ccanetwork

newsletter of the children's craniofacial association

Cher — honorary chairperson

spring 2010

inside

graci's journey

By Mary Brown

The day "Graci Girl" was born was the happiest day of my life. We found out early in pregnancy that Graci would be born with a cleft lip. The news was so devastating, and the hurt I felt that day will never be forgotten. But praying to God helped me come to realize that Graci was put in my life for a reason. I knew in my heart that I had a job to do and that was to be the best mother I could and to raise her to be strong and determined, so she could overcome the obstacles that she may face.

The day came, and Graci was ready to enter into this world. I had prepared myself for the worst because research showed that most babies are born with cleft palates as well. Graci was just as beautiful as I had expected. However, there were other issues — Graci was

see **graci,** page 10

message from the chairman

There are many different people who will read this issue of the CCA newsletter. You may be an individual or family member affected by a craniofacial condition. You may be someone who purchased a raffle ticket for a chance to win a motorcycle. You may be a medical professional who works with craniofacial patients. You may be someone who has supported CCA by hosting a fundraiser, or you may have attended one of these fundraisers. You may be someone who has donated to CCA. You may be a

see **chairman,** page 9

meet jack simmons

Jack **Simmons** is a four-year-old preschooler from Salt Lake City, Utah. He has a sister Emma, who is 7, and two brothers, Parker, who is 12, and Nick, who is 14. He adores his siblings, and they love him so much. (Read all about Emma, Parker and Nick on page 4.)

Jack also has a black kitty named Onyx. "We got her for Easter last year," he said. "She is so soft. I love her."

Jack really loves watching movies. Some of his favorites are *Toy Story*, *Barbie and The Three Musketeers* and *Jurassic Park*. He likes to watch "Go Diego Go!" and "Minute to Win it."

Jack loves to play "army guys," "dinosaurs" and "Woody," and he likes to sing songs at school. And Jack's into the music his brothers like — Muse and anything ska.

When he grows up, Jack wants to be a pirate. He saw his mom in a spoof on Pirates of the Caribbean and now plans to be Jack "Sprat."

Jack's first CCA retreat was in Salt Lake City, but he was just a baby and doesn't remember any of it. His family, however, had a great time. Recently, he and his family went to the retreat at Myrtle Beach and had a ball. He said it was fun to go to the beach and play with Wade and his family. He misses them and looks forward to seeing them again at another retreat.

So far, Jack has had eight surgeries. He was so little, he doesn't recall them. He recently started wearing the reverse head gear to bed. He calls it his mask, and he thinks he is pretty cool wearing it. His next planned surgery will be the bone graft for his gumline. His family hopes and prays every day his shunt will keep working.

Here are some wise words of advice from Jack for any other kids going through similar situations: "Bring your favorite toy when you go to the hospital. And your mom." Well said, Jack!

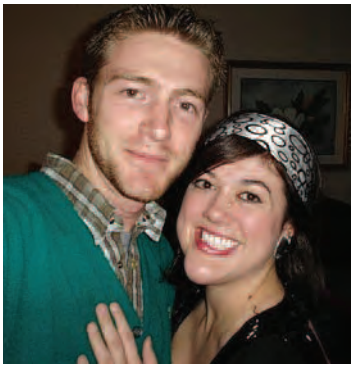
ccakid

ccaadult

meet erica crabtree mossholder

hi! My name is **Erica Crabtree Mossholder**, and I serve on the board of CCA as the secretary. I heard about CCA a few years ago from a good friend, Tony Davis, who is also on the board. I would have loved to be a part of CCA as a kid, and I am so excited to get involved with them as a "grown-up."

I have several types of tumors — osteomas, neuromas and other growths that are all on the right side of my face and head. My mom noticed these when I was about 2 years old and starting to brush my teeth on my own. I would pull out "bumps" from my jaw and lip and tongue and tell her they were in the way. As with all of my tumors, we would have them removed and more would grow back.



In second grade, we found a bony projection in my ear canal. To date, it's only been removed twice because it grows back so fast — both times within a month, larger than when it was removed. Since then, I have had several other growths, but nothing too serious. I have been tested for many syndromes, but I have never been formally diagnosed. Our family vacations were always to towns with great medical centers. I did not mind the doctor visits along the way, because we visited Michigan, Ohio, Georgia, Vanderbilt and so many other fun places. Despite my mom's diligence, the doctors would just say, "It's the Erica Crabtree syndrome."

After about seven unsuccessful surgeries to remove the growths (some minor, some more involved), most of the doctors assumed that when I finished growing, my bones and soft tissues would settle down and stop over-growing. However, they are seemingly doing the opposite! The biggest issue I have right now is my jaw bone is growing rapidly and I am slowly losing range of motion in my jaw (the ability to open my mouth). I always laugh when I go to the doctor or dentist because they exclaim, "How do you eat?!" I simply reply, "Does it look like I've missed many meals?" Laughing helps me take things in stride, and my husband is always making jokes with the doctors I visit.

