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message from the executive director

Individually we are rare, but together we are strong.

This is the tagline for Rare Disease Day, which the world celebrates every February 28. We celebrate this day because one in 10 Americans live with a rare disease or disorder, and 50 percent of those patients are children.

“Celebrate” may seem an odd word to use for recognizing this day, but we use it because we are celebrating the fact that we can travel this difficult road *together*. We are not alone in our moments of despair, and we are bound by the

thankful for crouzon syndrome

By Ashley Rhodes

I grew up with a moderate case of Crouzon syndrome. It was both my curse and my blessing. I thought once I finished having all my surgeries, grew up and became an adult that the syndrome would be behind me.

I was wrong. What I found out is it is always with you and is always a part of you. It shapes you and how you see the world. What I once hated, feared and could not wait to get rid of, I am now so very blessed by, grateful for and I cannot imagine my life without it.

I was raised in Kentucky, the middle of three kids in a middle-class family. I was the only person in my family with the syndrome. A spontaneous mutation is what it is called when you are the first person in your family to get

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ccakid



meet delaney
cunha

five-year-old **Delaney Cunha** is only a Kindergartener, but she is one busy girl. She really likes school, where she gets to meet new friends and play with them on the playground. Her favorite subjects are art and recess, and she loves riding the bus to school.

After school, Delaney goes to Extreme Youth Sports. She has the chance to try a lot of different activities like karate and dance. Over winter break, all her grandparents came to her house, which she enjoyed. She also went to Busch Gardens and had a super-fun time, especially climbing in the big treehouse.

In her spare time, you may find Delaney painting pretty pictures, cooking or baking something yummy, or singing or dancing to songs from *Frozen*, *Doc McStuffins*, or anything by Taylor Swift. Or she'll be reading an *Amelia Bedelia*, *Pinkalicious*, *Curious George* or *Sofia the First* book.

Her favorite movies at the moment are *Tangled*, *Despicable Me*, *Minions*, and *The Little Mermaid 1 and 2*. As for TV, she loves just about anything on Disney Junior, including *Mickey*

and *the Roadster Racers*, *Elana from Avalor*, *Doc McStuffins*, and *Sofia the First*.

Delaney has plans for the summer. She's headed to Boston for appointments and to visit her family, plus she's headed to Virginia and Washington, DC, for the CCA Retreat! She also loves going to Orlando and Disney World for vacation, too.

Her first retreat was last year in Fort Lauderdale, and she had so much fun hanging out at the pool, dancing the night away on Saturday, and meeting new friends. She enjoyed the entire weekend, and so did her mommy and daddy. They are counting the days until this summer's retreat!

Delaney was born with Pfeiffer syndrome. Even though she is only five, she has some practical advice for other kids going through something similar: "Listen to your doctor and nurse, and tell someone if something is bothering you." *Well said, Delaney!*



Delaney with parents
Steve and Kelly

ccateen

meet alyssa rieger

my name is **Alyssa Rieger**. I am 14 years old and I am from New Jersey. I was born with Lambdoidal Craniosynostosis. Since my diagnosis, I have had six surgeries for my condition, including two cranial vault reconstructions and one frontal orbital advancement. I had my latest surgery on March 30.

I love to bowl, and I won a state tournament that led me to a national tournament in Chicago when I was just 12 years old. I also enjoy listening to music. My favorite artist is Selena Gomez. After my fifth surgery, I got to meet her at the Children's Hospital of Philadelphia. My favorite TV show is *The Vampire Diaries*.

I have an older sister, **Dayna**, and a younger brother, **Tyler**. They have

both been very supportive of everything that I have to go through, even though it is hard on them too.

When I am older, I want to work with children. I enjoy playing with and teaching toddlers. They are so much fun. I plan to teach kids early in life that bullying is not nice.

My first retreat was in 2016. It was one of the best experiences of my life. I met kids who were going through what I was, when I had previously thought I was all alone. This made me feel better about myself and made me feel good to know that my family and I had support all over. I can't wait for the next retreat to see old friends and make new ones.



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www.ccakids.org/matching-companies.html



my name is **Dayna Rieger** and I am 15 years old. I'm a sophomore in high school and am in band, which keeps me very busy, but I love it. I play the marimba and the piano extremely well.

This summer I will be traveling with the Jersey Surf Drum Corps, this is just the beginning of all that I wish to accomplish. This opportunity will bring me to many cities and states this summer to perform.

Music is my greatest passion. My dream is to get a degree in music education and then go to law school. I'm working hard for the grades it takes to achieve this goal.

My friends help me with everything, and they have really been there to support me through everything my sister has gone through. I spend all my time with them, and they're my

favorite people to be around. I love keeping in touch with friends from retreat and am sad I will miss being there with my family this year.

Living with a sister with Craniosynostosis has been hard but can also be cool because I always have a story to tell. I went to my first retreat in Ft. Lauderdale. It has helped me because it exposed me to other people with other conditions besides Craniosynostosis. I met amazing people and other siblings whom I could relate to. I was afraid that I was going to feel left out, but I ended up, of course, being just fine.

meet dayna and tyler rieger

my name is **Tyler Rieger**. I am 10 years old and I am in fifth grade. My favorite things to do are watch YouTube videos and play games.

When I am bored, I like to hang out with my friends and family, and sometimes we play games. I also like to watch and play Pokémon. I am in band and play the xylophone. I also sing in our choir in school. I'm very good at math and I get good grades.

I love my family and friends very much and spend as much time with them as I can. That is

why retreat is so fun. I get to spend time with my family and I make a lot of friends. I really enjoy going and meeting new people, with new conditions, and from new places that I can hear all about.

I feel special being the sibling of a CranioKid. My sister shows me how important it is to be nice to everyone and teaches me how to be strong through the worst of times. I hope that I can help teach others everything I have learned by being Alyssa's brother.



ccasupersibs

gingertown dallas: a sweet holiday tradition

CCA is honored to be the beneficiary of the annual Gingertown Dallas event at NorthPark Center once again. The 2016 event marks our 7th year as the recipient charity, and the theme this year was “London.” The intricate creations were displayed on the first floor of the luxury shopping center, so visitors could enjoy it as part of the art experience that NorthPark offers. Each year, teams of local architects, engineers, and design professionals build



PHOTO CREDITS: NORTHPARK CENTER



a stunning miniature town out of candies, sweets, treats and, of course, gingerbread!

The Gingertown event was established in 2006 by **David M. Schwarz Architects** in Washington, DC, and started in Dallas in 2010. We are so grateful for this unique and fun event that encourages visitors to donate to CCA

when they view the display. We visited the exhibit and captured some fun photos and enjoyed seeing all the kids checking out the tasty town and finding their favorite buildings and recognizing London landmarks. Even Santa picked his favorite while visiting **NorthPark**—the London Eye Ferris Wheel!

This delightful event raised **\$20,494** for CCA, and we are so grateful to everyone who participated and donated. We extend our special thanks to **RJ Reissig, Project Manager of NorthPark Management; Pamela**

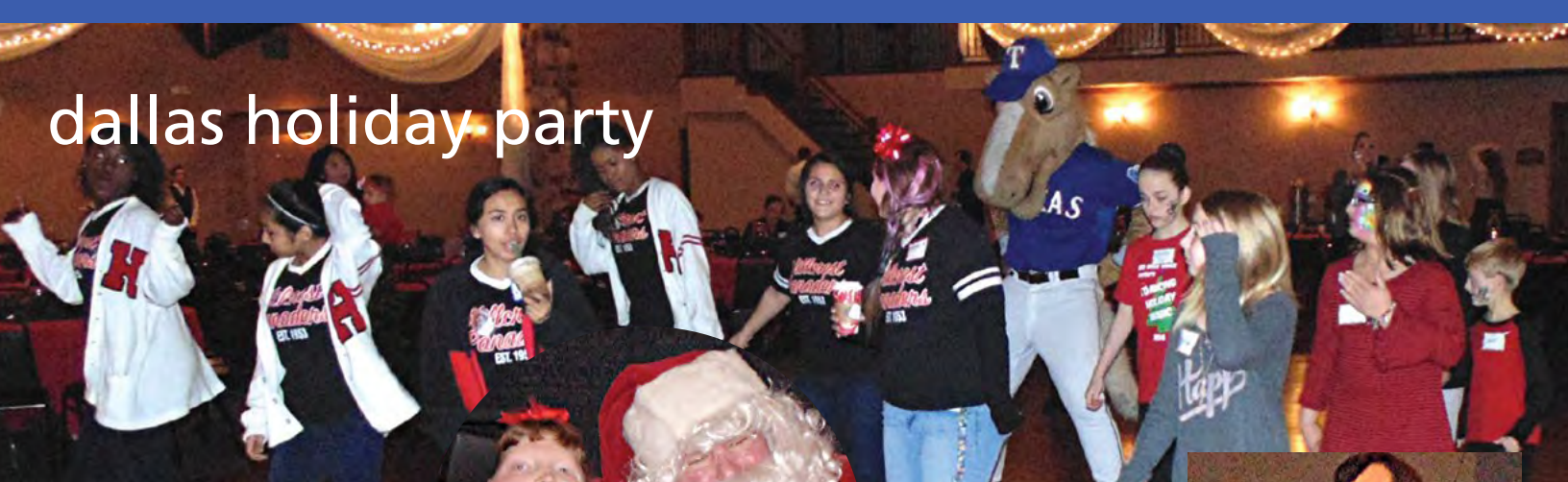
Mitchell, Isabel O’Neill, and Shelby Foster of NorthPark Center; The David M. Schwarz Architects Charitable Foundation, and the Gingertown Dallas construction crew!

