

# ccanetwork



newsletter of the children's craniofacial association

Cher—national spokesperson

2015: Issue 3

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## kryzanowski family

By Michelle Kryzanowski

In 2004 I thought I had my life perfectly planned out. I was 26, happily married for seven years and working full-time while getting my master's in psychology part-time. My husband, **Garret**, had a great job, and we had just purchased a beautiful acreage. We had a five-year plan, a 10-year plan and probably a vague 20-year plan. Garret and I got pregnant our first month trying, and nine weeks later discovered we were having twins. We were both surprised, excited and a little scared, but we easily imagined them fitting right into our plans with just minimal tweaking.

I had several ultrasounds that were all great; we loved seeing our babies and proudly showed off the gray, grainy pictures. We were concerned that the babies might come early, but as I moved into my 36th week, we knew they would be a nice size. The last week of my pregnancy I developed pre-eclampsia and was hospitalized. I needed

see **kryzanowski family**, page 16



## message from the development director

What an amazing year we've had, our 26th year as a large "family" for the many we serve who are touched in some way by a craniofacial condition or facial difference.

June arrived quickly and we held our 25th Annual Family Retreat—the second largest to date—in California, with more than 100 families in attendance and a special performance of our "Wonder Reader's Theater" performed by a mix of our own CCA Kid, sibs and professional actors, including television star **Ed O'Neill**. That excitement set the tone for a fabulous

see **development director**, page 6





# ccakid

**m**y name is **Brock** and I was born October 18, 2005. I am 10 years old and in the fourth grade at Orchard Hill in North Canton, Ohio. I live with my mom, **Amber**, and I have two younger brothers: **Hunter**, 7, and **Liam**, 3. I love my brothers very much. We all get along for the most part, but we are boys and we do argue sometimes; my mom says "That's normal."

My brother Hunter loves to play with trucks and dirt.

He is good at digging holes and getting as much dirt on himself as possible. Hunter and I love to play our Nintendo 3DS together and help out one another when we get stuck. We also enjoy watching movies and riding our bikes. Hunter is awesome, and I'm glad he is my younger brother.

My brother Liam is still young, but he loves sports. He's really good at basketball and is always asking me for help when he's practicing. Liam is into

# ccasupersibs

## meet brock, hunter and liam fryer

trucks and dirt just like Hunter. I love having Liam as my little brother. I am his role model as I am for Hunter.

I know I was born different, missing my right ear, short jaw on the right side and a Limbal Dermoid on my right eye. All of my right side is affected. I have had 20 surgeries since I was born. My next surgery is in November.

I know that my mom, Amber, has been my biggest supporter. She is always there for me, and I am thankful. My brothers are very supportive of me too. I remember when Liam was a baby he came to the hospital to support me on my big day when I had my

reconstructive earsurgery in 2012. Although Hunter didn't come to the hospital, he is always there when I get home making sure I have everything I need.

My brothers have never seen me as being different; they know I am the same as anyone else. They are my protectors, I feel so loved by their support. I am proud of Hunter and Liam. They always embrace everyone else's differences. My mom taught us "It's always better to be different than the same." Her words mean the world to us. My mom does a good job at making others aware of my Goldenhar syndrome.

As for me, I love math and want to be an engineer when I grow up. My brothers seem to be following in my footsteps. I have been on the chess

team for three years and have won several awards. I also enjoy archery, and my Grampie takes me to the range so I can continue to get better aim for that bullseye! Legos are awesome, and I am always making something creative. And wherever I am, you'll find my brothers, too. Like I said before, they just want to be like me.

Over the summer we went to our first retreat in Newport Beach, California. It was a life-changing experience, I am thankful Hunter got to be a part of it, since, he has always been there for me. Liam didn't come this time; he's still too young but soon enough he will come!



## andersons 35th birthday wish

CA parents, **Dave** and **Liz Anderson**, both turned 35 this past summer, and celebrated in an altruistic way by holding an online "Birthday Wish" fundraiser to benefit CCA Kids! Altogether friends and family contributed gifts totaling **\$1,360** in honor of their birthdays! Thanks so much to everyone who donated to Children's Craniofacial Association in lieu of presents for this couple of birthday un-gifters! And thank you Dave and Liz!

Click on  
**DONATE**  
at [ccakids.org](http://ccakids.org)



# ccaadult

## meet tiffany haney

I was born in 1970 into a middle class, Southern Baptist family in the heart of the Appalachia. At birth I was deaf and had facial differences, so, at 3 days old, I was whisked off to Lexington, KY, where I was diagnosed with Treacher Collins syndrome (TCS). A year before my birth, my parents experienced the death of my brother, **Trevor**, at only 11 days old. He was born with a congenital heart defect and developed pneumonia,

which is thought to have been related to TCS. Still grieving from Trevor's death, my mother became pregnant again and gave birth to me, exactly a year and a day later, on October 12. My family, who was still dealing with so many emotions from Trevor's death, now had a child who was deaf and had a craniofacial syndrome.