For me, the most important thing about being a part of CCA is knowing, no matter what you look like, that you belong. Growing up, I looked different from everyone else. Many surgeries later, most people do not comment on the "bump" in my lip or my chin. In fact, even I barely notice it anymore! But when I was growing up, it was a different story. Every day it seemed like someone would ask what was wrong with me or call me names like "Big Chin." I think the hardest part of my life was when I started wearing make-up. I wanted to wear it, because all my friends were swapping colors and trading tips, but when I looked in the mirror, I thought, "What's the point?"

Thankfully, I am at a great place in my life now. It took me until college to finally love myself, but when I moved away and went to such a big place, I noticed that everyone had something they were uncomfortable with. A lot of people looked differently, but they were succeeding in academics, art, sports and student life. **I felt as if I was just another face in the crowd and what I did made me stand out, not what I looked like.** It was amazing to realize that there were so many different kinds of people in the world, and for the first time in my life I was meeting dozens of new people every week and very few of them ever mentioned my looks — unless it was a compliment!

Now, I am all "grown up." I am married to a wonderful man who is kind, compassionate and just as quirky as I am. I love being a part of CCA, too. We are excited that we will be attending the retreat this year in Boston. I cannot wait to meet you all there!

ccasupersibs

meet the simmons

Nick is 14 and currently a freshman at Murray High School. He loves hanging out with friends, and he really likes to eat! He thinks he's cool because he can eat a slice of pizza in two bites! He is an avid gamer and can usually "beat" a game within the first week.

Jack always looks forward to Nick coming home from school, so they can play Assassins Creed together. When Nick was little he was obsessed with dinosaurs and Toy Story, and he has now passed his love and knowledge onto Jack. Nick's newest passion is astronomy. He hopes to study it when he goes to college.

Nick loves being a Boy Scout, and has been on more campouts than anyone in his troop! He is currently working hard on earning his Eagle Scout before his 16th birthday, because his mom said he can't get his license until he earns his Eagle! He is hoping to do something at Primary Children's Medical Center, since they have done so much for Jack.

Nick's Grandma calls him Jack's "Knight in Shining Armor." He is a *great* big brother! He has always been there for Jack to protect him — and chase him around the yard!

Parker is 12 and anxiously awaiting for his elementary school days to be over. He is a very well rounded young man. He loves being in musicals (he has been in six!) and playing the bass guitar. He's also an amazing soccer player. He hopes to be able to do all those things in high school! But when will he sleep?

Parker is a self proclaimed goofball and will tell you regularly, that he is "awesome" (which is fine, because he is!). He loves ska music and was beyond excited to go to a Reel Big Fish concert recently. Even though he had to go straight from the play he was in, still wearing his "dog" stage makeup, he didn't even care!

He is so much fun and loves playing army guys with Jack whenever he can! Every time Jack goes to "the kid's school," Parker and his friends run up and give him high fives and fist bumps! Too bad they can't be CCA SuperFriends, because they all love him like he was their own little brother!

Emma is 7 and loves being in first grade. She takes ballet and tap lessons and is a great singer. She adores being onstage and has been in three plays. Her favorite was "Beauty and the Beast" with her mom and Parker last summer. She loved getting to hang out with Belle everyday! Her claim to fame though is performing on the same stage where Troy and Gabriella filmed "High School Musical!" She is an *amazing* artist too and is always drawing pictures to make people happy!

Emma loves giving hugs and telling people she loves them. She is such a good big sister. She is always helping Jack with his speech and how to say things "right" and often translates for her mom. She was also a great helper during physical therapy when Jack was a baby. Emma loves it when Jack comes to her class, and Jack fits right in! He loves to sit on the rug for story time and go to lunch.

When Nick, Parker and Emma first heard Jack was going to be special, they were all really excited! They love him unconditionally. Just before his first surgery to repair his lip, they kept asking if he could *not* have the surgery. They loved him just the way he was! They have been to the CCA retreat in their hometown of Salt Lake City as well as the retreat in Myrtle Beach. They're super duper excited to be coming to Boston this summer! All because Jack is their brother, they get to do so many fun things. They think he's very cool!

calendar of events

date	event	contact
Jun 24, 2010	**Craniofacial Symposium** Hyatt Regency Cambridge Cambridge, MA (overlooking Boston)	AReeves@ccakids.com 214.570.9099 800.535.3643
Jun 24-27, 2010	**20th Annual Cher's Family Retreat** Hyatt Regency Cambridge Cambridge, MA (overlooking Boston)	AReeves@ccakids.com 214.570.9099 800.535.3643
Jul 25-30, 2010	**Camp Courage** Atlanta, GA	www.choa.org/campcourage
Jul 30-Aug 1	**Moebius Syndrome Conference** **Moving Mountains for Moebius** Bloomfield, CO	Coloradomoebius2010@q.com Vicki@moebiussyndrome.com www.moebiussyndrome.com 303.814.2144 or 660.834.3406
Aug 28, 2010	**5th Annual Wendelyn's Course of Dreams Golf Tournament** Country Club of Arkansas Maumelle, AR	wendelynyvonne@hotmail.com
Sep 2010	**3rd Annual Ryan's Road** Big Flats, NY	ngulich@yahoo.com
Sep 9, 2010	**Raegan's Rally/Walk for CCA** Deerasic Park, 3 PM Cambridge, OH	Ashley Daugherty adaugherty@mvesc.k12.oh.us
Sep 11, 2010	**4th Annual Seth's Stride for CCA** Canton, OH	mythreekids@neo.rr.com Stacy Swihart www.firstgiving.com/sethsstride
Sep 19, 2010	**Smiling Through the Mask – A dinner to benefit CCA** Restaurant 1620 Little Rock, AR	wendelynyvonne@hotmail.com
Sep 20, 2010	**Jylian's Links of Love** Golf Tournament The Golf Club at The Resort on Eagle Mountain Fort Worth, TX	JPatterson@ccakids.com www.ccakids.org 800.535.3643
Sep 25, 2010	**Little Fire, Big Heart Dinner/Auction** Melwood Art Center Louisville, KY	TarynSkees@gmail.com www.littlefirebigheart.com
Oct 2, 2010	**6th Annual Friends of Jeremy Golf Tournament** Corning Country Club Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com