NorthPark Gingertown Dallas-2016 Participants & Donors:

Nunzio DeSantis
Mark E. Brohard
William R. Carroll
Mark & Rebecca Lowry
HKS Architects
Brazos Restoration & Waterproofing Inc.
Droese Raney Architecture, Inc.
Kpost Roofing
A&A Concrete Sawing
Access By Design, Inc.
Kpost Company
WJE Associates
Boka Powell, Inc.
Walter P. Moore and Associates, Inc.
Datum Engineers, Inc.
Merriman Associates/Architects, Inc.

HCBeck, Ltd.
GFF Architects, Inc.
Omniplan Incorporated
Blum Consulting Engineers, Inc.
Nedderman & Associates Inc.
The Whiting-Turner Contracting Company
Pacheco Koch
Morrison, Dilworth & Walls
CallisonRTKL Associates Inc.
Gensler
Page
The Theodore Restaurant
Mrs. Fields Cookies
Corner Bakery
Chick-fil-a
Fuzziwig’s Candy Factory

dallas holiday party



CCA, together with **Dr. Jeffrey Fearon, David Genecov and Carlos Barcelo**, hosted its 27th annual holiday party at Southfork Ranch, in Parker, TX. The much-anticipated event was held Saturday, December 10, and around 350 attendees joined us for a morning full of fun!

DJ Joe Mir was the entertainment, and everyone really enjoyed participating in the fun, music and games. Parents had just as much fun as the kids, especially during the wrap-your-mom-and-dad dance competition. **Captain** from the **Texas Rangers** also joined in the fun and danced with our kiddos!

Everyone enjoyed cake, punch and other goodies as well as arts and crafts. The kids made crafts, and some dads decorated their own extra-large cookie. Some even had their faces painted! 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 tickets to the **Dallas Zoo**, a gift card to the **Magic Time Machine**, passes to **Amazing Jake's** and more! Each year, the highlight of the party is the big guy from the North Pole, **Santa Claus**, and this year was no different. Children had their pictures taken with Santa, and everyone went home with a toy and keepsake photo.

CCA would like to thank **Southfork Ranch** for hosting as well as their amazing staff! Huge thanks go out to our wonderful volunteers from the **Italian Club of Dallas, Gerardo Seltzer, Clif Bar & Company, Tyler Hanson, KLS Martin, Medical City Children's Hospital of Dallas, Dr. Kenneth Salyer and World Craniofacial Foundation.**





midwest holiday gathering

Santa also stopped by at the **Parkway Chateau** in Kenosha, Wisconsin, to visit with CCA kids and families who gathered for a pizza lunch, crafts and visiting. Regulars joined a few new families, and lots of networking and sharing made the afternoon successful and fun.

Special guest, **Peggy Lightfoot**, came to meet the kids and hand out gifts, representing **Cher Crew** fans who raised funds during Cher's birthday month last May to care for our kids. Our friend **Christian Scalise** also came to present CCA with

a photo of his latest poster pic taken with a celebrity, this time none other than our own spokesperson, Cher!

Kids young and old sat on Santa's knee for photos and to tell him what they wanted for Christmas, and each received a bag of gifts to tide them over until his official visit, compliments of the **Jaskowiak family** and their **Project Angel Eyes NFP**. Big thanks to them, Santa, and all those who attended, brought snacks or helped in any way! A good time was had by all. See you next year!



THIS ISSUE OF THE
CCA NETWORK IS DEDICATED
IN MEMORY OF
**EMMANUEL GUTIERREZ,
JAXSON HOFFMAN,
AND MARISA VAN TIL**

alexa's



campaign

Alexa Rast made a pledge at the 2016 Retreat to raise funds for Retreat Scholarships for 2017. We created her Facebook page called, Alexa's CCA Give Back and our family surpassed our goal by raising just **over \$5,000**.

We held multiple fundraisers, including a lemonade stand, casino bus trip, online auction, a GoFundMe page, and jewelry and food parties. Also, Alexa and her sister, Hadley, collected donations instead of birthday gifts. We have been blessed by the friendships we have made through CCA and we know the importance of CCA retreats. We are excited to give back and our next big project is our golf tournament in Modesto, CA, on May 20, 2017. Please join us in FUNdraising for CCA retreat scholarships!



change
the
world
with
wonder

Thanks to the incredible dedication and hard work of CCA volunteer **Carolyn Johnson**, CCA now has full-scale lesson plans available for middle-grade teachers wanting to use *Wonder* in their classroom curriculum.

This is what Carolyn says of the project:

I wrote this Curriculum with Classroom Guide on behalf of CCA, and it is intended to accompany **R.J. Palacio's** award-winning children's book, *Wonder*. I am an instructional consultant with 45 years of educational experience as a classroom teacher, reading specialist, trainer and facilitator. Most recently, I serve as an independent consultant providing training and technical assistance to schools to assist with student achievement.

The lessons were written and correlated to the National Common Core Curriculum standards and the Texas Essential Knowledge and Skills, since I am a Texas-based educator. These correlations are merely suggested skills, and, certainly, the classroom teacher can make determinations as to other skills that may be addressed.

The three-dimensional graphic organizers, or "foldables," used as performance assessments were inspired by the work of **Dinah Zike** and are used with her permission. Both CCA and I offer our sincere gratitude to Dinah. (See more of her work at www.dinah.com.) We also offer our sincere thanks to **Jennifer Johnson**, my daughter, for the design of the lesson plans. See more of her work at JenniferJohnsonArt.com.

Finally, sincerest thanks to R.J. Palacio for her brilliantly written novel and for the impact that it is having on adults and children everywhere. As a parent of a child born with a facial difference, I can tell you that as more people approach the world with kindness in their hearts, the weight of being different and the associated burdens will be greatly lightened. This poignant little book is a great reminder to all of us to "Choose Kind."

it made a difference to *that one*



In honor of **Char Smith's** 27 years as Executive Director, CCA started the Starfish Scholarship Fund based on the parable, "The Star Thrower."

Once upon a time, there was an old man who used to go to the ocean to do his writing. He had a habit of walking on the beach every morning before he began his work. Early one morning, he was walking along the shore after a big storm had passed and found the vast beach littered with starfish as far as the eye could see, stretching in both directions.

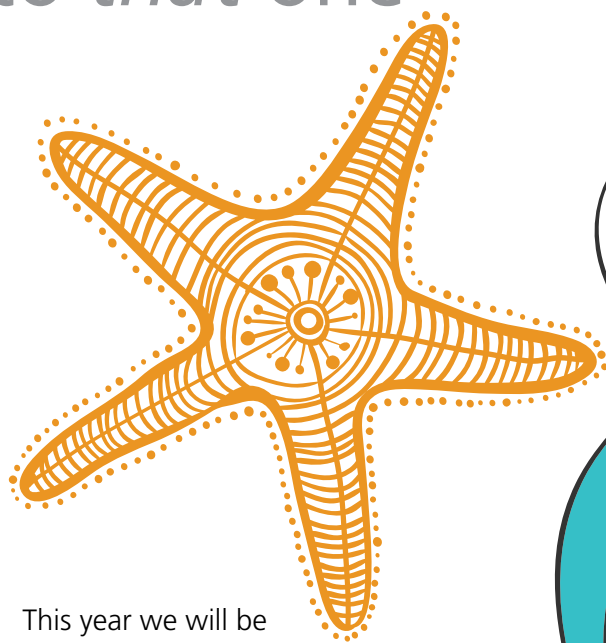
Off in the distance, the old man noticed a small boy approaching. As the boy walked, he paused every so often and as he grew closer, the man could see that he was occasionally bending down to pick up an object and throw it into the sea. The

boy came closer still and the man called out, "Good morning! May I ask what it is that you are doing?"