My mother was, and still is, a devout Christian. In the days and months that followed, she, as well as

the rest of my family and their friends, prayed about my condition. When I was around a year old, she dropped a bottle of baby oil near my bassinet and according to her I jumped. She dropped it again, just to make sure what I was reacting to because that meant that I could hear on some level. When I was thirteen months old I had my first of many surgeries. This surgery was to create an opening of the ear canal and to make me an ear drum so I would be able to hear. The doctors decided to only open the right ear because it was the easiest and there were increased risks of ear infections in opening both.

I was raised as any other child, except for the surgeries. My mother insisted I not be treated differently and that I not see myself as different from anyone else. I was allowed to run, play and climb just as any other child would. My father and grandparents were a bit more cautious and would tend to hide any of my toys that they feared would potentially cause injury to my face, but I always

managed to find them, being the precocious child that I was.

I was fortunate in so many ways. I grew up in a small town and the people I went to school with had known me my entire life. They loved me for me. However, beginning in adolescence, I started to struggle with my appearance. At this point, I'd already had multiple surgeries, including cheek and chin implants and another surgery on my ears. I was done.

I decided when I was around 15 years old, that God made me this way for a reason. Think about that for a second....He made ME, this WAY, for a REASON. What was the reason? This is a question I have struggled with most of my life. But, way back then, I knew, in the deepest recesses of my soul, that God was in control of my life. He wanted me this way and I had to make peace with it, so I tried.

My high school years were difficult because I wasn't able to hear well and I refused to wear a hearing aid. Are you kidding? That wasn't

cool. I was involved with sports, went to parties, had friends, and boyfriends and suffered heartbreak, like any normal teen. I developed a great relationship with my church youth group in high school and my foundation of faith was laid.

I went to college and graduated with a bachelor's degree in social work and then went on to receive a master's in social work from the University of Kentucky. It was in graduate school that I met my husband, **Michael**, and we've been married since 1996. I can honestly say that he is my best friend. He loves me unconditionally and doesn't see anything wrong with me.

After we were married, I contemplated studying genetic counseling, but that meant moving to New England, and neither of us really wanted to move that far from our families. I decided instead to enroll in the Gestalt Institute of Cleveland to receive my certification to provide Gestalt Therapy and specialized in Physical Process. This was probably the best decision I've ever made, both personally and professionally. I was able to work through some grief issues around "not being normal" that I thought had been dealt with long ago.

When my first nephew was born I began to get "mommy fever," but I had been cautioned from an early age about having children and the risk of passing the TCS gene on to my child. I truly felt tormented, there's just no other word that better describes having to make that decision. We thought about adoption, but nothing ever worked out.

I finally got pregnant and lost the baby at about 11 weeks. I thought this was a sign from God that I wasn't supposed to have a child. I just knew it. So the torment became anguish and obsession. It was ALL I could do to function. I was clinically depressed. I functioned on auto pilot most of the time and just did what I had to do. Keep in mind, during this time, I was the Director of a Partial Hospitalization Program and had a small private practice on the side in West Virginia and managed to keep it together for nine months.

One night I can remember crying in bed, rolling from one side to the other, in so much emotional pain. I just wanted relief. WHERE WAS GOD? Then, it dawned on me—when was the last time I prayed? I was so angry at God for taking my baby. I was angry at God for making me this

way. I was angry at God for putting me in this position to have to even make a decision. "Where are you?" I asked out loud.

I began to pray as earnestly and honestly as I knew how. I remember saying, "OK... I get it... you are in control, not me. I just need help... I can't do this anymore. I really want a baby, but if I'm not meant to have a baby, then just take this pain and desire for me to have one away and let me feel normal again."

I instantly felt a hot/cold sensation going all over my body and I felt a peace like I've never felt before. I immediately started to cry and got up to tell my husband it was going to be okay, and that we could have a baby. I'm certain at

that point he thought I'd lost my mind. He just said, "Okay, honey. Go back to bed and we'll talk more tomorrow."

I became pregnant shortly thereafter and my entire pregnancy was wonderful! I wasn't anxious, and I didn't worry if the baby was okay, because I knew, whatever the outcome, God would take care of my baby the way he has always taken care of me.

**Mara Camille** was born on October 7, 2000, by caesarian. My eyes were fixed on the Doctor that was delivering because he knew my story and I knew by my education and training that I could see his reaction and be able to tell if she was okay or

see  
**tiffany**,  
page 7



# testimonial

Our family was abruptly introduced to a life-changing experience in the fall of 2012 when our son, **Caleb** was involved in a bicycle accident that left him with a broken and dislocated jaw and traumatic brain injury. For the next 2.5 years Caleb underwent a handful of surgeries and endless hours of rehabilitative services to regain some lost cognitive skills. The care and services Caleb received from the childrens' medical systems in Portland and Seattle were nothing less than extraordinary.

Unfortunately, we live 4.5 hours away from Seattle and to attain the specialized medical care we sometimes had to negotiate remarkable logistical challenges just to make it happen. This is where Children's Craniofacial Association (CCA) was a Godsend by answering the call to one of these challenges and making his final surgery a possibility.

