

ccanetwork



newsletter of the children's craniofacial association

Cher—national spokesperson

2013: Issue 1

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scott's story

By Bob Guzzo

It's 1983, and we were expecting our first child. After seven years of marriage, this is "way cool." We told everyone, got the ultrasound, amassed baby supplies, got another ultrasound, bought a new house, had baby showers, yet another ultrasound.

Wait, why so many ultrasounds?

After the first one, the doc said he'd like to be thorough. After the second, he said, "Something doesn't seem quite right. You should go to Indianapolis and see a prenatal specialist. Go. Now." Indy perinatologist: "Blah, blah, medicalesse, intrauterine growth retardation, blah, blah, cyst, chromosome abnormality, triploidy, blah, outcome guarded, in our experience, consider termination."

What to do? The first decision was the easiest and best one we ever made: He will be born, and we'll take it from there.

see **scott**, page 12



Wonderful message from the executive director

Spreading awareness of individuals affected by facial differences is such an important endeavor and something for which CCA has long strived. We feature children and adults affected by craniofacial conditions in our newsletters to show that these individuals have hobbies, skills, likes and dislikes just like everyone else. When we are really lucky, we get a Public Service Announcement (PSA) on television or radio or an article placed in a

see **executive director**, page 15





cca kid

meet brandon williams

brandon Williams is a happy, adventuresome two-year-old—a “big boy” who wants to explore everything. He puts his skills to good use in preschool, where, apart from playing, laughing and napping, he can also be found creating masterpieces with crayons.

And this toddler loves to build. Not just with Legos, but with anything that can connect or stack: blocks, bowls, cups, you name it. Just ask his **Yamma** (grandma). In addition, Brandon really likes *SpongeBob*—he thinks he’s the man—and he loves watching *Mickey Mouse Clubhouse* shows on TV.

Brandon also has seven stuffed buddies that live in his bed: Roar the lion, Hearts the bear, two “gwinos” (penguins), Goofy, Big Rabbit and Mater from the movie *Cars*. He will throw a fit if each one is not in its place. Before bed, he has to kiss all of them. Then whoever is

tucking him in has to kiss them. And then he kisses each one again before lights out.

Most of all, he loves his big sister, **Ravyn**, who will be six years old this May. Last summer they went to their first CCA retreat, where they had a blast. They even took their first-ever plane ride together — a big, fun adventure for the both of them.

Brandon was born with a cleft lip and palate and has become an old pro with medical procedures. He has already had one major surgery and will have another when he’s five or six. He also has speech therapy every week. Still, throughout it all, Brandon bounces right back to his curious, energetic self. “He’s a Superman,” his mom, **Robyn**, said.



ccateen

meet daniel pfeiffer

hHi, my name is **Dan**. I am 13 years old and was born and raised in Philadelphia. I was born with Saethre-Chotzen syndrome. My parents found out that it runs in my family. My mom, grandma and great-grandma carried the gene. I never thought that I looked different because we all looked similar.

When I was younger, I never really knew that I was any different from anyone else. My mom and dad told me that it was a genetic twist in my DNA, but I never thought about it or tried to understand.

Doctors, hospital visits, and therapists were always part of my life. I have had four vault advancements. Last August I had a surgery which really sparked an interest in becoming more aware of myself. I wondered why I have what I have. I imagine every CCA kid has asked that question! My parents, my team of doctors at Children's Hospital of Philadelphia, and CCA have really helped me.

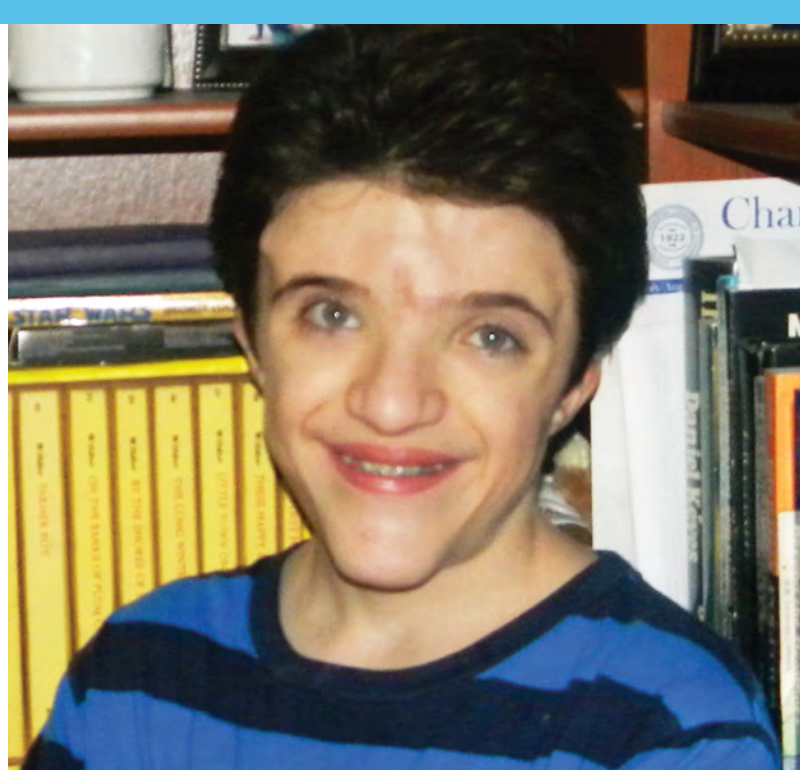
I am a busy, fun-loving kid with many hobbies and like to make people laugh.

I am always on the go and do not let my medical issues slow me down. I love to read. I also swim for Neshaminy CORE and hope to join their USA team next year. This year, I made the top 50 in backstroke for my age group in the Suburban Athletic League.

I play the piano in a jazz ensemble at Settlement Music School. And, I am a straight-A student at Pennsylvania Virtual Charter School as well as the president of the PAVCS National Junior Honor Society chapter. One of my honor society service projects was a slideshow to help create awareness for people with facial differences.

I like to play video games, but who doesn't? My favorites are Banjo-Kazooie: Nuts and Bolts, Minecraft and the Halo series. I also take art classes at the Philadelphia Museum of Art. Living in Philadelphia, I love to visit all kinds of museums and historical sites.

I have a great, supportive family. I do not have any siblings, and it is good because I have my own room! My cousin Carly is



like a sister, though. She is always there for me. My grandma and grandpa spoil me, since I am the only grandchild on my mom's side of the family!

My grandma and grandpa are somewhat like Auggie's grandma in the book *Wonder*. They do everything and anything with me. They even play Halo on Xbox 360! Picture two 67-year-olds playing Xbox 360—it's fun!

I have a cat named Blue Bee who is eight. (I got him when I was five and I thought we were going to get another cat that I was going to name Pinky. Mom and Dad said "Maybe someday.") I can always count on my mom and dad no matter what the situation, whether it be daily life or surgeries. They have my back!

When I grow up, I am going to be an engineer and figure out how to build a hover car, robotic body parts for people without limbs and awesome Iron Man suits. I have a mechanical mind and want to invent. I love Leonardo Da Vinci and Thomas Edison, both great thinkers that were ahead of their time! I also have a new interest in genetics. (Hmmm, I wonder why?)