The young boy paused, looked up, and replied "Throwing starfish into the ocean. The tide has washed them up onto the beach, and they can't return to the sea by themselves," the youth replied. "When the sun gets high, they will die, unless I throw them back into the water.

The old man replied, "But there must be tens of thousands of starfish on this beach. I'm afraid you won't really be able to make much of a difference."

The boy bent down, picked up yet another starfish and threw it as far as he could into the ocean. Then he turned, smiled and said, "It made a difference to that one!"



This year we will be adding \$27,000 to our retreat scholarship fund for families to attend the Retreat. The hope is that we can offer these scholarships to new families and families who have been unable to attend for many years but live in the region of the event. We are awarding these scholarships based on applications and nominations.

If you would like to participate, please know that you too can make a difference. We are asking individuals, workplaces, teams, neighborhoods, schools and churches to come together and fund a named Starfish Scholarship. We encourage you to work together to raise the \$1,000 it takes to sponsor a child. You have until May 15, 2017, to pledge to sponsor an attendee for this year's retreat.



3 cheers

for volunteers!



call from a family during your child's surgery, visit: bit.ly/ccasurgery.

Mavis is the proud grandma to **Emily**, 25 and **Danny**, 23. She is one of the most generous, caring, friendly, and talkative people you'll meet! She loves to sew, crochet, knit, bake and volunteer. When I asked if she'd like to donate some blankets to CCA She said "I'd love to! How many would they like!" Mavis says that CCA means a lot to her because it has been special to her granddaughter Emily and her family. Emily has Treacher Collins syndrome, and Mavis loves to see retreat photos of Emily with her "mini me" TCS friends!

Thank you, **Denise Paulson** and **Mavis Lura** for the incredible donation of handmade blankets for our care packages! These comfy and cozy blankets mean so much to the kids who receive them, and it is all the more special when they are made with so much love. Thank you so much, Denise and Mavis for sharing your hearts with our CCA Kids! If you would like to sign up for a care package, get well card, or



donor in the spotlight

Thank you, **Christian Scalise!**

Christian is the founder/CEO of **Country Stars Central** and **Showbiz Deluxe**, two websites dedicated to covering celebrity and music news and interviews. Christian first learned about CCA because of his Midwest (Wisconsin) connection with buddies **Jill Patterson** and her son, **Robbie Gorecki**. Initially he used his websites to run advertisements for CCA to help raise awareness and funds during Craniofacial Acceptance Month. He then met some of the younger CCA Kids, which only increased his desire to spread the word about CCA.

Now, Christian continues to bring along the CCA poster on his exciting celebrity interviews and asks each famous face to pose with it to further spread the message of acceptance and hope. Christian has also secured valuable donations of concert tickets and meet-and-greets, which he generously donates to CCA to auction on CharityBuzz.com. His hard work has resulted in hundreds of dollars for CCA, a true gift for which we are so grateful. Read our exclusive interview with Christian, and see more of his celebrity photos, on our blog, CCAKidsBlog.org.

Thank you, Christian, for using your energy, enthusiasm, and celebrity sway for CCA!



executive director, from page 1

often lonely and difficult decisions we face. So, each February, we celebrate our ability to connect, share, and ultimately, advocate as a larger constituency to create the change we want to see in the world.

But this slogan—Individually we are rare, but together we are strong—is more than a great T-shirt to me. It is my driving force.

As a person with a facial difference, I often feel singled out in a crowd. My “individuality” is not a choice; it is a fact of life. It comes with the territory of living with a difference. Fortunately, the older I’ve gotten, the more I have learned that my physical presence can invite or dissuade questions—and I can use that presence as a tool to my advantage.

When I’m out representing CCA, I welcome questions so I can encourage others to see the value in the work we do, and help them understand why I believe we must raise funds and awareness for our kids. However, if I am at the grocery store or the DMV, my presence can also dissuade unnecessary or rude questions by acting assertively, cheerfully and politely.

But these are “hacks” that we all employ as part of the *individual* experience. We come

to terms with and learn to navigate the tricky situations, just like everyone else out there. However, my fervent passion these days is the second part of this Rare Disease theme—*together, we are strong*.

Our board of directors and I have big goals for CCA—goals that preceded all of us, but that we intend to nurture and grow. Our hope is that together CCA families support each other on our journeys and bring a powerful, joyful awareness to the world that **we are more alike than different**. We want our community to realize that when we work together, we can accomplish amazing things—like distributing more than 5,000 *Wonder* books last year to students and sending families on more than 100 travel trips.

So this is my request to you: We must practice reaching out and bringing others into our community of kindness and hope. We must fight against cliquishness and challenge ourselves to say, “You can sit with me,” at every single lunch table across America. I ask that you pass along a *Wonder* book—or any book—to the newest person at your workplace, then invite them out for coffee to talk about it.

And possibly most importantly, at the Retreat this year, I challenge CCA attendees to meet at least five new families you’ve never met before. I promise it won’t be hard to find them, as we are projecting this to be the largest Retreat to date! It may be hard to step out of your comfort zone and speak up, but it will be worth it.

While we had 29 scholarship families in 2016, because of support from generous donors, we have 50 this year! No matter how big our group gets, our Retreat mantra remains, “we are family.” Please be open to the new faces you see and don’t just smile—go up, introduce

yourself, and exchange text messages. Work together to decide how you’ll bring kindness back to your classrooms, clubs, teams and neighborhoods. Then, tell us at CCA what we can do to help.

Our motto extends beyond Retreat, if you are reading this newsletter, **we are family!** Let us know how we can work with you. Email me your ideas, your hopes, and your availability and together, let’s make the world a kinder place. It’s up to us and we are strong.

EMossholder@CCAKids.com

Erica Mossholdeer
CCA’s Executive Director



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thankful, from page 1



it—lucky me. Most all of my surgeries were done in Charlottesville, VA, by **Dr. Milton Edgerton**, so we were always traveling back and forth for appointments and procedures.

The syndrome was a part of my life but certainly not all of it. I had a very normal childhood. I was a good student. I fought with my siblings, had friends, was involved in all kinds of activities and even played sports. I did the things that were expected. Eventually, I graduated from college and moved away from home. I made it to Tennessee, where I would work with children that had similar craniofacial anomalies.

While still in college in the late 1990s, I found a group on the Internet called Children's Craniofacial Association. Keep in mind that the Internet was just then

becoming commonplace in homes across America. I had just received an email address and there certainly was not any social media.

My world had been awakened. I immediately told my Mom I wanted to go to a retreat. I was so excited at the possibility of meeting someone else like me because I had never met anyone else with Crouzon syndrome. It was an amazing experience, just like it is today. It gives people with craniofacial syndromes a place to be accepted. Where there once was isolation, there was now a community.

As one can imagine, for people with craniofacial anomalies, dating was not always easy, but then again it isn't easy for anyone. There was one particular guy that did not pursue things further with me because I was "genetically flawed." Shocking I know. But it dawned on me that while others may not have said it, they probably thought it.

It did get a little easier as I became more comfortable in my own skin. I ended up breaking a few hearts and got my heart broken. Then in 2003, I met **Patrick**. I told him all about the syndrome and it did not matter. When we began to discuss marriage, I told

him he did not want to marry me because I could not give him a house full of perfectly perfect children. It did not matter. None of it mattered. We married in December 2004.

For many years, things were fine, just him and me. Then my biological clock started ticking. I did not know it then, but that clock would signify the beginning of a long journey to having a family. Eventually, Patrick and I, now living in South Carolina, went to see a geneticist in Charleston.

You see, I always knew my risks of having a child with the syndrome—it was a 50/50 shot. It was because of those odds that we had not yet had children. I knew full well that if I had a child with it that he/she could be less severe or more severe than I had been.

I was scared of having a child worse than me. I was afraid I would not be able to handle it. At the geneticist appointment, we both went through a series of tests. They told us that the option of IVF (in vitro fertilization) with pre-genetic implantation was available. It was a mouthful, but what did it mean? Well for us it meant a long time praying and determining what was best for our family. In the end, we decided against it.

If we were not going to birth children, we would adopt. In December of 2010, we went to an adoption seminar and had plans to begin taking classes in January. But God had something else in mind. That night, I found out I was pregnant. Shocked, scared, terrified



and excited are the words I use to describe it.

I realize that many people have varying opinions about people with a craniofacial syndrome having their own children. Why would you want to bring a child into this world with something so bad? It is too high of a risk—I truly get it—I even had people criticize me too. One girl made snide remarks about my pregnancy. She did not understand how anyone could possibly be so excited about bringing a child into the world that may be deformed. It did not matter. Nothing anyone said mattered. But, what people forget is that for the person with the syndrome, they are having all the same feelings that anyone else who is expecting is experiencing.