The surgery required us to remain in Seattle for a 7-day stay and we were faced with multiple difficult choices, from finding accommodations (and how to pay for them), whether

or not we could bring his siblings and if both parents could even be by his side during his surgery and recovery. CCA made the impossible possible by their generosity and genuine concern for the health and morale of our family. Through CCA's bountiful contribution it allowed for all of us to be in Seattle for the week and resolved the unknown for our family. Most important, it allowed us the opportunity and ability to concentrate on his care and recovery.

I believe whole-heartedly that since we had the ability to provide our undivided attention toward his care and welfare during that critical week, it made for a speedy recovery. On CCA's webpage their mission statement reads: "...to empower and give hope to individuals and families affected by facial differences." I believe they fulfill this statement, because since Caleb's surgery, he now has the ability to smile, to really smile, and this gives us hope. Thank you CCA.

**The Moore Family**



**development director**, from page 1

weekend, kicking off the summer and the many wonderful CAM (Craniofacial Acceptance Month) celebrations in September ended the season. (See pages 8-9.)

Donors and in-kind supporters may continue to feel gratified, knowing those they are helping with their contributions are also striving to help themselves and others as our Family and Friends Fundraising is still responsible for a substantial portion of our income budget. We can't thank those parents and friends enough who put their CCA kids in the spotlight for the greater good. They hold funders in their own child's or a friend's child's name to benefit all CCA kids and their families.

It's crucial for the mission of Children's Craniofacial Association that we continue to increase our donor base just as the numbers of those we serve is ever increasing. Since CCA doesn't buy or rent lists, this organization grows from within. These "funders" make both sponsors and individuals aware of our cause, and many sponsors have become ongoing corporate and individual supporters.

Social media has allowed us to take our message to the general public, and we are enjoying

growth in awareness and engagement on Twitter, Facebook and now Instagram. We've increased our followers and fans, and a lot of that fundraising is now happening online!

Our CCA Kids are impressive representatives of Children's Craniofacial Association and are growing to be young philanthropists themselves! Just one example is **Morgan**, who left a prayer request with her church for her birthday asking for a donation to her favorite charity. Her prayer was answered with a check to CCA!

You'll read about another one of our "Philanthrokids," Issaih, on page 24. And, still other kiddos and young brides and grooms too, are asking for contributions made to us in lieu of gifts.

There is just so much to be thankful for this holiday season. We're always reminded of the Charles Dickens' classic, *A Christmas Carol*, when Tiny Tim exclaims, "God bless us, everyone!" We wish everyone all the best in the coming new year, and I leave you with another Dickens quote: "No one is useless in this world who lightens the burdens of another."

Jill Patterson, Development Director

**tiffany**, from page 5

not. When she was born, he looked up toward the ceiling and whispered, "Thank you." I began to cry because I knew she was fine. The nurse wouldn't let me have her right away, I'm sure they wanted to check her out first, but then they brought her to me and that was the best feeling in the world, feeling her cheek next to mine.

Several years later, I was given the opportunity to fly to Los Angeles to possibly be on the "Dr. 90210" TV show. I knew someone who had a brother-in-law that was one of the doctors on the show. The producers were looking at changing up the show a bit from breast augmentations to human interest stories and thought I might be a good candidate.

That trip was very hard emotionally. I allowed myself to become excited about surgery, something that I had said I would never have again. Once we were there and had the consultation, I was able to see the computer enhancements of my image and what I would actually look like afterwards. It was amazing. I couldn't stop looking. The reality, unfortunately, was that I was not a candidate for the surgery because of the possibility of the skin and tissue dying around

my eyes after the implants were removed. What a balloon burst.

The day before we left to come home, I prayed all night. It was one of those nights where you fall asleep praying, feel like you wake up praying, and fall back to sleep praying again. I just asked God for a sign as to what to do or how to gain a sense of peace.

We flew back home on the red eye. When we landed in Columbus, a little boy who had been sitting in front of me the entire flight, whom I had not noticed, stood up, turned around and caught my eyes. He had Treacher Collins and was wearing bandages around his head. Until that day, I had never seen or met anyone else in person with Treacher Collins syndrome.

I knew this was a God Wink. I hurried off the plane, trying not to cry, and caught up with the boy's father. The mom had taken the little boy to the restroom and I chatted with the dad for a bit until the little boy walked out. He introduced us and we went on. I was in tears on and off the rest of the day. I felt such a sense of relief that I was on the other side of where that little boy was. I realized then, that this was the answer to my prayer. God allowed me to see for myself and I was okay. I

have a good life and I have been blessed with so many wonderful people and opportunities in my life.

There is not a doubt in mind that I would not be where I am today if it wasn't for Jesus and the prayers of so many faithful people that love me. It's now my turn to give back. I thought for so long, like many Christians, that going to church and getting your own "cup filled" was what was supposed to happen. That is true to a point, it's good to pray and worship to "get your battery recharged," but the church is outside of the four walls of the building you attend on Sundays.

God has been gracious enough to allow me to have a brain, given me the opportunities to get an education and specialized training to help people, and a special gift called Treacher Collins. Why would I not use those wonderful things to reach people? I am living proof that family and faith matter, and the concept you have of yourself is so much more important than the concept others have. I feel so strongly about the integrity and value of a person's character, and my life's goal is to be able to help others find that in themselves.