become cca's "friend" on facebook and twitter!

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

follow us on twitter at twitter.com/ccakids or twitter.com/ccateens.

cca mugshots

▲Peter and Jacob Dankelson enjoy cocoa in their CCA mugs after playing outside on a snowy day last winter in Highland, Michigan.

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)

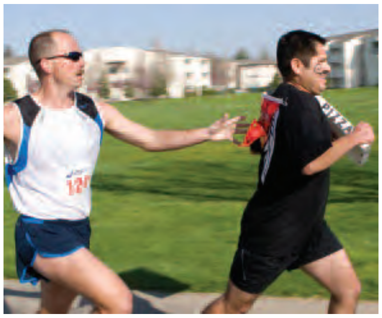
To purchase and/or sell, email or call Jill
JPatterson@ccakids.com • 800.535.3643

henry's march

TJ, Rachel, Laurynn and Henry Johnson

Henry's March 2010 was an incredible success. As they say, "Third time's the charm!" While we were planning the third annual event, we felt momentum build as more than 300 runners pre-registered for the races.

Our participants enjoyed a day of exhibitors, music, face painting, medals, T-shirts, goody bags and breakfast. Race day was warm and sunny with temps reaching nearly 70 degrees! Henry's March has truly grown beyond our initial expectations, and we were so proud of our turnout this year. Nearly 2,000 people attended, and the crowd was so positive and upbeat.



The 5k was exciting with about 200 runners and walkers on the route. The first place overall male winner was **Luis Roque** with a time of 19:4. Our overall female winner in the 5k was **Stephanie Morris** with a time of 20:36!

Of course, our Mascot Race was a hit with the kids as we had about 10 area mascots participate. Another highlight was a fun new feature we added to the 1 mile race called "The Great Waiter Chase," presented by **Angelini's Italian Restaurant**. A "waiter" (good friend and local track coach, **Jose Perez**) had a pizza-shaped flag attached to his waiter uniform. He had a two-minute head start, and the first runner to capture the flag earned **free pizza for a year** from Angelini's. The winner was **Mike Boyer**, who also took the first place medal in the 1 mile with a time of 5:15. Our first place female in the 1 mile was **Alexandra Guerro-Macchia** with a time of 6:04!

Angelini's also sponsored a pre-race carb load spaghetti dinner on March 6, which netted **$750** — now that's amoré for CCA kids! Thank you, Angelini's!

The Kids Dash is always fun and Henry's favorite part of the day. Beautiful medals were donated by **Turlock Livestock Auction Yard** for all children in the Kids Dash. They felt like Olympic champions!

Each year our community and local businesses go above and beyond to contribute to our cause. We'd like to especially thank and acknowledge **Foster Farms, California State University Stanislaus, Reed Realty, Memorial Medical Center, *The Modesto Bee*, Rush Advertising** and **Gallo Winery** for their continued support of Henry's March for CCA. We'd also like to thank our 100-plus volunteers and dedicated committee.

We are proud to share that we raised more than **$21,000**, bringing our **three-year total to over $70,000** for CCA! Putting on the race is a lot of hard work, but giving to CCA is so rewarding! We can't wait until next year.

Photography by www.bicekphotography.com

cca 20th anniversary t-shirts

Our limited edition 20th Anniversary Logo T-shirts are still available for purchase, now on sale for just $15 each, plus shipping.

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).

motorcycle raffle winner!

Motorcycle winner, Tucker Woods, with Lily Walker

Last December, CCA held a drawing for a **Johnny Pag Motorcycles ProStreet** and Tucker Woods of Lindon, UT, our lucky winner, chose the black edition of the bike. Tucker purchased his raffle tickets at "Lily's Dinner" last October. Special thanks to Johnny Pag. Congratulations Tucker!

JohnnyPag
MOTORCYCLES

www.johnnypag.com

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**

(Firefox seems to be the easiest browser to use.)

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…"

www.permissionskincare.com

good news!

Laurynn Johnson, big sister to Henry (see Henry's March, page 6), of Turlock, CA, was among a select few invited to try out for the "Brainsurge" game show at Nick studios and just as we closed on this issue, she got word she was called back to tape the show! Congrats and good luck Laurynn!

Rob Gorecki (right) and older brother, **Erick**, (left) got up close and personal with Mavs owner, **Mark Cuban** when they were in Dallas for a game (and to visit mom, CCA Development Director, Jill Patterson). Wow!