Four months into the pregnancy, we found out that the child I was carrying tested positive for Crouzon syndrome. We were crushed. I had hoped and prayed that the baby would be spared. I was mad and angry. After all, I had done everything right. I had lived through it myself; I worked in it; now I would have to walk through it again, only this time, as a mother.

The doctors gave us “options.” After the “options” had been

mentioned too many times to count, my husband told them that abortion was not an option for us so they could stop mentioning it. We had more appointments, tests and ultrasounds than I can remember. I asked questions that they did not know the answers to. I was a mom that knew too much.

I asked the ultrasound tech to tell me how many sutures were closed on the baby. The tech would not tell me. Instead, the doctor came in and told me that the baby had something called “cloverleaf” skull. I knew exactly what it meant and I cried. Later, I even asked them if fluid was passing through the baby’s nostrils. Why did I ask that question? Because I wanted to know if my child would be able to breathe on their own or if he would have to be trached. My greatest fear was that my child would have a trach. When the tech told me yes, I breathed a sigh of relief that I would not have to worry about that. We wanted to be fully prepared for what was coming. What I quickly found out was that I knew more than they did about the syndrome and that I would never be fully prepared for what was about to come.



In July 2011, I began having complications from too much amniotic fluid. After a two-hour ambulance ride to Charleston, 48 hours without sleep for Patrick or me, and nearly six weeks premature, **Jack** came into the world. Upon first seeing my new son, I knew his skull was bad. But within a short time, the “rose colored glasses” that all moms wear kicked in. I convinced myself that maybe it wasn’t really that bad. After all, he had just come through the birth

canal, so some of it would smooth out with time.

While I was wrapping my mind around his skull issues, the doctors and nurses were trying to get Jack to breathe. Within a few minutes, my husband went with the nurses up to the NICU where he was immediately intubated. He was stable, for now.

Over the next few days, we were given lots of information. At one point, Patrick, myself and my mom were all sitting in my room searching the Internet. Mom looked up at us and said, “What

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a difference 30 years makes." She told us that when I was born, all she got was a piece of paper that described Crouzon syndrome and was told that I would probably die, but if I lived I would more than likely be mentally disabled. But here we were

get rid of it. The doctors told us that according to the scan, his nostrils were completely blocked and that they would never open on their own. I shared with them what we were told during the ultrasound.

When they went in for surgery, they found



in the year 2011 and we had all the information we could ask for at our fingertips. I defied the odds, and I was determined that my child would too.

In less than a week, we knew that Jack could not breathe on his own. I spent my days by his bedside and my nights scouring the Internet and making phone calls looking for alternatives to a tracheostomy. I felt like if he went home with a trach, then he would never

that there was indeed an opening albeit a very, very small one. They put in a nasal stint to see if it would work. For three weeks, we waited. Jack never got better, only worse and worse. The stint was not enough. Things were bad, very bad. After nearly losing him, the realization that a tracheotomy was inevitable finally set in. Surgery was set and we were finally at peace with the decision. After surgery,

we began learning how we would care for him at home with all the machines and medical care that it would require.

Then there was the matter of the cloverleaf skull. It was bad too. We were told that all his sutures but one had fused. Due to this, his brain was growing and pushing out of the one open suture on top of his head. He looked like one of the old Saturday Night Live characters, the Coneheads. His skull had been stretched so thin that it was like "Swiss cheese" the doctor told us—so many holes and very little protection. The procedure that the neurosurgeon used was called the "springs" procedure. It was not a conventional procedure and very few neurosurgeons used it, but ultimately we decided to go for it. After a few starts and stops, it worked for Jack.

In September, we finally brought him home. My mom and Patrick's mom came to help us get acclimated to being new parents. We were both his parents and his nurses. Our world was forever changed. I learned that how we acted and treated him would be how the world would. One of the first things we decided was

that we would live our life as best as we could and we would discover a new normal. If we went to the grocery store, so would he. If we went to the mall, so would he. I knew that if I sheltered him, the world would not ever accept him.

I discovered that friends we had would no longer be our friends because it was too difficult for them and that was okay. I understood. Conversely, friends we would never have imagined would become people we would come to rely on.

By March 2012, it was time for the frontal orbital advancement—and a shunt. By now, Jack's head had grown quite large and the shunt was the only thing to do to relieve it. If we did not, permanent brain damage would surely set in. This surgery was the most complicated and the most trying for Patrick and me. After it was over, we all three came home changed for the better.

The first year of Jack's life was the hardest of mine. The shunt, the trach, the cloverleaf—these were all things that I did not have as a child. I knew going into this these were possibilities, but I never thought my child would get all three. Well, he did; lucky him. He won the



trifecta, but he would make it through. There were so many surgeries that year that at his 12-month checkup we were told that he was functioning as a 6-month-old. I kept telling myself he would catch up. I knew that with every surgery there would be developmental setbacks, and catch up he did. By the time he reached 24 months, he was functioning right on target.

Today, Jack is a very normal 5-year-old little boy. He still has his trach, but it has now become a part of our lives. I am now grateful for it because I believe that he would not be thriving had he not had it. He is in Kindergarten this year, and cognitively he is above average. This year he took swimming lessons and he played on a baseball team.

He has learned to answer questions about his trach himself, by giving a simple, "It helps me breathe," answer.

A close friend of ours describes Jack in the following way, "He is just like any other 5-year-old boy in that he runs, jumps, gets dirty, plays tag, gets in trouble sometimes, loves to play superheroes and is learning how to read—oh and he happens to have a trach."

As CCA was a part of my life, I want it to be a part of Jack's as well. This past summer, my husband and I were able to take Jack to his first retreat. While Jack does not really get it yet, I certainly do. I no longer see the retreat through the eyes of someone with a syndrome. I see it through the eyes of a mom. I don't

compare his syndrome to other people. Instead, I see the connections he made this year with two other little boys his age. I see the support he will have through the years whether it is online or in person. I see that he will not grow up feeling isolated because he is the only one. I see a sense of normalcy and acceptance.

So, knowing what I know now, would I do it over? Absolutely! Jack is my greatest joy, and love can give you the stamina to walk through anything. His life is worth living just as much as a child that had been born without complications.

Jack's syndrome is just a genetic mutation

that people can see. But what if he had been born normal on the outside and then a genetic mutation that manifested itself in the form of some other disease? Would I do anything less than get him the best treatment? No. Would it mean that I should have terminated the pregnancy years ago? No. Would it mean that his life is not worth living? No way. I have learned that children like Jack have a purpose. Now, I don't know what that is, but there is a purpose. Maybe it is just simply to show God's glory. The miracles He can do when these children defy the odds. The miracles He can do when He brings this mother and father to their knees. Sometimes it is to show hope to others. Whatever plans God has for Jack, I can't wait to find out.





JWELib @JWELibrary1 · Feb 23
 It's Mardi Gras float time!! Choose Kind! @RJPalacio
 @CCAKidsTweet #jwepride pic.twitter.com/R797DHVv

Thank you **Capistrano Unified School District** and **Katy Independent School District** for participating in CCA's Choose Kind *Wonder* program!

testimonial



CCA is an assembly of the most devoted, caring and compassionate miracle-makers the world has known. This team is fueled by the love for every child ever born with a craniofacial anomaly. Every person on this team will move mountains and bend over backwards to do everything within their power to help a child.

My husband and I are so very blessed to have had the opportunity to see the miracles they perform firsthand. Back in 2007 we were blessed with a beautiful little girl. She was born with a heart of gold

and a special smile. Her name is **Autumn**.

Autumn was born with a severe complete bilateral cleft lip and palate. The severity of her condition made it very challenging to find a surgeon with the experience necessary to treat her condition.

After months of research we found **Dr. Mulliken** at Children's Hospital Boston. Autumn has had six operations, the first being 12-and-a-half hours long. Each surgery has required a one-to-two-week stay in Boston, and the lodging, airfare, transportation and food cost combined are extremely expensive. CCA

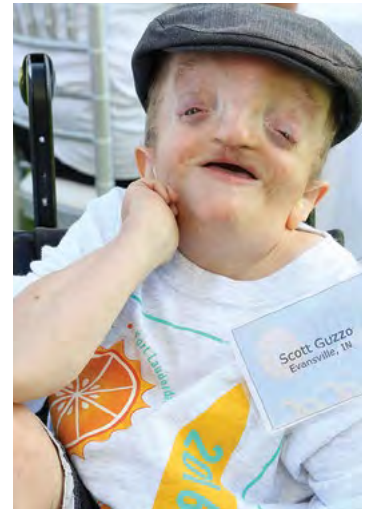
has been very generous in financially supporting these trips. Without them, they never would have happened!