## annie's birthday wish

One of those who has inspired the "Birthday Wish" fundraiser bandwagon is our own **Annie Reeves**, and once again she set the bar high in order to beat her own record from last year! This year was special—it was her "milestone" 40th birthday—and her total came in at **\$1,615** for our CCA Kids! Thank you Annie, your friends and family—you've done it again!!!

We send a big shout out to everyone who holds Birthday Wish campaigns on Facebook for CCA throughout the year because these funds add up and that really IS icing on the cake!

# craniofacial acceptance month

beyond the face is a heart



CS MOTT'S CHILDREN'S HOSPITAL, MICHIGAN

This year marked the 11th year CCA observed September as Craniofacial Acceptance Month across the nation. CCA families, friends, volunteers and related support groups widened

the circle of acceptance for individuals with facial differences. The goal is to create awareness and help others see beyond physical differences to engage with each other on a deeper level.

Many of our CCA families were able to get their local newspapers to feature them in the paper and some were even featured on their local news stations. Radio stations also ran PSAs throughout September. We mailed out more than 200 Craniofacial Acceptance Month packets to 31 states! And, for the eighth year, CCA held National Picnic Day in September as part of Craniofacial Acceptance Month. CCA families across the nation held picnics in Florida, two in California, two in Michigan, Nebraska, New Jersey, South Carolina, Texas, Utah and Virginia. We would like to thank all of our amazing families and friends who held picnics, fundraisers, online funders, and shared our website and blog posts.

CCA thanks everyone for all their hard work in making Craniofacial Acceptance Month another great success!



CS MOTT'S CHILDREN'S HOSPITAL, MICHIGAN



CS MOTT'S CHILDREN'S HOSPITAL, MICHIGAN



NEW JERSEY



NEW JERSEY



MICHIGAN



OROVILLE, CALIFORNIA



NEW JERSEY



SOUTH CAROLINA



FLORIDA



FLORIDA



FLORIDA



TEXAS

SOUTHERN CALIFORNIA



MICHIGAN



TEXAS



UTAH



SOUTHERN CALIFORNIA



UTAH



UTAH



SOUTH CAROLINA



UTAH

# 5th annual reagan's rally

By Ashley Daugherty

Hard to believe this was the 5th year for Raegan's Rally—and what a year it was! **Raegan** is in first grade, and we really wanted to get the kiddos, staff and families from her school involved in this awesome event, so we made some changes!

This year, we made the 5k a Color Run! Those participating could run the Color Run 5K or a Fun Run (which incorporated all the Color Run color dashing, just at a shorter distance).

We had more than 100 participants register! Through the generous donations of the **Melillo**

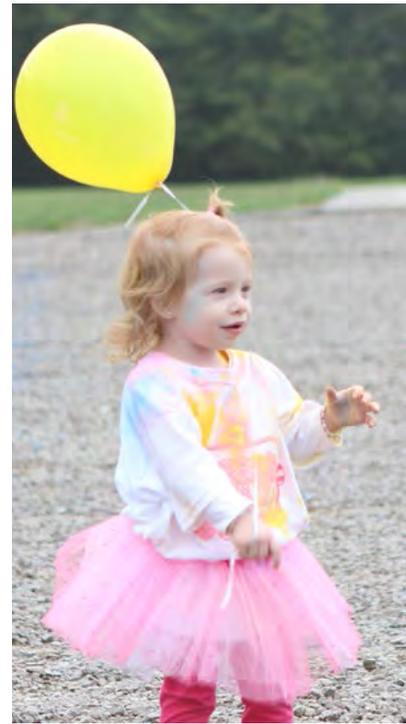
family, we had 100 pounds of colored powder and a 25-foot inflatable slide.

**Mark Meeker** with **Deerassic Park** offered the perfect location for the event. **Dave Vance** provided music with his DJ service to entertain the guests as well. **Cathy Gadd** and **Bryce Cree** painted faces. **Conn's Potato Chips, Kennedy's Bakery, Connie Daugherty, Michele Long, Nancy Arthurs, Cheryl Hlad, Ada Kunkle** and **Christi Smith** dished up some delicious food and desserts. **Joy Hannahs** even made a princess dress out of

cupcakes for Raegan and her friends complete with wand and crown!

The Color Run kicked off at 9:00. Friends and family manned six color stations for the participants to run through, where they were sprayed with an array of fantastic colors. Everyone was a winner in this race because everyone had a blast! The kids even got in on the action of throwing powder on the 5K participants at the finish line. (I think far more color ended up on them, though.)

Following the run, the raffles got under way. Prior to the event many



sold chances to win the following: A VIP tent at the 2016 Deerassic Classic (donated by Mark Meeker with Deerassic Park) and a Dirt Track World Finals package, which included seats, pit passes and camping (donated by **Matt Long** with **Charlotte Motor Speedway**).

