

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