I believe that kids with craniofacial differences are unique. We go through a lot of challenges. It makes us who we are. I am grateful to have CCA in my life. I am lucky to be able to meet kids like me. Not many people can relate to having the same types of surgery. But no matter what the world throws at me, I will always hold my head high!



meet ravyn williams

By Robyn Curtis

When **Ravyn O. Williams** was younger she had the standard little girl fears — the dark, monsters, and pain. She also had dreams of being a princess ballerina who has a lot of horses; being a great swimmer like her aunts, **Natasha** and **Jordan**; living at Disney World with Mickey, Minnie and all the princesses; and going to Chuck E. Cheese’s every day. Day-to-day activities included playing with toys—all toys, even things that are not toys. She loved to do projects—although it took her quite a while to realize when you

get messy, you really can clean up.

When Ravyn was three years old, she was told Mommy had a baby in her tummy. You could see her excitement of getting someone to play with night and day. Of course she had all the regular questions of a three-year-old: “Was it a boy or girl? What is their name?”

A couple months later after an ultrasound, Ravyn asked me, “Mommy, why are you sad? When you’re sad is the baby sad too?” I didn’t know that answer, but I could answer one of the other questions: “The

baby is a boy. You’re going to be a big sister.” I also said the doctor told me your new brother might have a cleft lip (a special mouth) and you have the big sister job of being my helper.

Months later **Brandon** was born. Now that Ravyn was a big sister, her brother could do no wrong (at least at the time). When he cried, she yelled for help. When he fell, she cried with him. When a little girl said “Momma, a baby monster,” Ravyn immediately said, “No, my baby boy.”

Ravyn is now five and will be six in May. The majority of things have not changed. She still wants to be a ballerina princess, and own a thousand Barbies with all the clothes and shoes. She now wants to hang out with Mickey (he’s a boy) but live with Minnie and the princesses. She tried swimming and realized you have to put your face in the water so, that is a big NO. Projects and cooking are a must with **Grandma** (who doesn’t mind the mess and knows all messes big or small can be cleaned).

When meeting Mr. and Mrs. Claus at the Chicago Indian Center, Ravyn made

Mrs. Claus a necklace. I think it was to get those extra “brownie points” to guarantee a spot on the nice list. She said it was because they make sure everyone gets something—even coal—and all they ever get is cookies.

This past summer was her first retreat, riding on a plane for the first time. I thought she’d be intimidated and shy, but from the very first day she made tons of friends. She had the time of her life and still talks about it.

Now Ravyn’s a kindergartener. When she leaves each morning she gives her brother a kiss and tells him to have a good day: “Don’t worry today. I have your back.” Brandon is the first person Ravyn sees in the morning and the last at night.

Even through all the fighting and bickering, both of them are very lucky to have each other forever. In fact, when she cries, Brandon points and yells for help.

In Ravyn’s eyes, there has never been a difference in his looks — or anyone else’s, for that matter. And that makes me really proud.

friends of jeremy golf tournament 2012

By Kristine Dale



The Eighth Annual Friends of Jeremy Golf Tournament was held on Saturday, September 22 at the **Corning Country Club** in Corning, NY. There was an incredible turnout and overwhelming support from the community, our co-workers, friends and family.

We are so grateful for the tremendous support of our 137 golfers and more than 55 generous sponsors who helped to make the day a success! The tournament included a raffle, silent auction, closest-to-the-pin 50/50, closest-to-the-line prize and a skins game. There was a special raffle

for a 40-inch LCD TV and an iPad.

The silent auction included many autographed memorabilia, including items from the **New York Giants, New York Rangers, Buffalo Bills**



and a **Derek Jeter** photo!

A very supportive local car dealership, **Simmons-Rockwell**, was not only one of the major sponsors but also provided a new car prize for a hole-in-one contest. Unfortunately no one won the car, but everyone had fun trying! The event was a huge success, netting more than **\$34,000** for CCA!

Jeremy was again joined this year by fellow CCA kid **Ryan Gulich**, and we had a special surprise visit by CCA friend **Freddie Seitz!** It is so wonderful to have CCA friends join us for the tournament each year. The golfers really enjoy meeting new kids and catching up with kids they have met in the past.

We are so grateful to everyone who supported this event and the kids from CCA.

rick's raffle 2013

The Third Annual Rick's Raffle started February 14. Founders of the effort, **Ann and Doug Burgin**, established the annual raffle in memory of their beloved grandson, **Rick Dornier**.

The prize for this year is a Thomas Train Table. To go with the deluxe set-up, they've also included a set of four "Thomas & Friends" Wooden Engines. The prize retails for more than \$250.

Thomas the Tank Engine toys were among Rick's favorites, and the winning ticket will be drawn on Rick's birthday, April 25. In accordance with the wishes of the Burgins and Rick's family, all funds raised go toward CCA's Patient Financial Assistance program in Rick's name, to help families defray expenses while seeking medical care for craniofacial conditions.

Tickets are just \$5 each, five tickets for \$20, or 15 tickets for \$50.

You may use our regular online donation site to purchase tickets if you indicate Rick's Raffle.

Or call CCA at 214-570-9099 or 800-535-3643, email Jill at jpatterson@ccakids.com or contact her through CCA's Facebook messaging page.

pledge to choose kind

inspired by #thewonderofwonder



thank you for choosing kind!

[Peter's Precept](#) video has been viewed over 900 times on Youtube!

How wonderful that the "Choose Kind" message from **R.J. Palacio's book, *Wonder***, is being embraced in classrooms around the country! Teaching students to be accepting of differences and choosing to act kindly toward others is a powerful lesson that will stay with these kids throughout their lives. Having them connect with real-life people who have facial differences solidifies that lesson even more.

If you have been following our blogs about *Wonder*, then you know that CCA began selling the book just a few months ago. [The Power of First Impressions](#) announced our endorsement of the book. We then participated in the *#WonderSchools Blog Tour*, by posting [Every Kid Needs a Hero](#). A 5th grade class in Baltimore saw the blog and, after reading *Wonder*, acted on its message by choosing to give a real-life Auggie his first standing ovation. What a wonderful

way of embracing the book's message to "Choose Kind." Here's the [Standing Ovation for Peter](#) video that **Reilly Posey's 5th graders** created.

As a real-life Auggie's Mom, I can't recall ever being so touched as I was when watching this video. I have always said that our CCA kids leave a powerful impression on everyone. As their parents, I believe it is up to us to make sure that impression is overwhelmingly positive. After drying my eyes, I told Peter that he should send a video message back to Reilly Posey's class thanking them and sharing his opinion of the book. What ensued was a great evening where my two boys wrote a skit, rehearsed, and eventually produced [Peter's Precept Video](#). What a fun family project. We had a lot of laughs together that night—lots of ear humor!

Peter's Precept video has now been viewed over 500 times on

YouTube, and I'm proud to say that my family is doing our part to spread CCA's message that "Beyond the Face is a Heart," while also promoting Ms. Palacio's campaign to "Choose Kind." But, it doesn't end there...

This morning, I was blown away to read the following email from **Deb Tyo** who teaches at Versailles Middle School in Ohio. "Dede—Please tell

Peter how much he has inspired us. Because of Peter this is happening... [To Our CCA Friends](#). I believe the entire middle school from grades 6-7 shared the book as a school-wide read. How amazing is that?! And, how about that video? I'm still choked up and overwhelmed with gratitude. This book and these teachers are improving the lives for CCA



families everywhere—the affected kids, their siblings, and their parents.