Silent Auction items included a handmade wine rack and storage bench (donated and made by Nancy Arthurs), glass pitcher and cup set (donated by **Mindy Mosser** with **Mosser Glass**), OSU packages (**Ann Lanzer**), two necklaces (donated by **Ray Bradshaw** from **Kay Jewelers**) and a framed deer print (donated by Deerassic Park).

The White Elephant Auction is always a hit, and this year was no different.





Some of the items up for grabs included spa packages (**Allure Spa, Shear Dimensions, Jaquilienes Day Spa and Nautical Spa**), **Mary Kay** (**Allana Decker**), **Wild's** and **Zoo** passes (**Arin Harper** and **AVC Communications**), **Target**



gift cards (**Kaci Cree**), OSU packages (**Ann Lanzer and Friends**), Paintings (**Georgia Parsons** and **Cathy Gadd**), kids' baskets (**Michele Long** and **Learning Jungle**), **Pink Zebra** candles, oil changes, car detailing (**Classic Ford**), pizza packages, car washes (**Dunning Motor Sales**), crafts, a giant candy cake (made by **Christi Smith**), restaurant gift certificates and many, many other things. We are fortunate to have some very talented photographers close to us that helped capture the event—thanks **Mike Meeker** and **Mark Broom!**

Special thanks to **Pike Home and School** for their generous donation,



which allowed many of Raegan's friends to come participate in the event. And thank you to the staff at **Pike Elementary**, especially principal, **Ann Troendley**—without her help we wouldn't have been able to pull it off! It was a very heart-warming experience to see all of Raegan's friends from school, their families and staff from Pike Elementary

coming out to support Raegan and CCA. She is a very lucky little girl to be surrounded by such awesome people.

Also this event would not be possible without the support and help of all our friends and families! It takes the efforts of a lot of people to make such a sublime event this successful each and every year.



# new direction for seth's stride for cca

By Stacy Horne

2015 came with many changes for Seth's Stride for CCA as we broke away from our traditional 5k Walk and Family Funfest.

In the midst of revamping and brainstorming the future of Seth's Stride we were approached by a running company in our area called, **RunCanton**. They offered us an exciting opportunity to be one of four charities featured in the **Canton City Charity Chase**, a 5k and 10K run/walk.

The purpose of the Charity Chase is to simply recognize and support local charities trying to make a difference in their community. Needless to say, we were thrilled for the opportunity and recognition.

We are also happy to report this will be an ongoing relationship and the future of Seth's Stride.

More than 700 runners showed up on Sunday, August 30, at 8:00 am, presenting 700-plus opportunities to raise awareness!

**Sandy** and **Sam Klinger** once again came out to support us and help with the Seth's Stride booth. Our booth offered a basket raffle, face painting, and balloon animals, which

gave Sandy and me ample time and opportunity to have many conversations with those unfamiliar with craniofacial differences. The opportunity to educate others and playing a small part in the mission of CCA never gets old.

As we continue to make Strides for acceptance, we want our CCA families to know that our efforts are not only for our son **Seth** but for all children and adults with facial differences. It is for YOU! And it is an honor every single year!

Seth's Stride would like to thank our sponsors, **Marathon Petroleum** and **E&M Liberty Welding**, our loyal private donors and volunteers. And special thanks goes to RunCanton for giving us this incredible opportunity.



**FREE SHIPPING ENDS  
12/31/2015**

cozy shirts available in  
the **cca** web store



Long Sleeve Black T-shirts  
(Youth Sizes S-L \$20)  
(Adult Ladies/Men S-XL \$25 2XL \$28)

## dyson's cam raffle

**d**arryl, Deena, and **Teresa Joy Dyson** answered the question "What Time Is It?" with their "Acceptance Time" raffle to celebrate CAM (Craniofacial Acceptance Month). The raffle was for two Apple Watches and raised **almost \$2,000** for CCA in raffle tickets purchased from across the country!

**Tara Blackburn** of La Jolla, California, a repeat contributor to Dyson fundraisers for CCA, was the happy winner!

## Wonder Gift Sets

now available  
all the time!

Go to [ccakids.org/wonder-gear](http://ccakids.org/wonder-gear)  
to order yours!



### CCA Wristbands!

Order your wristbands today  
in Adult 8" or Youth 7" - \$1 each



# 5th annual trevor's trip to triumph motorcycle ride for cca

by Kim Trzanowski



Once again, the Trevor's Trip to Triumph Motorcycle Ride for CCA was a great success. We had about 40 riders this year and close to 100 attendees, including family and volunteers. We are so blessed to have the support we had this year—together we raised about **\$2,000!** Thank you from the bottom of our hearts.