Francis Smith passed the "ultimate" exam of his graduate school career—it was the qualifying exam in which he gave an oral defense of his proposal for his PhD thesis project. They approved Francis's proposal, so he is officially a candidate for his PhD. Francis was told that this is the biggest milestone in his career besides getting his actual PhD. Francis hopes to complete his degree in 2012.

cca spreads awareness on national tv!

CCA has a new Public Service Announcement. **C.R. Conant** and **Liquid Logixx** donated their expertise to produce the 30-second spot. And on February 16 it hit the big time. The PSA aired during America's most popular TV show, "American Idol." CCA was immediately inundated with calls from families wanting to become a part of the organization, individuals wanting to volunteer and donate, and folks just interested in learning more about CCA and the families we serve.

This was not CCA's first collaboration with **FOX**. In 2008 CCA's logo aired following an episode of "House" that featured a patient with a facial difference.

A huge thanks to FOX for making it possible to spread awareness to such a vast audience!

chairman, from page 1

volunteer who has supported CCA programs. You may be the parent of a newborn visiting your first craniofacial clinic in hopes of learning more about your child's condition.

What do all of you have in common? Without you, Children's Craniofacial Association would not be beginning its third decade of service to the craniofacial community. You are all vitally important to helping us achieve our mission.

You have attended a family retreat and networked with other craniofacial families. You have provided medical services for craniofacial patients or written articles or syndrome booklets to help everyone learn more about craniofacial conditions. You have raised or donated money that has allowed CCA to develop, grow and deliver its important programs and services. You helped to raise awareness in your community during Craniofacial Acceptance Month.

Because of you, in 2009 CCA was able to connect with thousands of new craniofacial families. These families may have attended family retreats or networked with other families by phone, email, Facebook or message group. They attended holiday parties, read syndrome booklets or qualified for financial assistance for travel to craniofacial centers for care.

Because of you, more than 400 people attended the 2009 family retreat in Grapevine, TX. At the largest retreat ever, many CCA families learned they are not alone in their journey as a family impacted by a craniofacial condition.

Because of you, friend and family fundraisers are one of the largest sources of financial support for CCA, growing each year in size and in the number of people who participate.

Because of you, a whole generation of CCA kids whose families got involved with CCA 20 years ago have developed into strong, confident young adults.

Because of you, my family has benefitted from the services that CCA provides. In 2003, my family attended its first family retreat and realized for the first time the tremendous support network that CCA provides.

As CCA enters into its third decade of service and support to individuals affected by craniofacial conditions, we want you to know that we cannot achieve another 20 years without you. You all have an important place in the future success of this organization. Thank you for all you have done for this organization and for all that you will do in the months and years ahead.

George Dale
Board Chairman

torey's distraction

Photo courtesy of Katherine Robertson Photography, katherinerobertsonphotography.com

torey's Distraction, an award-winning documentary by **Tisha Blood**, premiered in Dallas on February 18th at the Angelika Film Center at Mockingbird Station.

Torey's Distraction tells the story of three children with Apert syndrome-a rare genetic condition that causes craniofacial anomalies and skeletal mutation.

Filmed with love and humor over ten years, filmmaker Tisha Blood provides an intimate glimpse into the transforming powers of science, family, hope and compassion.

CCA was honored to be a part of this very special night and looks forward to working with this amazing team in the future. Thank you for everything!

READ ME!

HELPFUL TIP!

updated baby product recalls

a variety of baby products that have been recalled are spotlighted on this site (download the newsletter online for an active link): **http://www.parents.com/baby/safety/toy/gear-recalls/?sssdmh=dm17.435669&esrc=nwpmmdailytips031810&email=550050104**.

graci, from page 1

diagnosed with hemifacial microsomia. She had a cleft lip, cleft palate, cleft in her eye, underdeveloped jaw and absence of an ear (microtia).

Luckily, we had been introduced to a wonderful craniofacial center early in pregnancy, and they were so helpful. Nevertheless, I still felt alone. Then I got involved with Family Support Network, Children's Craniofacial Association, Smile Train and the Cleft Palate Foundation, and I realized I wasn't alone. There were other families going through the exact same thing.

Graci had her first surgery to repair her cleft lip when she was four months old. It was truly amazing to see the work of modern technology. I have to admit I missed her crooked smile and her hole between her nose and lip. It was something that I had grown to love just over a short period. At 14 months, Graci had her palate repaired and was able to eat solid foods.

Currently, Graci is on her journey for "An Ear for Graci." It has been such a remarkable and amazing journey watching a brave 6 year old go through four stages of ear reconstruction. Graci's brother, Griffin, has been beside her all along the way. We have traveled to California to a well-known plastic surgeon, who has been constructing an ear to look like Graci's other one. Graci sees her ear as a gift, and she is ready for it to be complete.

We have faced many obstacles through Graci's journey, especially dealing with insurance and financial issues. However, through lots of fundraising and generosity of the community, family and friends, Graci's dreams have come true. CCA is always willing to help families, and we appreciate their help with travel. We are so thankful to the CCA angels and what they do for families with facial differences.