Not only have they assisted us in paying for the trips but every time that we speak with **Annie**, CCA's Program Director, it is just a reminder of all the good in the world. She is nothing short of an angel.

While we still have several more surgeries to go, Autumn is doing well. Every day when we look at her smile we thank CCA!

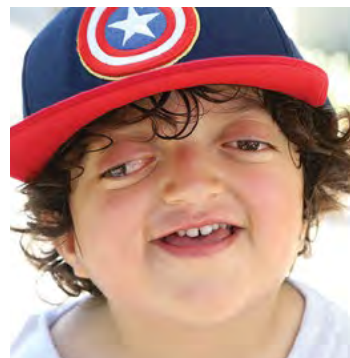
The Grady Family

Very rarely in our lifetime do we have the opportunity to experience something truly miraculous, and what we experienced with CCA Kids is nothing short of a miracle!



Thank you to **Rick Guidotti** and **Bieke Kreps** of Positive Exposure for attending the 2016 Annual Family Retreat and capturing these gorgeous photos for us!

Learn more about their work at PositiveExposure.org



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calendar of events

date event contact

2017

April 5-6	6th Annual Morgan Meck's Match Play Invitational Coto de Caza Country Club Coto de Caza, CA	
Apr 28	5th Annual Texas Moms' All the Way for CCA Golf Tournament Wildcat Golf Club Houston, TX	Becky White ledestiny@gmail.com
May 20	Alexa's Ace for CCA Creekside Golf Course Modesto, CA	Denise Rast Drast074@gmail.com
May 20	2017 "Miles for CCA Kids" Benefit Ride	lewisboykin55@gmail.com
Jun 29-Jul 2	27th Annual Cher's Family Retreat Hyatt Regency Reston Reston, VA	ARees@ccakids.com 214.570.9099 800.535.3643
September	13th Annual Craniofacial Acceptance Month Nationwide	ARees@ccakids.com 214.570.9099 800.535.3643
Sep 9 11A-1P	10th Annual National Picnic Day Sandy Lake Amusement Park Carrollton, TX	ARees@ccakids.com 214.570.9099 800.535.3643
Sep 29	10th Annual Links of Love Golf Tournament Firewheel Golf Park Garland, TX (Dallas area) 11:30 AM Registration, 1 PM Shotgun start	emossholder@ccakids.com 214.570.9099 800.535.3643

Wonder Gift Sets



Go to bit.ly/wondergear to order yours!

check it out: new wonder shirts

We have redesigned our *Wonder* t-shirts with the anticipation of the movie coming out! You will love them! Designed by **CCA Adult Jennifer Johnson** (merchandise designer for Andy Grammer, Reba McEntire, Rachel Platten and more) they say, "Change the World: Choose Kind." Get one for yourself online in our webstore or contact us for school bulk orders. For orders of 48 or more, we can give you a great discount so your whole class can participate in the Kindness Movement.



a living legacy



We are so grateful for those who have thought ahead—many arranging planned giving according to their wishes—many times without even telling us. Those who have made the decision

to champion CCA by leaving our charity in their will are providing a lasting legacy for years to come with their gifts.

For this reason, we initiated the CCA Legacy Society, for those who name Children's Craniofacial Association as a beneficiary. Through this effort, we will chronicle information about our Legacy donors who care for our future and the wellbeing of our CCA kids.

If you wish to fill out a declaration form and become a Legacy member, please contact us. If you have already set up a bequest in CCA's name, please allow us to include your intentions in our records, describing your gift of security for the future of Children's Craniofacial Association.

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Malte VonAnrep
Shannon Von Hasseel
Susan Walker
Lindsay Wall
Doug Wemple
Rebecca White
Barbara Wiedenman
Lee Wist
Linda Wohlford
Rodney Woodman
Rich Ziegenbalg
Eric Zimeskal

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Claire L. & Abby Cullen
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Bonnie Dresner
Ellen Dreyfuss
M. Brian Evans
Heath Fisher
John & Carrie Follett
Ashley Galban
Casey Gardner
James Haack
Darryl Heckle
Cheryl Hlad
Christopher Hood
Margaret Iannelli
Jessica Johnson
John Kinney
Brian Krassa
Leslie Lahoud
Daniel & Anne Larkin
Dave Larking
Andy Lehrner
Mary Lytle
Joshua Mallett
Deborah Mecklenburg
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Rene Rodriguez
Patty Ann Romero
Socorro Sade
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Geraldine Brill
Joe Briscoe
Martha & James Brown
Justin Buskirk
Wincie Campbell
John & Peggy Carr
Denny Coker
Martin Curran
Lizsi de Leon
Graham Doran
Jennifer Dunn
Daniela Flaschka
Fred & Judi Freeman
Roland & Dottie Freeman
James Gawne
Beth Gibson
Johnny Griego
John Grimes
Jackie Halpin-Ostean
Darryl Heckle
Clayton & Kathy Huck
Mike Huggins
Chen Kantikovit
Richard Kinas
Haney Labriola
Dave Larkin
Jim & Sue Lavender
Christopher Lawrence
Jodi Lindgren
Brandon & Annie Martin
Ralph Martinelli
Tony Martinez, Jr.
Tony Martinez
Marcy Matson
Elizabeth Modde
Natalee Morin
John Nickens
Francis Obrien
James & Jennifer Oh
Steven Page
Jana & Hugh Peace
Joe Pellegrini
Janette Perkins
Dale & Kathleen Philippi
Paul Pokladnik
R.J.Reissig
Jessica Roche
Jeffrey Robison
Randolf Schafer
Paul Schulze
Melissa Sewell
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Alisa Shelton
Tony Tripeny
Joshua Warren
Marcia Weber
Rose Wiese
Robin Williamson
Angela Wojtyniak
Frank Zeb

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Peggy Dear
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Kara Edwards
Jennifer Ezzell
Tate Gorman

William Gorman
David Hardt
Ryan Henry
Robert Kacer
Stacey Lee
Ann & Don Lucas
Parker Megginson
Susan Moul
Dale Myer
Matthew Osburn
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Stony Welch

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Foundation
Mike & Marty Willson

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Dan & Denise Paulson
Jacob Tremblay

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Nellie Coudare Estate

CCA Shepherd

(\$35,000 +)
Robert Engelhorn Estate
Bill & Christine Mecklenburg

Memorials / In-Honor Gifts

Those with ten or more are
subheaded

Stephen & Vickie Ambrosch, in honor of
Claire Lillian Lewis
Geoffrey & Stephanie Amsel, in honor of
John Gorman
Ansell Healthcare Products, in honor of
Becky White
Kristi Arth to Sydney's Dance for Acceptance,
in honor of Erica Mossholder
James Austin, in memory of Dorothy Depel
Sem & Donna Aykanian, in memory of Lily
Ann Haley
Ellen Barry, in memory of Paul Roehrig
Michael & Sherri Beasley, in honor of
Kimberly Beasley
Nancy Bennett, in honor of Mark Randell
Cathy Biersack, in honor of Joe Brooks'
Birthday
Kim Bird, in honor of Parker
Mary Jo Blackwell, in memory of Paul
Roehrig
Booster Funder, in honor of Peter & Jacob
Dankelson's Birthdays
Margaret Bordonaro, in honor of Zachary
Francis & Laurie Brookes, in memory of
Dorothy Depel
Anita Cain, in memory of Sonny
Larry Carpenter, in honor of Cher for the
holidays
Eunice Caswell, in honor of Trevor Layrs & in
memory of Richard Richroath
Robin Chapurinov, in honor of Brandon
Joe Brooks, in honor of Char's Birthday
Joe Brooks, in honor of Jill Patterson's & Rob
Gorecki's Birthdays