In particular, we would like to thank all those that participated, donated and attended in person as well as sponsored our awesome T-shirt—thanks to **Belly Acres Designs** for always coming through with amazing work. Some of our sponsors were **Freehold Elks Lodge #1454, Freehold Elks Lodge MC, the Larys Family, Liberty H.O.G., Harrison East Newark Elks Lodge**

**#2326, Manasquan Elks Lodge #2534, Old Bridge Elks Lodge #2229, Edison Elks Lodge #2487, Millstone Elks Lodge #2613, Howell Elks Lodge #2515, Red Bank Elks Lodge #233, Visiting Angels of Matawan, Tara Gostovich, DMD, Dr. J's Window & Screen, P.M. Electrical Service, American Legion Post 5, American Legion Auxiliary Unit 5, Sons of the American Legion Squad 5, Andrew Prince Esq., Prosno, Honor Guard MC Avenel, VFW, Jerry Friedman, Esq., Mike and Tammy Walters.**

We especially thank **Donna Badilla** and **Greg Toth** (We could not have done it without their support and basket-making skills!) as well as donations

from **Karen Azzarello** of **Dove Chocolate Discoveries**, who made me the most delicious white chocolate raspberry drink; **Uncle Gino's** and **Livotis** for donating food, **Alberto's Italian restaurant, Dunkin Donuts of Marlboro** and all the people who personally donated food they took the time to make with love, including the most scrumptious desserts!

We had 45 tricky tray baskets to raffle off, three super-size prizes, and tons of donated food and desserts. Thank you also to **Classic Flashback** and band leader, **Richard Cusamano**, for donating



four hours of awesome live music.

We love you all, and look forward to continuing to support our beloved CCA family and all those who support **Trevor** on his journey—we couldn't do it without you.



# 2015 miles for cca kids benefit ride

The 2015 Miles for CCA Kids Benefit Ride was held on Saturday, July 11, raising more awareness for our kids as well as **almost \$5,000**. Once again, **Reverend Lewis Boykin** coordinated the event with wife, **Carla**, and enlisted volunteers **Gen White, Stephanie** and **Darren Pollack, Katherine Pels** and **Christina Mayo** to help with sponsors, prizes, registration and checkpoints for biker participants.

We would like to thank "Leaders of the Pack" sponsors **Adkerson, Hauder & Bezney, The Law Offices of Stephen Blaine Smith** and **Lauscus & Associates**.

We would also like to thank our "Road Captain" sponsors: **2nd Sunday Biker Church; Praise Hymn Fashions; Via Real, Las Colinas, TX; Lantern St. Grill & Tap**



**House; Redneck Heaven, Lewisville, TX; Rock 101, Little Elm, TX; Nick's Bar & Grill, The Colony, TX; Renegade Classics, Carrollton, TX; Maverick Harley-Davidson, Dallas, TX; Quaker Steak & Lube, Plano, TX; Hooters of Mesquite, TX; Hooters of Lewisville, TX; Ekvall & Byrne, LLP, and Complete Appraisal Services.**

Helping with our fundraising totals for the day were the general public, who patronized

each of the stops during the day and joined in with our raffles and fun. They helped our CCA kids and left knowing more about our cause.



Thank you one and all, and we hope to see you next year when the run will visit all the **Sports City Café**-owned locations, including **Nick's Bar & Grill** and **Sneaky Pete's!**



## NOW SELLING YEAR 'ROUND



### "I read Wonder!" T-Shirt

Stock sizes: Youth M-XL \$15, Adult S-XL Ladies S-XL \$20

**FREE SHIPPING ON T-SHIRTS!**

Special Quantities / Sizes / Prices available upon request



to have a C-section, and I remember by obstetrician saying, "These are big babies that will be ready to go home before you will."

On September 3, 2004, I gave birth to **Ella Grace** and **Anah Faith**, just a minute apart. They were a great size for twins at 6 pounds 3 ounces and 5 pounds 11 ounces. But while I was on the operating table the nurses told us there was something "wrong" with our babies. They quickly wrapped them up, showed me their little faces (that were very cute) and then took them to the ICU. Garret was going back and forth between the babies and me. He showed me cute pictures on our camera and kept tearing up as he updated me. I felt

very groggy and confused and kept asking him if he was happy or sad and he kept answering, "Both."

The first 24 hours were so confusing and scary. They didn't let me see my baby girls for eight hours while I was in recovery. We had no idea what our daughters had or what they were facing. A social worker from the hospital came to see me and just said, "Sorry about your babies, let me know if I can help." No words of encouragement or a congratulations. I began to worry that whatever Ella and Anah had, it must be awful or even terminal. I could not stop crying. I was in shock and so overwhelmed and scared. This was not part of my plan! Questions

and emotions flooded us. Would they walk, talk, survive? Did I do something wrong while I was pregnant despite trying to do everything right?

The next day a geneticist came to the hospital and gave us a clinical diagnoses of Treacher Collins syndrome (TCS) and that information was so encouraging. We felt such relief to have some answers to our questions, that our babies would indeed walk and talk and live a full life. Within a day we Googled TCS and came across a few websites that were very reassuring. We read about men and women who were educated, married and had children. Many of our fears turned to hope.

The first three weeks we just held our babies every

day, all day, and waited to take them home. However, it soon became apparent that the girls' small jaws were causing problems for them when eating and breathing, especially Anah. After three weeks in intermediate care at a smaller hospital, we were transferred to a larger hospital. We had no idea what we were in for, what our babies were about to endure. What was supposed to be a week-long stay turned into four months. What was supposed to be a simple surgery turned into several surgeries with multiple complications.