Graci's facial differences don't seem to stop her from being an outgoing, outspoken child. She enjoys shopping with her mommy, painting her nails, crafts with her brother, dancing, cheerleading and spending time at the beach with her family. Graci is quite the "little princess," and I am convinced she will be Miss America one day. She is so consumed with beauty both in and out. She is so confident with herself and loves helping others.

Graci has a long road ahead of her, and her journey doesn't end but her

continued next page ⇨

faith and courage continues. She will soon have nasal revision, alveolar bone graft and jaw reconstruction. Later, as a teen, she will undergo a facial reconstruction, including fat and bone grafts.

I know that we have challenges to face as she gets older, but we will continue to keep her strong and to inspire in her a sense of wellbeing. My dream is that one day she will give back to the world, and I hope her story will bring joy to others.

Kids Klub

children's craniofacial association

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

Contact Annie Reeves for a Kids Klub application today!

ccaprograms

and services in the spotlight

Families of craniofacial patients often call CCA to seek emotional support, discuss problems and identify resources. Through our database, we are able to network families with support groups and/or others who have similar conditions and experiences. We also keep a list of helpful resources and are always willing to listen and offer emotional support to family members who need a shoulder to lean on. For further assistance or information call Annie Reeves at 800.535.3643 or email AReeves@ccakids.com

programs we offer

- Toll-free hotline
- List of qualified physicians
- Information and support
- Educational booklets
- Financial assistance
- *CCA Network,* a quarterly newsletter
- www.ccakids.org website
- Annual Cher's Family Retreats
- Public awareness
- Family networking
- Advocacy
- Kids Klub
- Yahoo support groups
- Webinars

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**.

testimonial

Karter Box before surgery

Karter Box after surgery

thank you, CCA! When we took my second child, **Karter**, to the pediatrician for his four-week checkup, we had no idea what we would be facing in the next few months. After the doctor examined Karter, we were sent immediately to the hospital for an X-ray, which confirmed his diagnosis of sagittal craniosynostosis.

Surgery was our only option. After days of discussion and Internet research, we decided that the best treatment for Karter was a newer procedure, a less invasive surgical option that would limit the level of trauma and his time in the intensive care unit of the hospital. The only problem was that surgeon we chose was 600 miles away at the St. Louis Children's Hospital.

We were concerned about how we would be able to pay for all of the travel and expense of getting Karter treated in St. Louis, in addition to all of the medical bills, but we knew it was the best option for our son. When we called the doctor to set up our first appointment, we were given information about support groups and financial assistance. Of course CCA was highly recommended.

We called CCA and talked with Annie Reeves. Because of the support and financial assistance of Annie and CCA, we have been able to get our son the care he needed without having to worry about how we would be able to pay for all of our traveling!

Karter was 16 weeks old when he had his surgery. The outcome was incredible, and we were driving him home from St. Louis, Missouri, to Michigan just two days after! While the doctor was wonderful and was able to recommend a facility where we could get his helmets in Detroit, it was still necessary to return to St. Louis five times in the last year for check-up appointments. Annie and CCA were there every time to help us with our traveling needs.

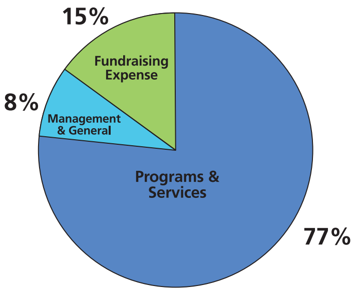
Thank you again from our entire family. We would not have been able to do this without your help!

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

financial assistance

do you travel to receive quality medical care? If you do, and need financial help, CCA has a financial assistance program that will help with food, travel and/or lodging. Call CCA for an application at **800.535.3643**. All we ask is that you **apply at least four to six weeks prior** to your next appointment.

CCA's 2009 Distribution of Funds



firstgiving fundraising

CCA families and friends can utilize our customized "Firstgiving" page to tell their story about why they support Children's Craniofacial Association and why this organization is important to them. Some families are holding events and the site is an additional place for folks to donate for their funders as well as for them to show funds being brought in for the effort offline as well.

Go to www.firstgiving.com/ccakids and check it out or create your own page!

Remarkable Results for 2009 Firstgiving Page efforts:

Dawn Page, Cole's story $1,000

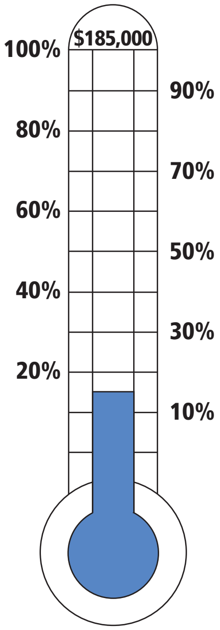
"Cole was born with Pfeiffer Syndrome, a rare craniofacial syndrome. We have to travel 3+ hours away from home in order for Cole to be seen by a craniofacial team. Some families who have a child with a facial difference may not be able to afford to travel for medical care, CCA has helped families pay for those expenses. Help us help them...to spread awareness and help other families like ours. Please donate for Cole and other children like him."

