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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, medicalse, 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
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.
Hi, 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!
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.
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.

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.
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 900 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)

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.

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.

Finally, my standing ovation goes out to the following for their amazing acts of kindness...
• R.J. Palacio for writing Wonder

see board chair, page 8
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](http://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](http://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
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.
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!

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!
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.

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 preschool 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.
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 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.

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
On December 8, CCA, together with Drs. Jeffrey Fearon, David Genecov, Carlos Barcelo and Craig Hobart, 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!

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 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!

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.
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.

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)!

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.

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.
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.
Road Scholar is an asset-based motor freight company based out of Scranton, PA with terminals throughout the Northeastern United States. Their staff is waiting to provide you with the highest level of service. They represent their customers from the belief that: “Our Point of Delivery is Your Point of Sale.” If you are looking for custom freight solutions that save you money and service that exceeds your expectations, then give Road Scholar a call today at 800.542.2301, or visit their website, www.roadscholar.com. Be sure to request the CCA truck!

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!

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

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<th>Date</th>
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<tr>
<td>Apr 17-18</td>
<td>2nd Annual Morgan Meck’s Match Play Invitational</td>
<td><a href="mailto:BMecklenburg@redwoodsgroup.com">BMecklenburg@redwoodsgroup.com</a></td>
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<td>Coto de Caza Country Club</td>
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<td>Coto de Caza, CA</td>
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<td>Apr 26</td>
<td>Texas Moms’ All the Way for CCA Golf Tournament</td>
<td>Becky White</td>
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<td>Battleground Golf Course, CA</td>
<td><a href="mailto:ledestiny@gmail.com">ledestiny@gmail.com</a></td>
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<td>Houston, TX</td>
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<tr>
<td>Jun 27-30</td>
<td>23rd Annual Cher’s Family Retreat</td>
<td><a href="mailto:AReeves@ccakids.com">AReeves@ccakids.com</a></td>
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<td>Orlando, FL</td>
<td>214.570.9099</td>
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<td></td>
<td>800.535.3643</td>
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<tr>
<td>September</td>
<td>9th Annual Craniofacial Acceptance Month</td>
<td><a href="mailto:AReeves@ccakids.com">AReeves@ccakids.com</a></td>
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<td>Nationwide</td>
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<td>800.535.3643</td>
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<td>Sep 14</td>
<td>Seth’s Stride</td>
<td>Stacy Horne</td>
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<td>Canton, OH</td>
<td><a href="mailto:stacykhorne@gmail.com">stacykhorne@gmail.com</a></td>
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<tr>
<td>Sep 27</td>
<td>6th Annual Links of Love Golf Tournament</td>
<td><a href="mailto:JPatterson@ccakids.com">JPatterson@ccakids.com</a></td>
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<td></td>
<td>Bear Creek Golf Club at DFW Airport</td>
<td>214.570.9099</td>
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<td></td>
<td>Dallas, TX</td>
<td>800.535.3643</td>
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- Free pick-up
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*MMM – Morgan Meck’s Match Play

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

Extraordinary Fundraiser Sponsorships of $1,000 or more are also listed.

CFC (Combined Federal Campaign, federal-employee giving)
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, AReeves@ccakids.com

We hope to see you there!

Hurry! Registration ends May 24th.

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The Abilene Center for Birth Defects
The Abilene Center for Birth Defects

Memorials / In Honor Gifts

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Jennifer Anderson, in honor of Annie Reeves’ birthday

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Tate & April Gorman
Shelly & Dennis Green
Cheryl Gridley
Mark Hagan
Catherine Harper
Lisa Helseth
Christopher Hood
Clayton & Kathy Huk
Robert Kacer
Kim & Urban Koagedal
Bill Leary
Paul & Fran Leatherwood
Chris Lederer
Ann & Don Lucas
Mary Lytle
Doug & Janis Macut
Brandon Martin
David & Deborah Meeker
Robert & Margaret Mitchell
Joe & Allison Mossholder
Michael & Marti O'Brien
James O'Sullivan
Katharine Olsen
Matthew Osburn Family
Jana & Hugh Peace
Norma & H.W. Peace
James Reading
George Rodriguez
Randolph Schaefer
Fred & Rose Seitz
Ann Sickles
Amanda Smith
Joyce & Rodney Strickland
Joslyn Verona
Josh Warren
Jennifer Webber
Kenneth Wilson

C C A  S p o n s o r

($1,000 +)