Todd & Patricia Cook, in honor of Joe
Brooks' Birthday
Stephanie Cooper, in honor of Avery for
Retreat
George Dale, in honor of Char Smith's
Retirement
Dede Dankelson, in honor of Char Smith's
Birthday
Dede Dankelson, in honor of Char Smith's
Retirement
Janice Marie Delbert, in memory of Richard
Richroath &
In honor of Trevor Layrs
Jane Driver, in honor of great-niece, Debra
Rose "Rory" Eller
EMJ Development individuals, in memory of
Roger David Wincn
Michael & Kristine Eller, in honor of Lea
Cummings
Daniel Elliott, in honor of Rosemary
Michael & Christian Fant, in honor of Ginny
Wiese's birthday
Francis Fisher, in honor of Cher
Kristina Fisher, in honor of Wade White
Bonny Flemister, in memory of Frances
Harrington
Roland & Dottie Freeman, in honor of Rob
Gorecki
Mary Frings, in honor of Monica Shelton
Geraldine Gallagher, in honor of Vienna
Caldwell
Paul & Anne-Marie Galvin, in memory of Lily
Ann Haley
Elsie Garcia, in honor of Randy Urbay &
designated for Retreat
Sal Gionfriddo, in memory of Dorothy Depel
Christine Gorman, in honor of Louis &
Margaret Henschel
Tate Gorman, in honor of John Gorman
Tate Gorman, in honor of Char Smith's
Retirement
Jackie Halpin-Osteen, in honor of John
Gorman, and in lieu
of Christmas gifts for daughter Holly
Ruth Hargis, in honor of Shierry Lance-
Laugharn
Arleen Heirty, in memory of Elizabeth Barry
Arleen Heirty, in memory of Ben Johnson
Arleen Heirty, in memory of Linda
Arleen Heirty, in memory of Michael
Arleen Heirty, in memory of Joan Zaranti
Ilona & Scott Hicks, in memory of Rose Keny
& designated for Financial Assistance
Chris Hoeffel, in honor of Francis Smith's
Birthday
Jon & Karen Hoelscher, in memory of Lily
Ann Haley
Michael Hogan, in memory of Margaret
Hogan
Christopher Hood, in honor of Trevor Layrs
Janis Hood, in honor of Team Lentil
Glenda Hudson, in honor of Tami Laugharn's
Birthday
Brian Hughes, in memory of Tobyn Paul Brill
Jerome & Kay Hughes, in memory of Brian
Leslie
Russell & Carol Jenna, in honor of Elizabeth
Dalton
Joanne Jankowski, in memory of Richard
Richroath &
In honor of Trevor Layrs
Amanda Kastern, in honor of Nathaniel
Beitzel
Jennifer Kilmer, in honor of Char Smith's
Birthday
Ann Kimmell, in memory of Ricky Potter
Ted & Judy King, in honor of Francis Smith's
Birthday
Donna Klick, in memory of Ricky Potter
Audri Kocsis, in honor of Parker
Jean-Marc Laurin, in honor of Jérémy Gabriel
Margaret Lavender, in honor of Char Smith's
Retirement
Jennifer Levine, in memory of Roger David
Wincn
Shelly Livingston, in honor of James Culp
Megan Mahoney, in honor of Sophia
Susan Martin, in memory of Ellery E. Walker
Ken & Tanya Mattson, in honor of Ryan
Gulich, Jr.
Ellen McPadden, in honor of Jeremy Dale
Bill Mecklenburg, in honor of Tracy Carragher
Bill Mecklenburg, in honor of Char Smith's
Retirement
Lisa Mercer, in honor of Mark Elzey
Angie Mendoza, in honor of Joe Brooks'
Birthday
Elizabeth Modde, in memory of Howard &
Eldora Niedermiller
James & Maryjo Montalbano, in honor of
Jennifer Montalbano Small

Erica Mossholder, in honor of Char Smith's
Retirement
Erica Mossholder, in honor of Meg Storie's
Birthday
Motor Casting Foundation, in honor of the
Dankelson Family
Louis & Peggy Murray, in honor of Morgan
Meck
Tina Neal, in honor of Ashton Carter Neal
Ronald & Danielle Nelson, in honor of
Leighton Nelson
Dianne Newman, in honor of James
Newman, to assist children with Hemifacial
Microsomia
Robin Nichols, in honor of Shierry Lance-
Laugharn
Maryann O'Hern, in honor of Morgan
Mecklenburg
Diane Parker, in honor of Tami Laugharn's
Birthday
Jill & Greg Patterson, in honor of Joe Brooks'
Birthday
Jill Patterson, in honor of Char Smith's
Retirement
Jill Patterson, in honor of Meg Storie's
Birthday
John & Sheryl Paul, in honor of Char Smith's
Retirement
& Erica Mossholder's promotion
Dan & Denise Paulson, in honor of Char
Smith
Denise & John Peloquin, in honor of Joe
Brooks
John & Diane Pelletier, in honor of Camryn
Berry
Diane Perez, in honor of Roy
Susan Petersdorf, in honor of Molly
Stanley & Mary Pond, in honor of Jackson
Pond's Birthday
Cindy Preston, in memory of Stephanie
Sumpter
Phillip Price, in honor of Caroline
Sherri Ramsey, in memory of Ricky Potter
Anthony & Lisa Recchia, in memory of Lily
Ann Haley
Annie Reeves, in honor of Joe Brooks'
Birthday
Annie Reeves, in honor of Char Smith's
Retirement
Donna Rhoades, in memory of Donovan
Rhoades
Richard & Arlene Richroath, in honor of
Trevor Layrs
Darrell & Kim Ridenour, in honor of Colette
Lopez
Julia Rodriguez, in honor of Beth Henschel
Julia Rodriguez, in honor of Louis &
Margaret Henschel
Julia Rodriguez, in honor of Rose & Travis
Killion
Jeffrey Robison, in honor of families touched
by Craniosynostosis
Michael Rodell, in honor of Jenna Rodell
Marilyn Roehrig, in memory of Paul Roehrig
Zuilda Roig, in honor of son, Gabe Roig
Elizabeth Scheu, & Kniss in memory of Paul
Roehrig
Roberta Schini, in honor of Samantha Wayne
Paul Schmidt, in honor of Peter Dankelson
Gerald & Jeanne Schumm, in memory of
Dorothy Depel
Julie Scott, in honor of Cliare Lillian Lewis
Rose Seitz, in honor of Joe Brooks' Birthday
Rose Seitz, in honor of Meg Storie's Birthday
Patty & Mike Shay, in honor of Dorothy
Riordan
William Skarie, in honor of Jameson
("Jameson's Journey")
Pamela Skeen, in honor of Shierry Lance-
Laugharn
Sharon Slovenz, in honor of Trevor Layrs & in
memory of Richard Richroath
Robert Smith, in honor of Francis Smith's
Birthday
T.K. Smith, in honor of Meg Storie's Birthday
Anthony & Trish Snead, in memory of Richard
Richroath &
In honor of Trevor Layrs
Lewis Steinhoff, in honor of Joe Brooks'
Birthday
June Sweeney, in memory of Antoine Aparicio
Keith & Samantha Tanner, in memory of Paul
Roehrig
Lee-Ann Sewell, in honor of Shierry Laugharn
Elena Vontik, in honor of Anna Marie Wong
Susan Walker, in memory of Ellery Walker
Jennifer Wayne, in honor of Sammi Wayne
Steven Weiss, in honor of Char Smith's
Retirement
Westfield State University Dance, in memory
of Lily Haley
Barbara Wiedenman, in memory of Jennifer
Walker

Rose Wiese, in honor of Char Smith's
Retirement
Mike & Marty Willson, in honor of Avery Lyle
Lee Wist, in honor of Chelsea Wist
Linda Wohlford, in honor of Caroline Price
Chris & Nancy Wyant, in honor of all the
volunteers
Melanie Yarbrough, in honor of Erica
Mossholder

Olivia Rae's 8th Birthday Wish for CCA

Akaal Auto Repair LLC
American Legion Auxillary
American Legion Riders Post 5
Ginny Ashby
Donna Badilla
Diana Barnat
Christine Beardslee
Jonathan Behn
Bob Bendhardt
Bambi Bernstein
Greg Boadwine
Kenneth Boese
Deborah Boucher
James Boyd
Keith Bullard
Carteret PBA Local 47
Jennifer Cavaliere
Melissa Ciampa
Alicia Ciccone
Janet Ciccone
Christine Clancy
Jill Clancy
Scott Cornhill
Cynthia Costello
Anthony Cuda
Michelle Cummings
Jeremy Dahl
Joann Dalessandro
Joyce Daniels
Renee Davis
Kristin Demilio
Michael Deranek
Sylvia Dindayal
Lindsay Dobish
April Elliott
Georgette Evans
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Shannon Farrell
Cary Fields
Fine Line Transportation
Ken Freeman
Adam Friel
Heather Gagliano
Larry Giordano
Geri Gitto
Dawn Glinksy
Kara Goglia
John Goins
Gareth Gould
Jennifer Grasso
Louis Graziano
Elizabeth Groupp
Jennifer Guarrino
Louis Hunter
Anthony Ingrassia
Sonia Joseph
Timothy King
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Tina Koenig
Denise Krum
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Andrea Lauber
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Evelyn Maina
Peter Marston
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Audrey McKinney
Jeff McManus
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Nick Mirandi
Cheryl Monroy
Christina Muscaritolo
Cindy Naguib
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Elizabeth Paonessa
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Barbara Regula