Kathie Steinagel,
Hannah's story $545

Pamela Mishra,
Baltimore Marathon $900

Janis Cazares, Austin's story
(amount raised to date) $945
(see Janis' page, still online)

2010 FAMILY FUNDRAISER GOAL THERMOMETER



clear lake 8 ball

Children's Craniofacial Association was pleasantly surprised by the arrival of a check from the **Clear Lake 8 Ball** pool league of the Houston, Texas area!

Each year the league, run by **Charles "Mac"** and **Patricia "Pat" Vereen**, proposes a gift to a non-profit organization. CCA was given the honor back in 2007 and we are grateful to be chosen as beneficiary once again.

Team members were offered a raffle to win a custom pool stick donated by **Jerry Pechauer Custom Cues** for $2 per ticket. The 45 members purchased a lot of tickets and in order to increase the donation, some of the top winning players also gave their trophy money toward the effort which garnered a generous **$1,000** from the group. The contribution was given in honor of CCA kid, **Natalie Wardlaw**, granddaughter of league member, **David Guerra**. Thank you ALL!

girl scout cookies for cca kids

Girl Scout Troop 10038 from Baton Rouge, LA including **Julia Dornier** elected to donate the proceeds from their annual Girl Scout cookie sale to CCA in honor of the memory of Julia's brother, **Rick**. Troop leaders, **Anne Milneck** and **Keiko Teranishi** tell us they've never seen the girls so excited working on the project and we're amazed to hear they're sending CCA kids almost **$700**, saying, "They all loved Rick so much and they want to be a part of the support CCA can offer to other families like the Dorniers."

We're speechless. Thank you from the bottom of our hearts.

planning a vacation?

Here's a way to support Children's Craniofacial Association at the same time! Book all of your travel needs at **www.ytbtravel.com/ccakids** including flights, cruises, hotels, rental cars, even your passport. A percentage comes back in funds to CCA. And,you may rest easily, knowing the site is powered by reliable Travelocity.

free 2011 hotel stay!

Fundraising reward extended indefinitely!

For our 2009 20th anniversary year we had a special reward proposal to CCA families who helped with fundraising – any family raising $5,000 or more for Children's Craniofacial Association through December 31st of that year would be awarded one free hotel room for their stay at the following year's retreat (i.e. 2009 fundraising counted toward the 2010 retreat). This reward has been extended indefinitely!

This invitation is extended to all CCA families, including those already holding annual events throughout the year and it includes any type of effort. So all fundraising efforts for 2010 will go toward the 2011 retreat.

All families who wish to participate are asked to sign a confirmation form in order that we may track your success and budget for your room. Please contact the CCA office at 214.570.9099, toll-free at 800.353.3643 or email **JPatterson@ccakids.com** for more information.

Try creating your own Firstgiving page

A free CCA-customized "firstgiving" site is available for anyone who wants to help raise funds for CCA. Log onto **firstgiving.com/ccakids** and tell your personal story about why you support CCA or post an event you're having. Then, all you do is email your link to everyone you know and ask them to do the same! This is an especially easy way to "ask" for donations if you're uncomfortable with the face-to-face approach.

save the date

jylian's links of love

Monday, September 20, 2010
The Golf Club at The Resort on Eagle Mountain Lake

On Monday, September 20, 2010 Children's Craniofacial Association will hold its third annual "Jylian's Links of Love" benefit golf tournament, this year at The Golf Club at The Resort on Eagle Mountain in Fort Worth, Texas.

The tournament will begin with a shotgun start at 1:00, (registration begins at noon with lunch) and will end with dinner, awards, and auctions.

Call the CCA office at 214.570.9099 or visit www.jylianslinksoflove.com for registration and sponsorship details.

donors, january 1 – march 31, 2010*

Gifts from Individuals

CCA Friends

($100 +)
Stephanie & Shayne Anderson for Henry's March
Anonymous
Julia & Robert Boyce
Rose Burks for Henry's March
Beverly & Jim Butera
Julie Byerlein for Henry's March
Laurinda Calongne
Lisa Carter for Henry's March
Joan Dornier
Rene Dornier
Sue Dunn
Kim Duyst for Henry's March
Peg Elfers
Regina Farrell
Jarret Fino
Martin Grupp
Mary Lib Guercio
Darlene & William Hunter
Deborah Jett
Melissa & Richard Jones for Henry's March
Melanie Koscick
Adam Lamar
Roger & Carolyn Lamb
T. Shaun Larsen for Henry's March
Ellen Lomonoco
Ann & Don Lucas
Melanie Machado for Henry's March
Gerald Massimei
Wanda McDonald
Penny McKee
Anne Milneck
Tina Moore
Lorraine Mote for Henry's March
Beverly Ogden
Scott Paynter
Colleen & Michael Phelps for Henry's March
Paul Pokladnik
Andrea Richard, D.O.
Dr. Milton Richards for Henry's March
Robert Rutemiller
Randolph Schaefer
Warren & Donald Schmidt
Joanne Schraeder
David Sharpe
Chase Stehr
Gary Tindle for Henry's March
Jennifer Tinney for Henry's March
Jonathan Wagner
Nanette Whitson
Steven & Mary Wilhelm
Kenneth Wilson
Myrna & Ronald Zaccagnino