CCA parents have faced sadness, fear, grief, and anger following the birth of their child. They have spent anxious hours worrying about teasing and bullying at school. And, they have endured many agonizing days and nights sleeping in hospitals, waiting in emergency rooms, and driving to/from specialty clinics and therapy sessions. For all this, our CCA family is finally receiving some gracious acknowledgements of acceptance. Let's return the kindness by expressing our appreciation for those who are embracing the "Choose Kind" movement.

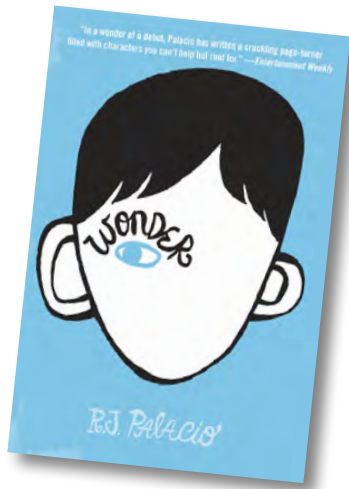
Take CCA's Choose Kind Challenge now at ccakidsblog.org/p/choose-kind-challenge.html.

CCA Families created the following video at the "2012 Cher's Family Retreat" as a thank you to all of those who support and embrace our vision of a world where all people are accepted for who they are, not how they look. I can't imagine a more deserving audience for it's debut.

Thank You from CCA!

Finally, my standing ovation goes out to the following for their amazing acts of kindness...

- **R.J. Palacio** for writing *Wonder*



Wonder is available at ccakids.org/wonder.html for \$12

- **Random House** for creating the [Choose Kind website](#)
- **@DavidAETkin**, the teacher from Buffalo who started [#WONDERSchools](#)
- **Reilly Posey (@PolkaDotOwlBlog)** & her 5th Graders in Baltimore for their [Wonder Blog](#) & [Peter's Standing Ovation](#)
- My two amazing boys **Peter & Jacob** for promoting the [Choose Kind](#) campaign and producing [Peter's Precept](#)
- **Deb Tyo (@ChocolateAir)** & **Versailles Middle School** for their [Wonder Blog](#) and [CCA Standing Ovation](#)
- **Sherry Gick (@LibraryFanatic)**, a school librarian from Indiana, for her assistance in launching [#WONDERSchools](#)

Dede Dankelson

Dede is the Board Chair for CCA and proud Mom of CCA Kid Peter (age 12) & CCA Sib Jacob (age 8)

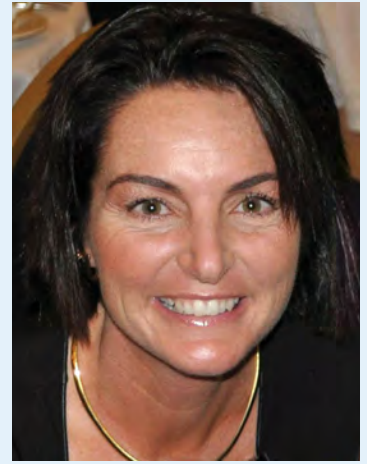
message from the board chair

Winter 2013

My family and I have been involved with CCA for more than a decade, and I consider it a privilege to serve our families. When my son **Peter** was born 12 years ago, we were overwhelmed with not only the medical responsibilities but also concerns about social acceptance. I kept thinking that the more people we could get to know Peter the more acceptance he would have growing up.

Today we have an organized effort that promotes this idea through CCA's "Beyond the Face is a Heart" campaign used in September for Craniofacial Acceptance Month. Twelve years ago, however, this campaign and the ability to connect through social media outlets were nonexistent.

In 2003, my husband and I began hosting an annual golf outing where many friends, family, and work colleagues came to learn more about Peter's condition. We chose CCA as the beneficiary of the event as I had been receiving the newsletter and liked the stories about the children and families.



I think the staff was a bit speechless when I asked permission to host the event even though we had never attended a retreat or met anyone from CCA!

"Pete's Scramble for CCA" was an annual event for five years. Most importantly, it inspired a new era of family fundraisers that have helped secure CCA's long-term viability. **About 40% of our annual donations now come from family-organized events**, which is a unique reflection of how much the organization is valued by its members. Without your help, our programs and services would be dramatically cut.

Today CCA serves 10,000 families across the United States and is recognized as the premiere craniofacial support organization in the country. Through our growth, we have retained a loving family atmosphere of support to one another. Cher's Annual Family Retreat is a huge part of ensuring this closeness continues.

board chair, from page 7

The influx of social media and technology, however, enables us to stay in touch with one another all year long. It is also increasing CCA's awareness beyond the craniofacial community. We are building recognition throughout the country via Facebook, Twitter, Pinterest, Yahoo! Listservs, CCA Kids Blog (ccakidsblog.org) and other venues. One long-term objective is that all communities, medical facilities, and schools nationwide recognize CCA as the primary resource and support organization to the craniofacial community.

The January 2013 launch of our beautiful new website (ccakids.org) is one tool we will leverage toward achieving this objective. Please join me in recognizing **Robin Williamson** for designing such a beautiful site, with much input from **Taryn Skees**, the **CCA Staff**, and the **CCA marketing committee**. CCA is also grateful for the **\$5,000 grant** from the **Tony Stewart Foundation** that helped fund the project.

We want the website to be a dynamic and resourceful tool for our families, so please contact the office if you have thoughts or suggestions regarding content. Our marketing committee is already working on expanding the site beyond this initial launch.

CCA's day-to-day operations are managed through our office in Dallas by three full-time professionals. **Char Smith** has been executive director for 23 years and is tremendously dedicated to CCA's families and vision. **Annie Reeves** has served as program director for 10 years and is our primary contact for families in need of financial assistance, registration for the retreat, materials for Craniofacial Acceptance Month, and all other things to do with education and outreach. **Jill Patterson** has filled the role of development director for 11 years. In addition to being "Robbie's Mom," Jill handles all fundraising and grant activities, including family fundraisers; please contact her if you wish to host an event or need help with suggestions. We also employ a cheerful part-time administrative assistant, **Jana Peace**, who may be your first point of contact when calling the office directly.

CCA could never achieve all we do with the support of only three full-time employees. Our board of directors is constantly at work on projects. We divide and conquer through committees that handle governance, marketing, programs/services, finance, audit and fundraising. The board is comprised of individuals who contribute

specific skill sets to assist the staff. Some of those skills include legal, finance, public relations, marketing, fundraising, education and grant writing. We currently have a board of eight directors comprised of outside professionals, parents of CCA kids and individuals affected with a facial difference.

Long-term director **Tony Davis** rotated off the board at the end of 2012. Tony will remain involved with CCA as our primary contact with **Cher**, our honorary spokesperson. He has dedicated years of support to our board, including the role of chairperson from 2006 to 2007. Thank you Tony!

Margaret Lavender, our newest director, was welcomed to the board this year. Margaret lives in Fort Worth and has attended some of our local CCA events and fundraisers. She works for **Honda Financial Services** and has an experienced background in generating revenue for nonprofits. We are always looking for professionals who possess specific skill sets and experience to serve on our board. Please contact the office if you have recommendations or skills that you can volunteer to the organization.