David Armstrong
Kathy Berrier
Veronika Boyd
Andrew Bustillo
Chris Campbell
Michael Carr
Diana Critchlaw
Ann & Ari Deshe
Adam Driscoll
Denise Duby
M. Brian Evans
Jeffrey Fearn, MD
William C. Godfrey
Kirk Gregg
Tom & Donna Leonhardt
Molly & Robert Lytle
Darlene Manwaring
Ron Mietcic
Carl & Kathy Michaelsen II
Kevin O'Reilly
Greg & Jill Patterson
Paul R. Pokladnik
Robert & Karen Reader
Blair Salz
Michael & Shelly Sprague
Heather Svit
Joslyn Verona
Bradley Walsh
Mike & Rose Wiese
Sarah Zimmerman

M. Brian Evans
Jeffrey Fearn, MD
William C. Godfrey
Kirk Gregg
Tom & Donna Leonhardt
Molly & Robert Lytle
Darlene Manwaring
Ron Mietcic
Carl & Kathy Michaelsen II
Kevin O'Reilly
Greg & Jill Patterson
Paul R. Pokladnik
Robert & Karen Reader
Blair Salz
Michael & Shelly Sprague
Heather Svit
Joslyn Verona
Bradley Walsh
Mike & Rose Wiese
Sarah Zimmerman

Mary & Robert Beck, in honor of
Freddie Seitz
Kathy Berrier, in honor of the Mickley Family September CMAD Picnic Fundraising effort
Yael Blasberg, in honor of Annie Reeves’ birthday
Bordonaro Family, in honor of Jill Patterson’s birthday
Zach Bordonaro, in honor of Jill Patterson's birthday
Lisa Boyd, in honor of Jolan M. Sentendre
Veronica Boyd, for all the kids on Christmas Day
Cheryl Papiak-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 Jothi, in honor of Annie Reeves’ birthday
Jimmy & Beverly Butera, in honor of Jana & Hugh Peace
Lorrell Bush & Colleagues, in honor of Carole & Rob Barrat
Andrew Bustillo, in honor of Morgan Mecklenburg

C C A  P a t r o n

($52,500 +)

Maria Amelio
Anonymous
Dan & Denise Paulson
The Estate of Jean Pond
Charlene & John Smith
E.C. Stbyбер
Mike & Marty Willson
Joseph & Anne Zangie

C C A  B e n e f i c a r y

($5,000 +)

David Bresnan
George & Kristine Dale
Dede & Darin Dankelson
Bob & Paula Guzzo
Greg Luetkemeyer
John Mahoney
Thomas Gillingham

C C A  G u a r d i a n

($10,000 +)

Anonymous
Bill Mecklenburg & Christine Condon
Mecklenburg
The Estate of Andrew & Juanda Seventy

C C A  L e g a c y  S o c i e t y

Dede & Darin Dankelson
Joy & Rod Strickland

Rabbi Jonas & Chelly Goldberg, in honor of Deena Coplin’s birthday
Jim & Kelli Griffin, in honor of Annie Reeves’ birthday
Joseph & Patricia Gwozdz, in honor of Kate Rogers
Jackie Halpin-Osteen, in honor of John Gorman
Allie Hart, in honor of Chase Ingram
Arlein Heirty, in memory of Eileen Herson
Jim & Arlein Heirty, in memory of Ann Alexander
Jim & Arlein Heirty, in memory of Milly Ask
Jim & Arlein Heirty, in memory of Jean Johnson
Jim & Arlein Heirty, in memory of Sharon Minor
Jim & Arlein Heirty, in memory of Mildred
Jim & Arlein Heirty, in memory of Ann Marie Sansone
Jim & Arlein Heirty, in memory of Dorothy Zelanko
Beth Higgins, in honor of Kim Grant
Beth Higgins, in honor of Mary Clarke
The Hitchcock Company, in honor of Kristine Dale
Joyce & Thomas Hoffman, in memory of Cynthia Wills
Christopher Hood, in honor of Trevor Layn
Andrea Horsch, in memory of Stephen Haycraft
Kristin Houston, in honor of Deena Coplin’s birthday
John & Margaret Ingram, in honor of The Ingram Family
Abigail Jaffe, in honor of Jen and Adam Kellogg
Rhonda Jones, in honor of Luke Bowen
Berlin Kaplan, in honor of Deena Coplin’s birthday
Luann Kines, in honor of Joe Brooks’ birthday wish
Kathryn J. Kitchens, in honor of Grandpa
Briar Douglas
V.V. Klink, in honor of Sarah Mickey
Stefanie & Richard Knauss, in memory of Cynthia Wills
Charlotte Kowitch, in memory of Cynthia Wills
Kerry Reed Lawson, in honor of Joe Brooks’ birthday wish
Duane Long, in honor of Casey Deakin’s birthday wish
Sylvie & John Loving, in honor of Ryan Holliday
Ann & Don Lucas, in honor of Brody Lucas, “Be Brody’s Angel”
Molly & Bob Lytle, in honor of Avery Betty Majors, in memory of Cynthia Wills
Sanford & Mildred Marateck, in memory of Cynthia Wills
Kathleen Martin, in memory of Cynthia Wills
Kimberly Martin, in memory of Ellery Walker
Susan Martin, in memory of Ellery Walker
Karen Clark McBride, in honor of Joe Brooks’ birthday
Ellen McPadden, in honor of Jeremy Dale
Ron Micetic, in honor of John Gorman
Constance Abrams
Ron Micetic, in honor of Joe Brooks’ birthday wish
Deana Davalla, in honor of Printer Chicks
M. Brian Evans, in honor of Erica Mossholder
Richard Faulkner, in honor of Constance Abrams
Richard Faulkner, in honor of Dale Gorman
Carl & Julia Feichtel, in memory of Cynthia Wills
Anna Fowler, in honor of her 2 sons, born with clefts
Mary Kay & Thomas Gardin, in memory of Natalie Wardlaw