CCA Extended Family

($500 +)
Rob Hough for Henry's March

CCA Sponsor

($1,000 +)
Walter Bettinger

CCA Benefactor

($5,000 +)
Bill Mecklenburg & Christine Condino Mecklenburg

CCA Guardian

($10,000 +)

CCA Legacy Society

Memorials / In-Honor Gifts

Anonymous, in honor of the Clay family
Anonymous, in memory of Rick Dornier
Anonymous, in honor of John Gorman
Monica Arcement, in memory of Rick Dornier
Melissa Asevedo, in memory of Rick Dornier
Agnes Beckett, in honor of Casey Deakins' Birthday
Constance Betts, in memory of Rick Dornier
Lisa & Michael Bock, in memory of Rick Dornier
Randy & Carol Bonnecaze, in memory of Rick Dornier
Julia & Robert Boyce, in memory of Rick Dornier
Richard Buchholz & Keiko Teranishi, in memory of Rick Dornier
Richard & Mary Buchholz, in memory of Rick Dornier
Heather Bull, in memory of Rick Dornier
Laurinda Calongne, in memory of Rick Dornier
Jeffrey Castor, in honor of Jeremy Dale
Dadami Family Trust, in memory of Rosaleen Egan
Martha Dartt, "in memory of little Rick Dornier with love"
Casey Deakins, to commemorate her birthday
Joan Dornier, in memory of Rick Dornier
Melisse Dornier, in memory of Rick Dornier
Rene Dornier, in memory of Rick Dornier, from the Dornier's in Klein, TX
James & Betty Doyle, in memory of Shelly Doyle
Sue Dunn, in memory of Rick Dornier
English Family Trust, in memory of Rosaleen Egan
Regina Farrell, in memory of Rick Dornier
Fox Rothschild LLP in memory of co-worker, Herb Stevens
Golden Girls, LLC, in honor of Seth Swihart by Michelle Collaner
Doug Goode, in memory of Rick Dornier
Mary Lib Guercio, in memory of Rick Dornier
Kimberly Haycraft, on behalf of the Greer family
Jim & Arleen Heirty, in memory of Robert Boehmke
Jim & Arleen Heirty, in memory of Les Kopecky
Deborah Jett, in memory of Rosaleen Egan
Jennifer Jones, in memory of Rick Dornier
Sharleen & Ray Juneau, in memory of Rick Dornier
Barbara Kelly, in memory of Rick Dornier
Nanine Kharey, in memory of Rick Dornier
May Klein, in memory of Rick Dornier
Joseph Logan, in memory of Rick Dornier
Adam Lamar, on behalf of the employees of Delray Lighting, in memory of Jerry Feig
Adam Lamar, in memory of his "beloved father, Roy Nickola Lamar
& blessed Patti Welch who went to the Lord at the age of 9"
Cheryl Landry, in memory of Rick Dornier
Ellen Lomonoco, on behalf of K.C. & John Haycraft
Mr. & Mrs. Lawson Lott, Jr., in memory of Rick Dornier
Marcia Mackay, in memory of Rick Dornier
Kristen Manning, in memory of Rick Dornier
Darryl & Kathleen McCauley, in memory of Dorothy Nester
Penny McKee, in memory of Rick Dornier
Christine Medici, in memory of Rick Dornier
Dolores Middleton, in memory of Rick Dornier
Anne Milneck, in memory of Rick Dornier
Jane Monell, in memory of Suzie Murray
Leanne Monroe, in memory of Rick Dornier
Tina Moore, in memory of Rick Dornier
Fredrick Muncy, in memory of Rick Dornier
Jeffrey Nicholson, in memory of Rick Dornier
Beverly Ogden, in memory of Rick Dornier
Stephan Orban, Joel Evans, Bob West, Jake & Joe Henson, in honor of Avery Lytle
Jill Patterson, in honor of Casey Deakins' birthday
Scott Paynter, in memory of Rick Dornier
Cynthia Perkins, in memory of Rick Dornier
Elizabeth Prince, in memory of Dan Prince
Caryl Rabedeaux, in memory of Rosaleen Egan
Tammy Raines, in memory of Rick Dornier
Michael Rice, in honor of JoAnn Kopshinsky
Randall Riddick, in memory of Rick Dornier
Laura Roark, in memory of Rick Dornier
Leslie Robidoux, in memory of Rick Dornier
Marie Rourke, in memory of Rick Dornier
Robert Rutemiller, in honor of Elia's birthday
Robert Rutemiller, in honor of wife, Maura's birthday
Tricia Sanchez, in memory of Rick Dornier
Warren & Donald Schmidt, in honor of Jeremy Dale
Joanne Schraeder, in honor of Rosaleen Egan
David Sharpe, in memory of Richard 'Rick' Dornier
Charlene Smith, in honor of Casey Deakins' birthday
Suzanne Smith, in memory of Rick Dornier
Nathalie Sousa, in memory of Rick Dornier
Erik Swanson, in memory of Rick Dornier
Beatrice & Eric Tamichi, in memory of Rosaleen Egan
Arthur & Gail Thomson, in memory of Rick Dornier
Tegan Treadaway, in memory of Rick Dornier
Michael & Mary Tuerck, in memory of Rick Dornier
Lynda Vince, in memory of Rick Dornier
Leona Vitolo, in honor of Zach Bordonaro
Jonathan Wagner, in memory of Rick Dornier
Nanette Whitson, in memory of Rosaleen Brigid Kane Egan
Jeffrey Wild, in memory of Rick Dornier
Steven & Mary Wilhelm, in memory of Rick Dornier
J.B. & Cynthia Wills, in honor of Reed Wills
Frank Wilson, in memory of Rick Dornier
Jean Zabady, in honor of Jeremy Dale
Cynthia Zumstein, in memory of Rick Dornier