One of the most exciting outreach programs we are focusing on this year is promoting the book *Wonder* by R.J. Palacio. This #1 *New York Times*®

Best Seller and winner of countless literature awards is making our vision that "all people are accepted for who they are, not how they look" become a reality. Its message to "Choose Kind" complements everything CCA stands for, and its ability to make a positive social difference for our children is invaluable. We want to see this book become a part of every school's curriculum. Please see the *Wonder* article in this newsletter to read more about our plans.

Although we don't always like the attention our kids receive, we can empower ourselves and our children to make as many positive encounters as possible. Every contact you make with someone is an opportunity to bring positive awareness to the craniofacial community. Peter's simple approach is, "Don't be afraid to be friends with someone who looks different."

All of us at CCA intend to make sure his words receive our full support! Please don't be afraid to reach out and be a difference maker in your own world knowing that hope and encouragement will always be available through CCA.

Dede Dankelson
CCA Board Chair

ryan's road for cca

9-Pin, No-Tap Bowling Tournament

by Ryan L. Gulich, Sr.



this year! **Crystal Bowling Lanes, Dandy Mini Mart, Home Depot, Reality USA and Swan & Sons-Morss Company Inc** were also top sponsors.

Thanks to everyone's generosity, we netted **\$5,548**. This is our family's fourth fundraiser for CCA, and we have been fortunate enough to have raised more than \$20,000 so far. And we look forward to raising even more!

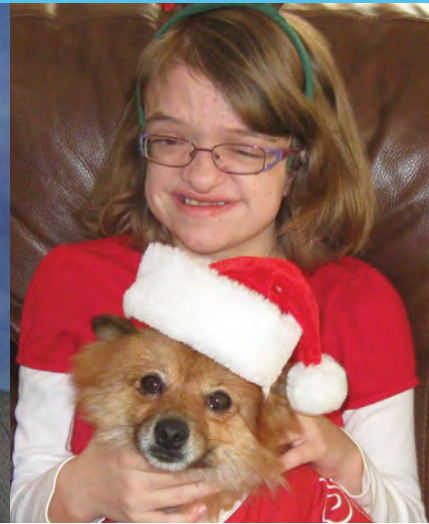
About Ryan

Ryan Gulich, Jr., was born on December 16, 2001, with Apert syndrome, which is a spontaneous mutation of a gene and affects abnormal growth of bones in the body, primarily the skull, midface, hands and feet.

Apert syndrome occurs in approximately one per 160,000 to 200,000 live births annually. Because of the effects of this syndrome our son has had 11 surgeries at Boston Children's Hospital over the past 11 years with his most recent surgery being a (Lefort III) midface advancement.

On November 11, 2012 we held our **Annual Ryan's Road for CCA Bowling Tournament**, and we were blessed by our family, friends and community, who, year after year, come out to support CCA. More than 150 people attended this year, and we cannot thank them enough for supporting such a wonderful cause. Raffles for the event included an autographed Jim Kelly Hall of Fame football, 4 tickets to a **Buffalo Bills** game won by **Rodger Keenan** and other door raffles.

A very special thank you to **Horizon Solutions**, and **Gas Field Specialists** for being our main sponsors



donors in the spotlight

J.B. (James "Bow") and Cynthia Wills have been donors to Children's Craniofacial Association for many years giving "in honor of **Paige Wills**, from Papa & Nonie." Paige is their granddaughter, who was born with Pfeiffer syndrome. Daughter of **Heather and Reed Wills**, Paige is now 11 and a confident CCA kid.

Over the past three months, first Cynthia, and then Bow, passed away. In honor of their memory, Reed and Heather, along

with Reed's five siblings (**Jim, Cindy, Ted, Tom and Mary**) are carrying out the last wishes of Cynthia and Bow, who requested that in lieu of flowers to please send donations to CCA in their parents' names. Friends and family are honoring their memory to benefit all CCA kids who will face surgery and other challenges like Paige once did.

We are so very grateful for this generous family, the Wills, our first "Donors in the Spotlight" of 2013.

cca mugshot

Send us your mugshots!



Jacob Dankelson (left) and Johnny Cipriano (right), sharing some hot chocolate after sledding.

pete's oktoberfest



The inaugural Pete's Oktoberfest benefiting CCA was held on October 5, 2012, by the **Dankelson family** in Highland, MI. The day started with a small golf tournament and ended with a fun Oktoberfest-themed party. The party festivities were quickly moved inside because of Michigan's unpredictable weather. Everyone enjoyed music by **Mr. Moody** and Oktoberfest-themed foods by **Sparkies Bar & Grill**. A few did brave the cold, rainy weather and stayed warm outside by the bonfire!

Many thanks to everyone who supported the event, especially the student volunteers who helped shuttle golfers, serve food and sell raffle tickets. The 2012 fundraiser grossed over **\$14,000** for CCA!



chocolate festival 2012



Chef Rick Chiavari and the **Aventura Mall** in Aventura, FL, teamed up on October 14, 2012, to hold the Fifth Annual Chocolate Festival for CCA.

Chef Chiavari's nephew, CCA kid **Seth Swihart**, and his mom, **Stacy Horne**, traveled from Ohio to represent CCA and volunteer for the day. Local chefs, restaurants, kiosk entrepreneurs and other businesses donated their time, talent and wares to the effort, and chocolate lovers



purchased tickets for \$1 each or \$10 for 13 tickets, trading tickets for a taste of each full-sized treat.

The event grossed approximately **\$15,000** for CCA. Many thanks to everyone who donated, created and tasted the yummy delights!



how to raise funds for cca

CCA depends on funds donated by individuals, proceeds from family and friends' fundraising efforts, corporate giving and foundation grants. As the number of families CCA serves grows, so does the need for additional funds. So, any help our readers contribute is most appreciated. Here are some ways to help.

- **www.goodsearch.com** (Powered by Yahoo) Enter Children's Craniofacial Association as your beneficiary charity. (You only have to do this the first time. You may add others if you wish.) CCA will receive up to a penny each time someone uses the GoodSearch search engine.
- **GoodShop.com and iGive.com** Go to GoodShop.com or iGive.com, online shopping sites, both featuring hundreds of great stores including Best Buy, Macy's, Apple, and more. It's easy! Just shop as you normally would! You get the same prices, but a percentage comes to CCA!
- **Cash for Trash!** Save your discarded cell phones, empty laser / ink cartridges, GPS devices, digital cameras, MP3 players and old laptops. Call CCA for more information.

- **Matching Gifts**

Many companies offer a matching gift program that could double—or even triple—your gift to CCA! Contact your human resources office to find out if your company has such a program.

One family donated \$2,500 and had it matched in order to get their free retreat hotel stay!

- **Planned Giving**

Tax preparation time is also a good time to consider long-term tax savings. When you consult an attorney or investment professional regarding your wishes for distribution of your assets in your will, consider a provision for CCA. Your planned gift in the form of an endowment will live on after you.

- **CCA Web Store**

You can shop at www.promotes.me/cca for your T-shirts, mugs, caps and more. So shop now and shop often!

- **Clubs / Hobbies**

Have your club organize a benefit for CCA. Use your hobby or something you love to do to raise funds.