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Heather Rizzo
Patty Ann Romero
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Meaghan Sowell
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Jordan Watkins
Jennie Willmott
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Kim Wohanka
JoAnn Wohler
Emma Yepez-Ziegenbalg
Frank Zeb
Rich Ziegenbalg

In Honor of Cher's Birthday

Anonymous
Stacey Arrighi
Asdruba
Dominique Bailout
Troy Lynn Hershman Betenbaugh
Jen Bechley
Zachary Bordinaro
Ann Bradley
Mr. Braun
Joe Brooks
Leda Brunzie
Mark Butera
Larry Carpenter
Gabe Cawford
Carolyn Chiappone
Laurie Chiavari
Jacqueline Cuneo
Deborah De La Rosa
Courtney Deno
Aaron Diener
Sue Dolby-Dawson
Mark DeLache
Saskia DeRidder-VanHarmelen
Ellen Dreyfuss
Timothy Duquette
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Karen Fisher
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Deborah Goguen
Asdrubal Gonzalez Rodriguez
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Jim Hensley
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Donna Holladay
Dee Horten
Terry Hughes
Heather Jay
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Brittany Jerstad
Darla Kramer
Brian Krassa
Mary Kriss
Manuela Kubisch
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Peggy Lightfoot
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Sandra Lombardi
James Lonsdale
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Debbie Matera
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Sarah McDonagh
David McGill

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Terri Rossman
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Aimee Wright

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Michele Aimore
Lisa Ainsworth
Joyce Albert
Tracey Alsip
Sue Amell
Pat Arlington
Kathy Aspinall
Norma Avalos
Natalie Avila
Leslie Balber
Gabriella Baldassarre
Brenda Barnette
Kathryn Baugher
Connie Bearden
Raf Beckers
Carol Belt Niemuth
Michele Berlin
Randall Bier
Zoe Bilski
Melantha Bobrick
Nikki Boone
Gayle Boring
Carol Borota
Christine Brocco
Kristie Brong
Evelyn Buday
Peggy Butterworth
Kim Capek
Carly Ceccarelli
Nicole Chaplin
Sherry Chapman
Annie Chastain
Terri Christie
Michelle Collar
Harriet Corbett Austin
Katrina Coreces
Cathy Cresta
Marina Davis
Lizl de Leon
Nancy Deakin
Kathy Degner
Diane Dehmer
Dakota DeLeo
Jean Deserabre
Matt Dougherty
Nancy Dreschel
Roseann Dumont
Heather Dyer
Bev Edwards
Mary Lou Elspas
Carolyn Epperson
Suehan Estrada
Robin Fagler
Joan Finnen
Judith Eagle
Kathryn Floyd
Melissa Ford

Jane Foster
Margaret Freund
Mary Gage
Regina Gallagher
Morgan Ganz
Carly Gerstman
Tina Gillum
Lynn Gonzalez
Sarah Goodyear
Suzette Govin
Lynn Graham-Eagle
Valentina Gualandi
Lynne Hallanan
Salet Handley
Sherri Hanlon
Patricia Hannon
Brandi Harris-Molin
Greg Haynes
Karin Henry
Jolene N. Andy Herrera
Donna Hertha
Sharon Hill
Mary Ellen Hindin
Jennifer Hobbs
Elaine Hochheiser
Susan Holman
Janis Hood
Sue Hoofnagle
Margaret Horn
Sallii Horst
Nancy Housteau
Felicia Humenik
Donna Hunter
Janet Hurwitz
Julie Isidro
Heather Jahn
Annette Jakubiak
Tammy Johnson
Brenda Kessler
Sarah Key
Ann Kincaid
Renee Kippa
Leslie Kliesh
Tony Knighten
Amy Koon
Dana Kurland
Donna Kurtz
Simon Lamont
Massimo Lampa
Tim Lance
Kelly Larcada
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Jill Laufbaum
Lynn Laughlin
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Tanya Lee
Christina Lemmo
Raymond Leon
Missy Leonard
Andrea Liddell
Ladonna Lilley
Maryann Lillis
Karla Lindblom
Renee Lippa
Danielle Lisowski
Barbara Long
Melissa Love
Naisan Madson
Maria Mariani
Linda Marowitz
Joni Martines
Lauraine McAlaster
Sandy McClintock
Susan McClure
Sheri McManus
Carol Metcalf
John Miner
Barbara Monroe
Michele Morawski
Jillian Morris
Leslie Morris
Lynne Moulton
Pamela Mueller
Jennifer Mussato
Doreen Myers
Aaron Near
Debbie Neff
Karen Orth
Lee Anne Owens
Jennifer Paris
Janette Perkins
Andrea Peters
Marian Purcell
Helen Racowski
Kathy Rain
Michelle Ramey
Meghan Read
Cheryl Reeves
Kristen Ressler
Luis Rivero Zubira
Kami Robey
Sheilia Roby
Cheryl Rossi

Karen Schrom
Melanie Scott
Dian Sharma
Darla Sheehan
Cindy Sherling
Connie Shewchuk
Ruth Simmons
Bonnie Slosburg
Donna Smith
Gregory Sorbello
Ingrid Strik
Valia Sturz
Aleksandra Svet
Beth Swanson
Diana Sweeney
Mary Szarejko-Bergstraesser
Vernette Tatum
Sue Taylor
Bernadette Thomas
Michelle Thompson
Sarah Thrower
June Vanvolkenburgh
Regina Vassallo
Sheri Voss
Sally Wackerly
Katie Walker
Susan Wargo
Renee Whitelock
Candace Williams
Carol Williams
Sandra Williams
Lesley Williamson
Simone Woodwell
Desiree Yannone
Stephenie Yeung

In Honor of Jakob Graudons' Birthday

Mercedes Cernuda
Sara Chambers
Jennifer Ford
Liane Gowen
Laura Graudons
Christine Lindberg
Michelle Nelson
Shawn Reynolds
Steve Robinson
Patricia St. Cyr
Barbara Santiago
Nicole Skinner-Graudons
Jennifer Sund
John Suslak

In Honor of Torey Harrah's Birthday

Kim Bird
Smyth Colm
Steve Cunha
Casey Deakins
Deena Dyson
Mary Lou Elspas
Michelle Gonzales
Susan Hoofnagle
Nancy Housteau
Kara Jackman
Ed Kern
Jennifer Kilmer
Sigrid Larson
Erica Mossholder
Beverly Ohanlon
Janette Perkins
Cheryl Rossi
Rose Seitz
Sally Wackerly
Mary Zimmerman

In Honor of Annie Reeves' Birthday

Kyle Aftimos
Michelle Aftimos
Jeremy Alarcon
Sharon Albright
Mica Anderson
Anonymous
Taylor Aumann
Joe Brooks
Kelly Dowd
Fred & Judi Freeman
Brooke Gladson
Michelle Gonzales
Kelli Griffin
Renee Hays
Arienne Johnson
Patsy Jones
Karin Karey
Ed Kern
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Jenny Locke
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Angie Mendoza
Erica Mossholder
Jill Patterson
Jana Peace
Amy Plummer
Cindy Podner
Sabrina Robineau
Julie Scouler
Rose Seitz
Char Smith
Robin Williamson
Ann & Joe Zaengle

In Memory of Doretta Hughson

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GST Boces
Barbara Braddock & Susan Kucko
Wilma & Lester Campbell
Betty DeNardo
Jon & Nancy Gilbeau
Robert Greaves
Horizon Solutions LLC
Ken & Tanya Mattson
Elizabeth Oldroyd
Mary Therese Owen
Roxanne Ragan
SHS Faculty / Sunshine Club
Leonard & Carol Simons
Victory Highway Wesleyan Church
Wellsburg Volunteer Fire Dept Auxillary

In Memory of Jennifer Litteken

American Federation Employees Local 494
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Samantha Brooks
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Adam Campen
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Debra Dowdy
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Erik Perks
Mike & Sharon Reed
Richard & Cathy Shipley
Hermine Valizadeh
Michael & Laura Wedekemper

In Memory of Fred Seitz, Sr.