Jilly Bean Bunch

(Donations to provide Financial Assistance to Families)

Corporate / Foundation Gifts

CCA Corporate / Foundation Friends

(up to $1,000)
AT&T (United Way Employee Giving)
Active Network (registrar for Henry's March)
Amalia's Cocina, Inc. for Henry's March
Arvest for Wendelyn's Course of Dreams
Bank of America (United Way Campaign Employee Giving)
Blue Bell Creameries.L.P. for Wendelyn's Course of Dreams
Community Foundation of N. Colorado by Brinkman Partners Fund
Costco Wholesale #782 for Henry's March
Delray Lighting Employees by Adam Lamar
E&J Gallo Winery for Henry's March
Emerson Climate Technologies (recommended by Stephen Orban)
Express Income Tax
Florshein Brothers Foundation for Henry's March
Funding Factory (Ink/cell recycle rebates)
Golden Girls, LLC
Honda Financial Services for Little Fire Big Heart
JackTheDonkey.com by David Katz
L&G Restaurant for Henry's March
Modesto Kitchen and Bath for Henry's March
Permission, Inc.
Pfizer (United Way Campaign Employee Giving)
Prudential Foundation (Employee/Matching Gifts)
Reed Realty for Henry's March
Rodig Smile Design for Henry's March
Rolling F Credit Union for Henry's March
Edwin Smith & Sons for Henry's March
Sutter Central Valley Hospital for Henry's March
Turlock Fitness & Racket Club for Henry's March
Turlock Poker Room for Henry's March
United Way of California,Capital Region (Donor-Directed Donations)
United Way of Central Maryland (Donor-Directed Donations)
United Way Mile High (Donor-Directed Donations)
United Way New York (Donor-Directed Donations)
Valley Lexus for Henry's March
Wellpoint Foundation Funds Management (Employee Giving)
Wells Fargo (Employee Giving)

CCA Corporate / Foundation Sponsors

($1,000-$5,000)
A grant from the Brotman Foundation
Charity Motors (CARS-Charitable Auto ResourceS, charitable auto donation)
Foster Poultry Farms for Henry's March
Great Coasters International, Inc. for Little Fire, Big Heart
The Redwoods Group (Matched Gift of Bill Mecklenburg)
Vivo Brothers, Inc.

CCA Corporate / Foundation Partners

($5,000-$10,000)
Fox Rothschild LLP, Attorneys At Law, 15 Offices Nationwide, Memorial Donations
United Way of the Greater Triangle (Directed Donations)

CCA Corporate / Foundation Patrons

($10,000 or more)
Grant(s) from the Jorge Posada Foundation

Fundraising Events

Up to $1,000

Cash Can / Kim Rogers, CCA Volunteer
Janis Cazare's Firstgiving Page
Ink / Cell Recycle for CCA / CCA Families & Friends
Jewelry Sale / Peggy McDannel
Lily's Dinner for CCA / Firstgiving Page /Tosha Walker, CCA Volunteer
Little Fire, Big Heart Dinner Auction for CCA / Taryn Skees, CCA Volunteer
Wendelyn's Course of Dreams Golf Tournament / Wendelyn Osborne, CCA Volunteer

$1,000-$5,000

Clear Lake 8 Ball / Raffle & Donation Collection for CCA in honor of Natalie Wardlaw

$5,000 or more

$10,000 or more

$20,000 or more

3rd Annual Henry's March for CCA / Johnson Family; Rachel, TJ, Lauren, Henry

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*Listed are **monetary donations of $100 or more through 1st quarter, 2010**. We are extremely grateful for these and all other fees, purchases, fundraisers and in-kind donations not recorded here. (Note: For space consideration, 2010 donations under $100, CCA "Supporters," will only be published in our year-end list. Cumulative $100+ donations and all In honor or In Memory dedications will continue to be published in each quarterly issue.)

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

CFC (Combined Federal Campaign, federal-employee giving)

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in the spotlight

Two of our favorite people, **Ann and Don Lucas** of Westminster, Colorado, celebrated their 45th wedding anniversary this year. To commemorate the milestone in their lives, they made a donation to Children's Craniofacial Association. In fact, Ann calls in a donation to commemorate virtually every family event. She also boosts our spirits when she calls by telling us what a great job we're all doing. The Lucas's have been continuous supporters of CCA since their 6-year old grandson, **Brody**, was born with Apert syndrome. Brody's family started a CCA family fundraiser inviting donors to **"Be Brody's Angel"** by helping all CCA kids in Brody's name. "Nana & Papa Lucas" were first to contribute and they continue to give through regular "in honor" donations. Many thanks, Ann and Don, for your ongoing commitment to Children's Craniofacial Association!

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