- **Denim Days**

Raise funds at work for CCA. Establish a special day or days for employees to make a designated donation (cash or check) to CCA in return for wearing

blue jeans. The donation is usually \$1 to \$5, depending on how often the event takes place (for example \$1 for a weekly donation, \$5 for a monthly donation). Any higher amount would be at the discretion of the donor.

- **Civic Organizations**

Public awareness leads to contributions. Contact and solicit opportunities to speak to your local civic organizations such as Rotary Clubs, Kiwanis Clubs, even HOG organizations (CCA has many 'biker' supporters). Distribute brochures and/or newsletters or other CCA-sanctioned materials for awareness and information. Ask for contributions.

- **Friends / Family**

Letter Appeal Draft a letter to family, friends and acquaintances—anyone who has met or encountered your child. Contact CCA for a sample letter.

- **Kitchen Shut Down**

Raise funds by raffling off chances to win meals for every day of the week, so the winner can "shut down" their kitchen. Local restaurants can donate meals or coupons. This idea could also be used for a week of entertainment, such as movie rentals or theater

tickets. Call CCA for more information.

- **Collection Cans** Ask local businesses to place a can or box (provided by CCA) to collect donations.
- **Get On Board!** Read our newsletter and learn about and participate in the events, raffles and funding efforts of CCA and our supporters. And, when you are finished with your copy of our newsletter, spread the news! Pass it along or leave it in a waiting room. (Remember to remove your address label.)
- **FirstGiving** There is a free customized CCA "firstgiving" site for anyone who wants help raising funds for CCA. Log onto firstgiving.com/ccakids and tell your personal story or post an event you're having. You can even set a goal and track success! When you tell your own story about your CCA Kid or why you are involved with CCA, folks will respond because they know YOU!

scott, from page 1

Robert “Scott” Guzzo was born two weeks early on August 5, 1983, via an emergency c-section. Dead silence in the OR. Nurses avert their eyes; no one wants to look at or speak to Dad. He was 2 lbs., 12 oz., a tiny, tiny body with a large, misshaped head and a miniscule face. He had a cleft lip and palate and almost no skull (but hair!), club foot, etc. No one has ever seen a baby that looked like this before.

A couple days after Scott’s birth, Paula was still an in-patient at the hospital, and was having some very reasonable post-partum depression given our baby’s extreme situation. We had a private room and the third-shift staff was ok with me spending the night. They gave me some surgical scrubs to use as pajamas. I slept in the chair. Early the next morning, I lay down in bed with Paula to comfort her. The first-shift nurse knocked on the door and opened it without waiting for a “come in.” She took two steps into the room and saw me in my scrubs, in the bed with Paula. She stopped in a frozen state, stammered “Sorry, I didn’t know your doctor was here,” and backed out of the room. We laughed till we cried.

The first three months were devoted to growing and staying alive. The

latter was a challenge at times. Scott had multiple occurrences of respiratory distress where we almost lost him. (Years later, when we got a diagnosis of his syndrome, we learned that the first two newborns known to have this syndrome died from respiratory distress.)

Scott did grow, slowly, both in size and personality. By six months, he was up to a whopping 9 lbs. but, more important, the playful, curious, laughing boy had started to emerge. More than anything, this told us (as well as relatives, friends and health-care staff) that a VIP was in that little body. Scott couldn’t hold up his head (too big for his scrawny, weak neck), could barely roll from side to side, fought infections, and had feeding problems, regurgitation and a lot of other physical issues. But his sneaky, funny, engaging self had us all trapped.

At three months, Scott’s first surgery was bilateral coronal craniectomies. At six months, he had a suboccipital (lamdoidal) craniectomy, cleft lip repair, and bilateral myringotomies and ear tubes. At seven months, a Nissen Fundoplication and g-tube.

Thus started the “surgery years.” By the time Scott was six, he’d had 20 surgical



procedures. After that, the surgeries were more rare and less critical, which allowed Scott to get through the school years pretty much without interruption. Only in the past two years has the surgery schedule become intense — 11 times in the OR between November 2011 and November 2012, involving about 20 procedures, mostly eye-related.

Scott is not afraid of surgery. He goes in with a good attitude and comes out thanking the doctors and nurses for their good care. Scott always tells the surgery staff “let’s rock this place” and plays “Cotton-Eyed Joe” on his iTouch while the anesthesiologist puts him to sleep. For him, it’s just another party that happens to be with hospital staff.

Scott started “school” in spring 1984 (after the

surgeries) with infant stimulation classes at the ARC. He moved on to pre-school for four years before entering the public school system, where he finished high school in 2004.

The big deal with the school system was moving him out of the segregated special-ed class at a school on the far side of the city to his neighborhood school when he entered 3rd grade, the same year his brother started kindergarten at the same school. This move enabled Scott to mingle and become friends with the “regular” kids. Scott took full advantage of his wit and charm to develop lifelong friendships. To this day, old classmates are always quick to engage him during chance encounters in the community.

Scott did not have a diagnosis until he was 10 years old — Crane-Heise

syndrome! Google it if you're curious, and don't dare say you've heard of it before unless you already know Scott. Yes, he's the only known living person who is a certain match for CHS. Not one in a million, not one in seven billion, but one in ... forever. There are a handful of cases of CHS births, but none other than Scott survived beyond two weeks. Being the only known living person with CHS, there's no good answer when we're asked about his prognosis, other than to say no one knows since there's no precedent. In other words, he's setting the standard for anyone in the future with CHS. Obviously, there's no "CHS support group," so you can imagine how much CCA helped fill that void for us.

As I write this article, I asked Scott what he wanted the *CCA Network* readers to know about him now. "Tell them I'm a bright young man, I'm not a baby (people think that all the time), I use a wheelchair, I love my iTouch, music and parties (especially the CCA dance), I have a job and volunteer at the library, I love to travel, and my brother Aaron lives in LA."

So let me expand on these. While there are things that are hard for him, Scott has remarkable intelligence.

He did well in school with an adapted curriculum where he participated in the same general education classes as everyone else. He was a good reader before his vision problems two years ago, and is starting to read again now that most of his eye surgeries are over.

While he doesn't have the skills to live independently, he is an active (oh is he ever!) and appropriate participant in social situations. Paula and I still get a kick out of his perception of issues and his really good questions. Scott often gets left out of conversations because of his speech difficulties or because people don't see him as an adult due to his size. My advice: Talk to him as the adult that he is! Paula or I will interpret for you.

When we fly to the CCA retreats, we bring Scott's manual wheelchair. He hates that. When we drive, we bring the power chair. That's the independence he likes. And, he can "burn rubber" to "Wipeout" at the dinner-dance. The iTouch is practically welded to his hand: Facebook, email, news, weather, sports, markets (really, he checks daily to see if it's up or down) and a couple hundred apps (most related to music in some way). His idea of a

good restaurant is one with free Wi-Fi.

Scott listens to music a lot (a lot!), plays the piano, loves concerts and will belt out a song at the top of his lungs when the urge hits him. Did someone say party? Scott enjoys receptions of all types (weddings, birthdays, conferences, etc.) not because of the good food (he's entirely tube-fed) but because there's a DJ kickin' out the tunes! He's first on the dance floor and last off. The CCA dinner-dance is an annual highlight. Get on his dance card early if you want to cut a rug with him.