Laurie Monnier, in honor of Jeremy Dale
Erica Mossholder, in honor of Meg Gray’s birthday
Gray’s birthday
John Mouton, in memory of Carol Mouton
Hykel & Amanuol Mulugata, in memory of Amanda from Lapa, MT
Robert & Diane Nagle, in memory of Cynthia Wills
Ann Nesbit, in honor of Megan Cronin and family
Mary Lou Onew, in memory of Cynthia Wills
Susanne Palombo, in memory of Cynthia Wills
Jill & Gregg Patterson, in honor of Joe Brooks’ birthday wish
Jill & Gregg Patterson, in honor of Melanie & Chris Pipkins nuptials
Jana & Hugh Peace, in memory of Jimmy & Beverly Butera
Jana Peace, in memory of Annie Reeves’ birthday
Michael Peloquin, in honor of Joe Brooks’ birthday
Tara Pfeifer, in honor of Luke Bowen
Thomas & Carol Porter, in honor of Sydney Rose Ford
Colleen & Walt Reinert, in honor of Annie Reeves’ birthday
Jodi Reintert, in honor of Annie Reeves’ birthday
Nicole Reinert Sailer, in honor of Annie Reeves’ birthday
Mary Carroll Roche, in memory of the Ingram Family
Marjorie Rubacky, in memory of Cynthia Wills
Rose Setz, in honor of Joe Brooks’ birthday
Rose Setz, in honor of Meg Gray’s birthday
E.B. Sheinbaum, in memory of Cynthia Wills
Dale Shepard, in memory of Megan Cronin
Ray & Laurie Sherrod, in honor of Annie Reeves’ birthday
Christine Sikes, in honor of Casey Deakin’s birthday
Paul & Denise Silverman, in memory of Cynthia Wills
Charlene Smith, in honor of Joe Brooks’ birthday
Chuck Smith, in honor of Ron Micetic
Chuck Smith, in honor of Jill Patterson’s birthday
Charlene Smith, in honor of Francis Smith’s birthday
Thelma Kathleen Smith, in honor of Meg Gray’s birthday
Ann & Michael Steffen, in memory of Kevin Wilson
John Steffen, in memory of Kevin Wilson
Michael & Ann Steffen, in memory of Kevin Wilson
Eleanor Strong, in honor of the 50th anniversary of M/M George Lesko, in memory of David Temple
Lisa Swan, in honor of Luke Bowen
Ann Talcott, in memory of Cynthia Wills
Diana Vallone, in memory of Cynthia Wills
Priscilla G. Voss in honor of the work of the Mecklenburgs
Louis & Francelle Ward, in honor of Brisa Dougan
Jennifer Webber, in honor of Madelyn Webber
Corporate/ Foundation Gifts