Chester Amedia
Mary & Robert Beck
Irma & Chuck Biroschak
Thomas Biroschak, Sr.
Becky Brady
Nick & Barbara Damico
Edward Fisher
James Fray
Jeffrey Geisler
Marianne Glover & Helga Matos
Donna & Ron Haas
Maryann & Todd Heston
Mandie Hiznay
The Kidney Group, Inc.
Christine Krygowski
Cathy & Wendell Schais
Chris & Nancy Stellato
Eleanor Tesner
John Thomas
James & Dolores Tripp
XCD Management Services

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American Express Foundation / Employee Giving & Matching
American Federation Employees Local American Legion Auxillary
American Legion Knowles Doyle
American Legion Riders Post 5
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Kohnen Air Conditioning & Heating, Inc.
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Liberty Burger Shire / Richardson
Macy's East
Marathon Petroleum Company, LLC
Metal Parts & Equipment Co.
Microvention
Munoz Family Realty
National Christian Foundation, Houston~ Donor Advised Fund
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The Options Clearing Corporation
Orange County United Way
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Pedison Capital Fund
Pike Home and School
Pioneer Natural Resources USA, Inc.
Portugese Fraternal Society of America
Prudential Employee Giving/Matching
Rahway Post 5 American Legion
Run Canton, Inc.
Rush University Medical Center
SAL Rahway Post 5 Inc
SHS Faculty / Sunshine Club
SJV Student Council
Southern Star Capital LLC
Southwest Stainless & Alloy
Specialty Tank Services
State Farm Companies Foundation
Sugarskull, LLC
Irby N & Marion Taylor Foundation
Time Tech
Truist, Citigroup & Macy's Employee Giving
Tuolumne Band of Me-Wuks
United Roosevelt Savings Bank
United Way California Capital Region / Directed Donations
United Way of Central Ohio / Directed Donations
United Way of Greater Philly & South New Jersey / Directed Donations
United Way of the Southern Tier / Directed Donations
Verizon
Jim Wade Investments
Wells Fargo Community Support Campaign
XCD Management Services
YourCause Corporate Giving
YourCause, PWC Employee Giving / Matching
YourCause, AT&T Employee Giving
Zanesville Gymnastics, LLC

CCA Corporate/Foundation

Sponsors

\$1,000-\$5,000

212 Management Group
Bristol-Myers Squibb Foundation
Clif Bar
CRB Construction
Charitable Auto Resources, Inc. (Auto Donations--Funds listed as donations by Donors)
Combined Federal Campaign
Corning, Incorporated Foundation
Credit Union of Texas
Dallas Children's Charities / Margarita Society
Dell (Employee Giving / Matching)
Deutsche Bank Americas Foundation (Employee Match)
EMJ Development Principals & Employees
Epic Health Services, Inc.
FairLease
L Hall THB Group
The June and Cecil McDole Charitable Fund
KLS Martin LP
The John Lazarich Foundation
The June and Cecil McDole Charitable Fund
Motor Casting Foundation
NMS Data, Inc.
Partner Reinsurance Co.
Praxair, Inc.
Praxair Employee Matched Gifts
R & J Management, Inc.
Razoo Foundation
Republic National Distributing Company Foundation
Schwab Charitable Fund (donor advised funds management contributions)
The Servants Heart Foundation
SES Inc Brokerage Services
Shell Oil Company Foundation/Employee Giving/Matching
Shelton Services Inc.
Spiegel Properties
TOPA Insurance Company
Victory Highway Wesleyan Church
Westfield State University
Willis Foundation
Martin Woodall Foundation, Inc.

CCA Corporate/Foundation

Partners

\$5,000+

The Theodore and Beulah Beasley Foundation
The Chatlos Foundation
Diamonds In The Rough
Everguard Insurance
Human Investments Org
Inshallah Trust
W.P. and Bulah Luse Foundation
The Tony Stewart Foundation, Inc.
United Fire Insurance Co
The Veritas Trust

CCA Corporate/Foundation

Partners

\$10,000+

Ansell Healthcare Products
Stephen and Mary Birch Foundation
The David M. Schwarz Architects Foundation
Wheeler Foundation

Fundraising Events & Other Efforts

Up to \$1,000

Bar Mitzvah & Bat Mitzvah Tzedaka Donations / Abraham Joshua Heschel School
"Be Brody's Angel" Fundraising Effort / CCA Kid, Brody Lucas & Family
Run Participant to benefit CCA / Nicole Abalde, CCA Volunteer Fundraiser
Joe's Birthday Funder / Joe Brooks
Booster "ChooseKind" Shirt/Cap Sale / Dede Dankelson
CCA Mom & Volunteer
Greg Caldwell Cash Collections for CCA / Vienna Caldwell, CCA Kid
CAM Pin & Keychain Sales / Dorina Watkins, CCA Mom & Volunteer
Cannister Collection for CCA / Various CCA Families & Friends
Alea Carter Fundraising Effort / Alea Carter / Nichole Nation
"Coins for Craniofacial" Funder / Madison Loucks, Volunteer
Keep Collective Funder for CCA / Jennifer Lang
"Kate the Great" Fundraising Effort / CCA Kid, Kate McAllister
American Legion Funder for CCA / Jaci Samhammer
Jakob Graudons' Birthday Funder / Jakob Graudons Family
Knightgram UCF College Funder / portion of proceeds to CCA

From Steven Petryk & Andrew Hamon
Lemonade for a Cause / Amelia Gerard CCA Volunteer
Selma's Pizzeria Restaurant Fundraiser / Mecklenburg Family
Seth's Stride / Stacy & Barry Horne & CCA Kid, Seth Swihart & Sibs
Char Smith's Surprise Birthday Fundraiser / Joe Brooks
Francis Smith Birthday Funder / Francis Smith, PHD
Meg Storie's Birthday Funder / Meg Storie
Westside Terrace Denim Day Funder / Daphne Sellers in honor of Lane Rosser

\$1,000-\$5,000

Chance Raffle / Retreat Attendee Families
Paint Nite CAM Funder / Dyson Family annual September fundraiser
Torey's Birthday Funder / Torey Harrah
Angela Wojtyniak Life Expressions party / Jill Alleavato rep
Alexa's Give Back for CCA Kids / Denise Rast, CCA Kid, Alexa Rast
Sydney's Dance for Acceptance / Sydney

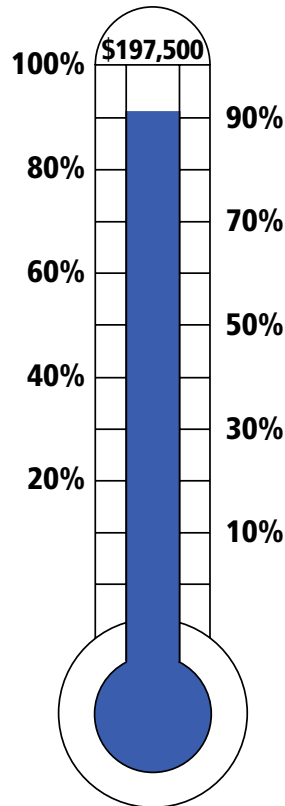
\$5,000 or more

are Package (& More) GoFundMe for CCA Kids / Petty & Steven Weiss
CherCrew Birthday Surprise for Cher to benefit CCA Kids
Friends of Jeremy "Unevent" Fundraiser / George & Kristine Dale
Lentil's 3rd Birthday Fundraiser for CCA / Lindsay Condefer, Lentil / Team Lentil
Miles for CCA Kids / Lewis Boykin, DWMC & 2nd Sunday Biker Church / Rob Gorecki
Olivia Rae's 8th Birthday Wish Fundraiser for CCA / Olivia Rae Vargas
Raegan's Rally / Ashley & Boz Daugherty / CCA Kid, Raegan Daugherty, family & friends
Annual "Links of Love" Golf Tournament / Children's Craniofacial Association

\$50,000 or more

All The Way For CCA / Becky White, Lisa Bock, Jennifer Kilmer
5th Annual Morgan Meck's Match Play Golf Invitational / Mecklenburg Family

2016 FAMILY FUNDRAISER GOAL THERMOMETER



Retreat Sponsors Needed!



Please consider sponsoring a meal or event at the Retreat by purchasing a named sponsorship.

Contact the office for a list of opportunities and benefits: 214-570-9099

registration is now open for 2017 cher's annual family retreat June 29-July 2 in Reston, Virginia

Please join us for an educational symposium, ice cream social, dinner/dance and much more!

For more information, please contact Annie Reeves,

AReesves@ccakids.com

We hope to see you there!

We are accepting applications for scholarships for this Retreat until December 31, 2016. Register by May 1st to get the early bird price of \$100. Registration will increase to \$125 starting May 2nd.

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alexis' ice cream meet-and- greet

CCA would like to send out a special "THANK YOU" to **Alexis Bellino** and her kids! They recently attended an ice cream social which was put together with the help of CCA Moms, **Dorina Watkins** and **Courtney Vysocky**. The Bellinos were able to meet several of our amazing families. Everyone had a wonderful time, and Alexis even brought gifts for the kids. Alexis has also donated sand buckets and beach toys for our 2015 and 2016 retreat! Thank you for your continued support!