Scott has been volunteering at the local public library twice a week since high school (sorting music CDs for re-shelving). For the past five-and-a-half



years, he's been a ticket-taker at the local arena: mostly concerts, Evansville Aces basketball games and IceMen hockey matches. He likes the crowds and lots of people see him. He's a favorite of the Icicles, the promotional team for the IceMen.

see **scott**, page 14





Scott loves to travel. Going and seeing new places is a thrill but his main thing is the hotel. And, he always works the front desk for an upgrade. Sometimes it happens!

Perhaps the biggest single event in Scott's life was the birth of his brother. As a five year old, Scott so anticipated **Aaron's** arrival. Aaron may be Scott's greatest source of pride. In many ways, even though Aaron has been 2,000 miles away for the past four years, Scott lives a big part of his life through Aaron's achievements. He follows him religiously on Facebook (careful what you post, Aaron!), loves to talk to him on the phone ("Hello, brat!"), cherishes Aaron's visits home and can hardly wait for our annual pilgrimages to Los Angeles. Of course, Aaron is always

amazed that Scott seems to find and meet as many celebrities in a week in LA as Aaron does in a year. Get used to it, Aaron!

Looking ahead, we will celebrate Scott's thirtieth birthday in August. Who knew he'd make it this far and be the force that he is? While he will always have physical limitations that require assistance from others, he has compensated with an equal set of emotive skills that will serve him well. He has already made his mark in this world and touched the hearts of so many people. There's little doubt he will continue to enlarge his sphere of influence. Paula, Aaron and I are honored to be a part of it.

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Beyond the Face is a Heart and NEW Wonder Wristbands!

CCA "Beyond the Face is a Heart" Wristbands: orange, lime, red and violet. Also available, the new Wonder "Choose Kind" wristband! All are available in Adult 8" or Youth 7"—each only \$1

sponsors needed for cher's family retreat!

In surveys CCA families have expressed to us that our retreat is the most important program we offer. Did you know it costs Children's Craniofacial Association approximately **\$100,000** to hold our Annual Family Retreat each June?!

Cher usually sponsors our pool party for the weekend event. From time to time we've had T-shirt sponsors. But, we are in need of more sponsors. If you know of anyone who might be interested in supporting this worthwhile program, please have them contact our office. Email contact@ccakids.com or call 800.535.3643.

Click on

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at ccakids.org

executive director, from page 1

magazine or newspaper. All of these are great ways to spread the word and hopefully foster acceptance of those with craniofacial conditions.

In 2012 a book was written that took the potential for awareness to a level beyond anything for which we could ever have hoped. That book is ***Wonder***, by **R.J. Palacio**. Since you are reading this newsletter, you more than likely have heard of *Wonder*, because CCA has been emailing, Tweeting, Facebooking and doing everything possible to promote the reading of this fabulous book.

The book is about Auggie Pullman, a fifth-grader, who has a craniofacial condition and until now has been home-schooled. But Auggie, who is an ordinary kid, with an extraordinary face, is about to become the new kid at Beecher Prep, where he will have to convince his new classmates to look beyond his face to see he is just like them.

Wonder first came to our attention through CCA Board Chair, **Dede Dankelson**. Dede heard about it and informed the

rest of the board and staff of its existence. When she read it she was blown away by the author's knowledge and the accuracy of her perspective and of Auggie's likeness to her own son, **Peter**, who has Goldenhar syndrome.

Gradually other board and staff members read the book and started spreading the word and getting it into the classrooms of their children and those of family and friends. We also found out that many schools and communities were already reading *Wonder*. In fact, so many teachers signed up for the #WONDERschools forum on Twitter that **Random House** organized a "Blog Tour" to share everything that was going on in classrooms.

In response to the interest in *Wonder*, Random House created the choosekind.tumblr.com website, where you can take the "Choose Kind" pledge. There is even a community read scheduled in California this spring in which one of CCA's kids, **Peter Dankelson**, son of Darin and Dede Dankelson, will participate. Other CCA efforts include selling the book and promoting it

on our all-new website at ccakids.org/wonder.html. Our page includes links to standing ovation videos students created just for CCA kids.

Early on it was very clear to us that CCA could be instrumental in helping get *Wonder* into the schools and keep the momentum of this book going, so we contacted Random House and developed a strategy to promote the book. We also created a packet of materials that will aid educators in teaching *Wonder*. The packet includes two of CCA's one-sheet overviews, "empowering children to cope with teasing" and "fostering tolerance: ways parents and kids can stand up to bullying," as well as an online resources guide and an invitation to connect with one of our very own CCAWonderKids (visit our [Wonder page](http://Wonder page at ccakids.org) at ccakids.org to download copies).

Our goal in 2013 is to get *Wonder* in the hands of students across the nation and to launch CCA's Choose Kind Challenge. In order to do that, we need your help. CCA has *Wonder* for sale and you can receive your

copy by calling the office at 800.535.3643 or by emailing CCA's Program Director at AReeves@CCAKids. We will enclose a teaching resource packet with your book order.

Please read the book and then share it—along with the information packet—with your child's school (teachers, librarians and principals are good places to start). Ask them to read the book and consider making it part of their curriculum. Some schools have selected *Wonder* for an entire middle-school read while others have incorporated it into their fourth- to seventh-grade reading programs.

Let's make 2013 the year of acceptance for all kids with facial differences! To borrow a quote from *Wonder*, "It's hard to blend in, when you were born to stand out."

Char Smith

CCA Executive Director

dallas holiday party

On December 8, CCA, together with **Dr. Jeffrey Fearon, David Genecov, Carlos Barcelo** and **Craig Hobar**, hosted its 23rd annual holiday party at **Southfork Ranch**, in Parker, TX. Around 500 attendees joined us for a morning full of fun!

Radio Disney was once again the entertainment, and everyone loved the fun, music and games. The parents had as much fun as the kids, especially during the dance contest. There was cake and punch as well as arts and crafts. The kiddos decorated their own cookies and picture frames, had their faces painted, and their pictures taken with the **Texas Rangers mascot, Captain**, and even had a chance to get up close and personal with some snakes! They were also able to see a real fire truck, thanks to the **Parker County fire department!**

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

Prizes included a gift card to the **Magic Time Machine, Cowboys Stadium Tour Vouchers** from the **Dallas Cowboys**, tickets to the **Dallas Zoo** and **Fort Worth Zoo**, signed merchandise from the **Texas Rangers**, beach bags and more! As always, the highlight of the party was the big guy from the North Pole, **Santa Claus**. Children took their pictures with Santa, and everyone went home with a keepsake photo and toy.

CCA would like to thank Southfork Ranch for hosting, as well as their wonderful staff! A huge thank you to our wonderful volunteers from the **Italian Club of Dallas, Tyler Hanson** and sponsor, **KLS Martin!**

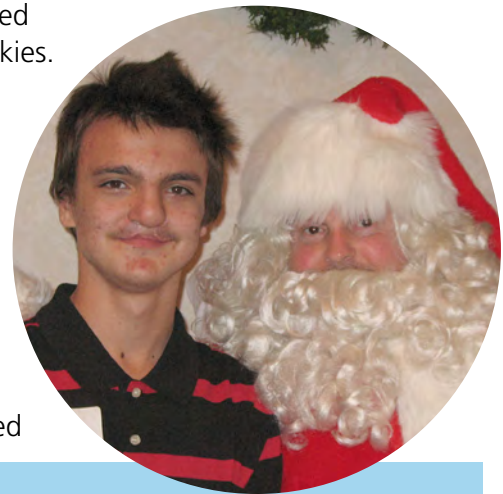


midwest holiday party

for pictures on his lap. Thanks, as always, to CCA Mom **Marla Verdone** from Janesville, WI, who helps each year and special thanks to **Karen Tamley** of Chicago, IL, for spreading the word about our party to more families!