CCA Corporate/ Foundation Friends up to $1,000

A.J. Miller Mechanical Inc. for Pete’s Oktoberfest
Ables Electrical
Afghans & Accents for Ryan’s Road
American Charities funds management
American Express Charitable Fund (employee giving)
American Legion Knowles Doyl
AT&T (United Way Employee Giving Campaign)
BC Restaurant Group for the Chocolate Festival
Bank of America (United Way Employee Giving Campaign)
Bank of America (Matching Gifts from 2012 North Texas Giving Day)
Beer Family Insurance Agency, Inc. for Trevor’s Trip to Triumph
Ben E. Keith Company for Links of Love
Best Buy Co., Inc.
Brown & Brown of Florida, Inc. for the Chocolate Festival
Cambridge Chapter Women Moose
Cameron Manufacturing & Desig
Chemung Canal Trust Company for Friends of Jeremy
Chemung Valley Veterinary Clinic for Friends of Jeremy
Columbia Gulf Transmission Co. (employee matched gifts)
Complete Security Systems for Trevor’s Trip to Triumph
Coming Credit Union for Friends of Jeremy
Corning Dental Associates RLLP for Friends of Jeremy
Couser for Ryan’s Road
Crowley Family Dentistry
CT Morgan Inc. for Raegan’s Rally
Cycles at 117 LLC for Trevor’s Trip to Triumph
DBK of Chemung, Inc. for Friends of Jeremy
Dandy Mini Marts, Inc. for Ryan’s Road
Dell Employee Giving / Matching through "Your Cause, LLC"
Dignity Health
Directed Technologies
Down Syndrome Information Network
Dr. Joseph Wheelan School (Wheelan Elementary Fund)
Dr. J’s Inc. for Trevor’s Trip to Triumph
Dunning Motor Sales for Raegan’s Rally
The Elena Melius Foundation
Eliminator Performance Products for Pete’s Oktoberfest
Emerald Isle LLC for Pete’s Oktoberfest
Foundation
Funding Factory
Gym Kids for the Chocolate Festival
Hargrove Oil Company, LLC
Harley-Davidson of Long Branch for Trevor’s Trip to Triumph
Heart of Illinois United Way, Inc.
Hudson & Marshall, LLC for Links of Love
Huron Valley State Bank for Pete’s Oktoberfest
Interludes
IBI Employee Services Center (employee giving)
James Benedict Trucking LLC for Rick’s Raffle
Jay C. Service Inc.
Joan’s Pooch Parlor for Trevor’s Trip to Triumph
Lee Law Offices
KRP Trucking & Excavating for Ryan’s Road
Kent’s Service Center for Ryan’s Road
Keyport Matalawan Elks #2030 LGCCC for Trevor’s Trip to Triumph
Kidder County Public School for Mrs. Heier’s Jr.-High Family Consumer Science Class Bake Sale
Kleen 1, LLC for the Chocolate Festival
Knights of Columbus St. Lawrence for Griffin Davies’ Fundraising effort
Last Man Standing Club 2009
Lee Law Offices
Lindenhurst UFSD for Lindenhurst H.S.
CCA Wristband Sale
MacDonell Associates for Pete’s Oktoberfest
Mario’s Cleaning Services, Inc. for the Chocolate Festival
Mark J. Gordon Foundation for the Chocolate Festival
The June and Cecile McDole Charitable Fund for Pete’s Oktoberfest
Olga & David Melin Foundation
Mengel, Metzger, Barr & Co. LLP for Friends of Jeremy
Mesquite Trail Drivess Assn for the Mason Leibman fundraiser
Metic Insurance Services
Microsoft Employee Giving Matching Gifts Program
Minier Brothers, Inc. for Ryan’s Road MissionFusion (Ebay, directed donations thru percentages of sales)
New York Life Insurance (Employee Giving)
Northside Mini Cleaners, Inc. for the Chocolate Festival
Northpark Presbyterian Day School for Sadie Bono Night
Northrup Grumman Employee Giving Organizations for the So. Tier for Ryan’s Road & Friends of Jeremy
PASCO
PJE Battery, Inc. for Ryan’s Road FWC
Paramount, Inc. for Friends of Jeremy
Parsons Collision Repair for Raegan’s Rally
Petroleum Women’s Club
Pfizer (United Way Campaign employee giving program)
PiPower Sports LLC for Trevor’s Trip to Triumph
Prudential Foundation (matched gift of Diana Critchlow)
Prudential Foundation (employee giving)
Random House, Inc. (employee matched gifts)
Rowe Woodworking Studio for Friends of Jeremy
Ruby Tuesday for Friends of Jeremy
SCR Design, Inc. for Pete’s Oktoberfest
Safeway, Inc. (purchases percentage incentives)
St. Thomas Aquinas College for Ali Cobo’s Wristband Fundraiser
Sarah Hall Productions
Security & Investigative Services, Inc. for the Chocolate Festival
Senu for Friends of Jeremy
Skyway Precision Inc. for Pete’s Oktoberfest
Slavin Construction for Friends of Jeremy
Spotmaster of South Florida, Inc. for the Chocolate Festival
Steve’s Discount Muffler
Swan & Sons-Morsos
Talamans Energy for Friends of Jeremy
TheaPro, LLC for Raegan’s Rally
Thompson, Coe, Cousins & Irons, LLP Time, Inc.
Tobacco Special Racing for Raegan’s Rally
Trust for Quest & USPS (employee giving)
Turnberry Ocean Colony Master Assoc. for the Chocolate Festival
The Vantage Group LTD for the Chocolate Festival
United Way of Greater Milwaukee (donor-directed donations)
United Way of Greater Philadelphia (donor-directed donations)
United Way of Natural Capital Area (donor-directed donations)
United Way of the Southern Tier (donor-directed donations)
United Way of Tarrant County (Bell Helicopter Employee Giving)
VFW Post 692
VA Home care LLC for Trevor’s Trip to Triumph
Vonnegut Federal Credit Union for Friends of Jeremy
Wiegand Heating and Cooling for Griffin Davies’ Fundraising effort
X-gen Pharmaceuticals Inc. for Friends of Jeremy
Xtreme Machines for Trevor’s Trip to Triumph
Your Cause, LLC (Dell Employee Giving)