The first time Anah went into surgery, I sobbed the entire time. I had never felt so helpless in my life. All I could do was pray and hope. Garret was my rock, but he was struggling too. We prayed together, and we begged our family, friends and church to pray with us. Anah's airway was a bit smaller, and so much of the focus was on her. She had several surgeries, including choanal atresia repair, a g-tube, a tongue/lip adhesion, a fundoplication, and, when she was two months old, she had a tracheostomy.

Every surgery on her little body had ended with complications. After her

first surgery, she developed a lung and bladder infection and needed a blood transfusion. I was so excited to hold her one morning after three weeks of intubation, and, just as I picked her up, she began to vomit huge amounts of blood and clots. I was pushed out of the way by nurses and doctors calling codes and trying to figure out what was happening. I truly thought she was going to die. They attributed the blood to ulcers and thankfully, she was fine after a transfusion. Soon after that Anah got her trach and fundoplication. She developed a large blood clot in her leg that required heparin needles for months and a severe site infection that we had to open and pack every day, taking months to heal. It has been 11 years, but when I think of these moments, I am still flooded with anxiety and tears.

Ella fared better but still ended up with choanal atresia repair, a g-tube and, at times, oxygen. One specialist suggested Ella needed a trach as well but others had a different opinion and she was able to go home without. She moved to a different floor of the hospital, while Anah had to stay in the NICU.

I loved when they finally got to share a room. From birth to three weeks they shared a bed but then were separated on different floors of the hospital for weeks. There was such a calmness and joy when they were reunited and we could all stay in one room.

We tried to keep a sense of humor and stay positive as much as we could. When CT scans showed the girls' ear canals were not open to their sinuses, we said, "Great, no ear infections." When Anah needed her fundoplication to stop her from throwing up, my husband joked, "Well, at least she won't be bulimic." We made fun of each other's sleeping habits in the hospital and how the nurses probably heard us snore and saw us drooling in our sleep.



We put down mats on the hospital floors and we played. Garret and I enjoyed our babies like all parents do; their warm bodies on our chests, their sweet smells, their tiny hands and feet. We delighted in their first sounds and smiles. Many days were a roller coaster of emotions—from fear and frustration to joy and

see **kryzanowski family**, page 18

**kryzanowski family,**  
from page 17



laughter. I'm just glad there was so much of the latter. Our faith, our supporters and our humor got us through those difficult months in the hospital.

After four-and-a-half months in the hospital, Ella and Anah were finally stable enough to go home. Although it looked much different than I had ever imagined, it was so wonderful to finally place them in their car seats and stroller and cribs that we purchased months before they were born. There was so much equipment: suction machines, humidity compressors, two feeding poles with pumps, oxygen, emergency kits, etc. Nursing agencies had shortages in our area and the hospital would not

allow us to leave without night nurses, so we hired several staff, many who became such a blessing and are part of our lives to this day.

Although there were many challenges, it was clear early on that Treacher Collins syndrome really is just cosmetic. Both Ella and Anah sat at five months and walked before a year old. They were so happy and social, they brought smiles and joy to almost anyone they met. We began going to a group for children who are hard of hearing. They were both signing over a 100 words before they were 18 months. We took Ella and Anah to church, the zoo, on holidays to the mountains, and even just weekly grocery shopping. Despite needing a diaper bag, an emergency bag, a suction machine, feeding pumps and for a short time, oxygen tanks, we ventured out anyway. Yes, there were stares, especially when we flipped on the suction machine!

At first it really bothered me, but it got easier the more we went out. We rarely notice anyone staring anymore (I'm sure they still do), because we are just enjoying our lives. We've had some extremely rude comments and experiences, and several broke my heart, but mostly people are friendly and curious. We really wanted to give Ella and Anah every possible experience we could give them. Not that it was an option, they were these happy and social little butterflies that craved to get out of the house more than I did. We had our share of tears and mourning our expectations, but there was unbelievable joy that first year too.

Anah was decanulated soon after her third birthday, and we were so excited! Unfortunately it soon became apparent she was not breathing well at night. The specialists said it would take her time to adjust to not having a trach, then they suggested oxygen, then c-pap and then bi-pap and then orthodontics. There have been some improvements, but she continues to struggle at night.

Anah's heart and development are tested every year to ensure her apnea is not causing any

damage, but her growth significantly slowed after she got rid of her trach. My identical twin daughters now look like they are two years apart in age. There are so many hard choices as parents, especially when different doctors give you different advice and the decisions are left to us. We do the very best we can with the medical information we have and knowing our children more than any specialist could. But there are always doubts and questions as to whether we're making the right decisions.

Ella and Anah just turned 11 and are in the sixth grade. Since Kindergarten they have been in a mainstream class at a small K-12 Christian school and are excelling and achieving A's and B's in every subject with only an FM system as support. They are social and have very close friends at school. Both have been in various activities over the years, such as swimming, gymnastics, piano, ice skating, basketball and dance. They love reading, going to amusement parks, playing outside and playing on all their electronics. They are boy crazy, and they love to design their future houses, both of which I blame on the "Property Brothers" from HGTV.