The annual CCA Midwest Holiday Party was held December 1, 2012, at the **Parkway Chateau/Brat Stop** in Kenosha, WI. The group had a pizza lunch (or they ordered in from the Brat Stop) followed by brownies and cookies. Yum!

The usual holiday crafts and visiting kept everyone busy, but of course the highlight of the day was a visit from **Santa** and some early gifts handed out as everyone posed



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.



Left to right: Jill Patterson, Martin Woodall, Char Smith and Adam Carriker

grants

Martin Woodall and **Adam Carriker** of the **Woodall Foundation** joined us at our Dallas Holiday Party to present CCA with a check for **\$5,000** in grant funds to be used toward scholarships for the Chers' Annual Family Retreat. Thank you!

CCA was awarded a **\$6,000** partner grant by **Speedway Children's Charities** in Dallas. Funds will be used to produce and implement a school program to deter bullying and promote acceptance of differences.

GO PAPERLESS and view the newsletter online in FULL COLOR! Email AReeves@ccakids.com and let her know you want to **save the environment and save money for CCA.**

gingertown more good news

Gingertown was founded by David M. Schwarz Architects and began in 2006 in Washington D.C. as a one-of-a-kind holiday initiative that brings together leading area architects, designers, and architectural firms, along with a community of building enthusiasts of all ages to create a town made completely of gingerbread! And, it's all for a good cause. The firm has since duplicated this successful holiday event in both Nashville and Dallas. See Gingertown.org.

Gingertown Dallas brings together talent from more than 20 local design, engineering and construction firms to create a gingerbread town. Each handcrafted structure is auctioned to benefit a select children's charity.



september is craniofacial acceptance month

This year marks the ninth year CCA will observe September as Craniofacial Acceptance Month across the nation. Each year CCA families, friends, volunteers and related support groups band together to widen the circle of acceptance for individuals with facial differences. The goal is to create awareness of craniofacial differences and to get people to see that "beyond the face is a heart."

As part of the 9th Annual Craniofacial Acceptance Month, CCA will hold its **5th Annual National Picnic Day** on **September 7th** (or other date in September of your choice). CCA families across the nation will hold picnics giving them a chance to get together with other families in their areas, while promoting awareness in their communities.

If you would like to hold a picnic contact CCA Program Director Annie Reeves. CCA will invite all of the families in your area and help you organize your picnic.

In addition to raising awareness and acceptance, CCA is raising funds to support programs and services available to all individuals with facial differences and their families. Contact CCA Development Director, Jill Patterson for materials about this year's fundraising efforts.

We hope you will join this important effort! Please call 800.535.3643.

The 3rd annual Dallas event was held at NorthPark Center on November 27, 2012 and the creations were auctioned on December 1, 2012. **NorthPark Center**, one of America's premier shopping destinations, prides itself in its ongoing commitment to the community and serves as host site for an array of important initiatives throughout the year, including the annual Gingertown Dallas.

Children's Craniofacial Association is proud to have been chosen as beneficiary of the Gingertown Dallas proceeds and was recently presented with funds of **\$6,843** from this wonderful community effort. Thank you, on behalf of all our CCA Kids (like "[Gingertown Dallas](#)" on Facebook!)

more fundraising news



sydney raises funds for cca kids

by Sydney's mom, Jennifer

Sydney Rose Ford chose to raise donations for her favorite charity, CCA, instead of gifts for her 5th birthday July 23, 2012. Sydney and her friends had fun dressing up as fairies, swimming, and watching a clown magic show. She handed out CCA information packets and raised **over \$130**. CCA has helped Sydney travel to her surgeon in Boston for cleft lip and palate repair over 7 times since she was born and her family hopes to "continue raising money for such a wonderful organization."

whelan elementary school for cca

by Stella's mom, Chelsea

Stella Francis Chicarella was born February 2nd, 2010 with mild Hemifacial Microsomia, affecting the left side of her face. She is unable to see out of her left eye but that doesn't stop her from anything. She loves to sing, dance and do gymnastics. Most of all she loves her big sister **Callie**. Callie is in 3rd grade at **Dr. Joseph Whelan Elementary School**, located in North Providence, RI. During Craniofacial Acceptance Month, Whelan teachers and staff raised **\$150** for CCA Kids. Whelan Elementary School does amazing things for the community, always doing whatever they can for their students and their families.



moss haven elementary walk-a-thon

fellow students of **Molly Bono**, big sister of CCA kid, **Sadie**, visited our CCA office for more insight about craniofacial conditions as they were reading the book, *Wonder*. Each year, their school hosts a Walk-A-Thon for a cause that affects a member of the community. This year, students walked laps (the "Walk-A-Thon") during elective class periods and had an opportunity to wear pajamas or a hat to school in exchange for a donation to CCA! Each class also read a picture book about people looking different. A big thank you goes to **Coach Sharon Barnes**, the coordinator for the event, the **4th grade Destination Imagination team** who helped facilitate everything with the students, and the entire **Moss Haven Elementary** community of families! The effort garnered **over \$400** for CCA Kids.





be brody's angel

throughout the year, friends and family of CCA Kid, **Brody Lucas** contribute

toward the "Be Brody's Angel" effort to raise funds for all CCA Kids in Brody's name. This year **over \$1,200** came in, thanks in no small part to Brody's grandparents, **Ann and Don Lucas** and friends like **Bill Peck** and **Tracey Fisher**. CCA Mom, **Jennifer Lucas** also hosted a Pampered Chef party and the **Lucas kids** helped with CCA Wristband sales and donations of their own. Thank you Everyone!



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state assistance:

did you know that many states offer funding/ small grants to individuals with disabilities and their family members to attend advocacy, learning events and conferences? The **CCA Retreat qualifies** because of our educational symposium. If you would like more information regarding your state assistance program, please visit ccakids.org/state-funding.html

calendar of events

date	event	contact
2013		
Apr 17-18	2nd Annual Morgan Meck's Match Play Invitational Coto de Caza Country Club Coto de Caza, CA	BMecklenburg@redwoodsgroup.com
Apr 26	Texas Moms' All the Way for CCA Golf Tournament Battleground Golf Course Houston, TX	Becky White ledestiny@gmail.com
Jun 27-30	23rd Annual Cher's Family Retreat Orlando, FL	ARees@ccakids.com 214.570.9099 800.535.3643
September	9th Annual Craniofacial Acceptance Month Nationwide	ARees@ccakids.com 214.570.9099 800.535.3643
Sep 14	Seth's Stride Canton, OH	Stacy Horne stacykhorne@gmail.com
Sep 27	6th Annual Links of Love Golf Tournament Bear Creek Golf Club at DFW Airport Dallas, TX	JPatterson@ccakids.com 214.570.9099 800.535.3643

matching gifts

We encourage you to consider **maximizing the impact** of your donations through your company's Matching Gifts program. **Please contact your Human Resources department** to see if your company will match your donations to double your contributions for CCA!