CCA Corporate/ Foundation Sponsors
$1,000-$5,000

BP Corporation of North America, Inc. (toward the Harley Company fundraising effort)
Bristol-Myers Squibb Foundation (Employee Matched Giving)
The Brotman Foundation
Car Inc. Trust / Charitable Auto Resources (Proceeds from Auto Donations by supporters)
Consolidated Sales and Engineering by Mike Wies
Children’s Medical Charities CFC 2008
Consolidated Sales and Engineering
Corning Beagle Club for Friends of Jeremy
Dartmouth-Hitchcock Foundation
E. C. Styerberg Foundation, Inc.
Encana Natural Gas / Employee Giving / Matched Gifts
Exchange Club of Lake Highlands
The Max and Victoria Dreyfus Foundation
Go Realty
Guy Carpenter & Company for MMM* Hardinge Inc, for Friends of Jeremy
The Hitchcock Foundation
Horizon Solutions LLC for Ryan’s Road Jenkins Gunn Foundation
KLS Martin L.P.
Kohl’s
Metal Parts & Equipment Co. for Pete’s Oktoberfest
Metic Insurance Service for Links of Love
Michael Klein Foundation for the Chocolate Festival
Orange County United Way / CFC (Directed Donation for MMM*)
Partner Reinsurance Co. of US for MMM*

The David M. Schwarz Architects Foundation
Simmons Rockwell for Friends of Jeremy
E. C. Styerberg Foundation, Inc.
Vivo Brothers

CCA Corporate/ Foundation Partners
$5,000-$10,000

American International Group for MMM*
The Chattoos Foundation
Char Charitable Foundation
Lexington Insurance Company for MMM*
GMI, Inc. for MMM*
The Redwoods Group for MMM*
Speedway Children’s Charities
Triangle Foundation
Martin Woodall Foundation, Inc.

CCA Corporate/ Foundation Leaders
$10,000 or more

B.B. Owen Trust
The Hartley Company

Funding Events & Other Efforts

Up to $1,000

Bake Sale / Kidder County Public School / Mrs. Heier’s Jr.-High Family Consumer Science Class
Barefoot Books Sale / Deana Dyson with Kathleen Von Raesfeld
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
Ben E. Keith Company for Links of Love
Chef Rick Chiavari in honor of Seth Sullivan
Pet’s Oktoberfest / Danberson Family

$20,000 or more

Morgan Meck’s Match Play

$30,000 or more

Friends of Jeremy Golf Tournament / Dale family

$5,000 or more

Be Brody’s Angel / Lucas Family
CCA Chance Raffle / Annual Family
Retreat Attendee Participants
Griffin Davies’ Fundraising Effort / Wriskband Sales / Awareness
Do Yoga, Do Good in honor of Nova Cox / Ananda Yoga, Justine Budhram
Luke Wambier’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 Lay

$10,000 or more

Chocolate Festival for CCA Kids / Chef Rick Chiavari in honor of Seth Sullivan
PETE’S OKTOBERFEST / Danberson 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
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