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* Listed are all Monetary Donations through 4th quarter, 2012. We are extremely grateful for these and all other fees, purchases, fundraiser, cash and in-kind donations, not individually recorded here.

*MMM = Morgan Meck's Match Play

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

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registration is open for 2013 annual cher's family retreat June 27-June 30 in Orlando, FL

Please join us for an educational symposium,
pool party, ice cream social, dinner/dance and
much more! For more information,
please contact Annie Reeves,
ARees@ccakids.com
We hope to see you there!
Hurry! Registration ends May 24th.

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Ruth Anderson, in memory of Cynthia Safford Wills
Anonymous, in honor of Deena Coplin's birthday
Anonymous, in honor of Alice Athena Esparza
Anonymous, in honor of Joe Brooks' birthday wish
Anonymous, in honor of Meg Gray's birthday
Anonymous, in honor of Roy Dennis
Anonymous, in honor of Francis Smith's birthday
Anonymous, in honor of Nick Wiese
Anonymous, in memory of Cynthia Wills
Anonymous, in memory of Kevin Wilson
Terry Lynne Ausmus, in honor of Natalie Wardlaw and in memory of Cecelia Guerra
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Julie Baird, in honor of Annie Reeves' birthday

Mary & Robert Beck, in honor of Freddie Seitz
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Yael Blasberg, in honor of Annie Reeves' birthday
Bordonaro Family, in honor of Jill Patterson's birthday wish
Zach Bordonaro, in honor of Jill Patterson's birthday
Lisa Boyd, in memory of Jan M. Sentendrey
Veronica Boyd, for all the kids on Christmas Day
Cheryl Papciak-Brooks, in honor of Joe Brooks' birthday wish
Joe Brooks, in honor of Jill Patterson's birthday
Joe Brooks, in honor of Annie Reeves' birthday
Ann & William Burgin, in memory of Rick Dornier
Patsy Burt Jones, in honor of Annie Reeves' birthday
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Larry Carpenter, in honor of Cher at Christmas
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Charlene Smith, in honor of Francis Smith's birthday
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Up to \$1,000

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 Barefoot Books Sale / Deena Dyson with Kathleen Von Raesfield
 Joe Brooks' Birthday Wish on Facebook / Joe Brooks
 Cash cans /placed by Kim Rogers, Bradley, IL
 CD Sales / John Moulton
 Be Brody's Angel / Brody Lucas' Family Fundraising Effort
 Deena Coplin's Birthday Wish on Facebook / Deena Coplin
 Do Yoga, Do Good / Ananda Yoga, Justine Budhram
 Film Festival for CCA Kids / Nick Wiese & Cranberry Cinemas
 Nora Fleming Fundraising Effort / Nora Fleming & Friends
 Sydney's 5th Birthday / Sydney Rose Ford
 Meg Gray's Birthday Wish on Facebook / Meg Gray
 Indoor Flea Market / Anjolene Whaley
 Pete Dankelson's Fundraising Page / Firstgiving Online
 Garage Sale / Michelle Bridgins
 Moss Haven Elem Walk-a-thon / Sharon Barnes & 4th grade DI Team
 Pampered Chef Sale / Stacy Swihart
 Annie Reeves' Birthday Wish on Facebook / Annie Reeves
 Francis Smith's Birthday Wish on Facebook / Francis Smith
 Waco Picnic Funder / Carmen & Ron Mickley
 Whelan Elementary Funder / Teachers & Staff
 Wristband Sales for CCA / St. Thomas Aquinas College & Alie Cabo

\$1,000-\$5,000

Be Brody's Angel / Lucas Family
 CCA Chance Raffle / Annual Family Retreat Attendee Participants
 Griffin Davies' Fundraising Effort / Wristband Sales & Awareness
 Do Yoga, Do Good in honor of Nova Cox / Ananda Yoga, Justine Budhram
 Luke Bowen's Jammin' Jeans Week / Judy Kemler & Flower Mound HS Faculty
 Rick's Raffle / Established by Ann & Doug Burgin
 Sadie's Night / Bono Family with Lake Highlands High School Baseball Team
 Trevor's Trip To Triumph / Family of Trevor Lays

\$5,000 or more

Raegan's Rally / Ashley & Boz Daugherty
 Robbie's Haircut / Mike Wiese, Janis Macut & Retreat Attendee Participants
 Ryan's Road for CCA / Gulich Family

\$10,000 or more

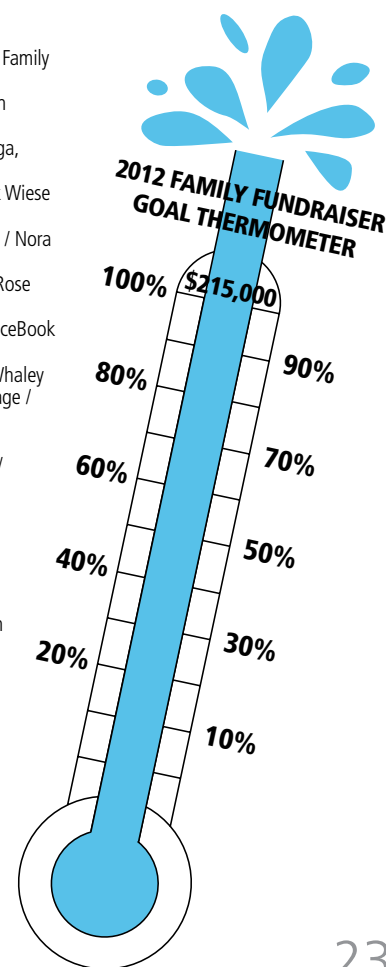
Chocolate Festival for CCA Kids / Chef Rick Chiavari in honor of Seth Swihart
 Pete's Oktoberfest / Dankelson Family

\$20,000 or more

Hartley Golf Outing / Hartley Company, Cambridge, OH

\$30,000 or more

Friends of Jeremy Golf Tournament / Dale Family
 Morgan Meck's Match Play Tournament for CCA / Mecklenburg Family



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Michael, Tiffany, Big Brother Devin and Keegan

Our 10-month-old son, **Keegan**, recently had surgery to correct metopic craniosynostosis. We live in a rural area in eastern Oregon, where seeing a specialist is

a three- to four-hour drive, especially in the winter time.

When we found out about Keegan's diagnosis, we knew it would be hard to afford the many trips for medical care, plus the lost pay from time off work during his surgery and recovery. After some research I found Children's Craniofacial Association, who helped us financially with travel, food and lodging. Also, their website has very helpful information and a list of certified care teams with experience in treating patients just like my son. Although I wasn't able to use a specialist on the list, I was able to ask a few of the specialists about recommendations.

My son bounced back after surgery fairly fast and is doing very well. I am so relieved we got him the medical care he needed to prevent any future damage, and it would not have been feasible without the generosity of CCA. They really took a load of pressure off by helping out financially and having such an educational website to use as a reference, and one day I will be in a position where I can pay it forward.

Michael, Tiffany, Devin and Keegan