Their biggest challenge is speech. Despite starting speech therapy at a young age, both girls have a phonological delay that is impacted by the structures of their mouths and pallets. It doesn't help they are tweens that talk a mile a minute. They are working on self-advocating and slowing down their speech with new people/situations. All of us who know and love them understand them just fine, but some people in the community have a more difficult time deciphering what they are saying.

Ella and Anah are very aware of having TCS and are overall confident and happy with how they look. They have been offered to have their ears reconstructed but they

are both happy with their little ears, just as they are. I remember a few years ago Ella said to me, "I feel bad, but sometimes I just think I'm cuter than a lot of kids." Garret and I desperately want them to not just be confident but to truly love themselves and know how amazing they are.

The girls really enjoy being big sisters to their adopted brother **Keanu**, 8, and baby sister **Maisie**, 18 months. When the girls were 6 we adopted Keanu after seeing him on a local news program that he was looking for a forever home. He was so cute and although he didn't have little ears, the girls noticed he had little hands (Arthrogryposis) and

therefore would fit into our family perfectly.

Ella and Anah have both become "little mamas" to Maisie, and I can completely imagine them being wonderful mothers someday. They are starting to understand that they have a 50 percent chance of passing TCS on to their own babies. For about two years after the girls were born I wondered if I had TCS. Garret and I had conversations about risks if we had more children; I imagine our girls will have those same discussions in the future. We pushed for genetic testing, which confirmed that neither Garret nor I have TCS. I was both relieved and strangely disappointed I didn't share that with my girls. Part of me has always wondered if maybe they were wrong.

It is far easier than I imagined having "difficult" conversations with Ella and Anah about babies, surgeries and their futures. They are both very mature when it comes to such topics. Garret and I will support Ella and Anah in their decisions regarding cosmetic surgeries and babies and anything else that comes along. We are beyond proud of who they are already and the young ladies they are becoming.

It's been 11 years and I'm so happy my five- and 10-year plans have gone by the wayside. Those plans were about an imaginary perfect life that, had they come true, could not have been as amazing as our life has actually been. That plan didn't include two little girls with TCS that would bring more to our lives than we could have imagined!

Ella and Anah have made us stronger, more positive, more humble and more compassionate and have filled us with joy. Without them I would not have met and befriended so many wonderful people, I would not have become an Early Intervention Consultant, I would not be a part of a wonderful craniofacial family that we feel so blessed to be a part of.

Garret and I believe that God has a beautiful plan for our girls and our entire family. That plan has been different, sometimes harder, but most definitely better, than our own plans. I'm still a planner, I think it's in my DNA; but much of that planning is about short-term goals, such as trying to figure out how to attend the next CCA retreat. We went this past summer for one of the best family vacation/experiences we've ever had.



## calendar of events

date event contact

### 2015

Dec 5 **CCA Holiday Party—Midwest** [JPatterson@ccakids.com](mailto:JPatterson@ccakids.com)  
11:30A-2:30P Brat Stop/Parkway Chateau 214.570.9099  
Kenosha, WI 800.535.3643

Dec 12 **CCA Holiday Party—Dallas** [AReeves@ccakids.com](mailto:AReeves@ccakids.com)  
10A-Noon Southfork Ranch 214.570.9099  
Parker, TX 800.535.3643

### 2016

Apr 15 **4th Annual Texas Moms' All the Way for CCA Golf Tournament** [ledestiny@gmail.com](mailto:ledestiny@gmail.com)  
Wildcat Golf Club  
Houston, TX

Jun 23-26 **26th Annual Cher's Family Retreat** [AReeves@ccakids.com](mailto:AReeves@ccakids.com)  
214.570.9099  
Hyatt Regency Pier 66 800.535.3643  
Ft. Lauderdale, FL



## joe's popcorn funder for cca kids

CCA Adult and Volunteer-At-Large, **Joe Brooks**, saw an opportunity in his community of

Fredericksburg, Virginia and went for it. **Jim Ford**, local owner of **The Popcorn Bag-Fredericksburg**, pledged to donate 20% of purchases on September 5th to CCA, and then promised to match whatever was raised. He also challenged other local business owners to join him in matching. It was a perfect time for Joe's funder since The Popcorn Bag was introducing some yummy new flavor combinations! When all was said and done, Joe sent us a check from Jim in the amount of **\$500!** That's a lot of popcorn! Thank you for Popping for a Purpose!

# good news

## northpark 50: fifty years of giving

**N**orthPark Center in Dallas celebrated their 50th anniversary by saluting 50 outstanding organizations from August 20 to October 28, 2015, (50 days) through NorthPark50: Fifty Years of Giving. CCA was honored to be named one of the organizations recognized. They realize our Annual Family Retreat is truly a life-changing experience for the entire family. The NorthPark 50 celebration gift to CCA makes it possible for more children and families to participate in 2016, and the funds will benefit all who attend. We're extremely grateful!

## a living legacy

**W**e wish we could thank those who thought ahead, arranging planned giving according to their wishes—many times without even telling us—all those who made the decision to champion CCA by leaving our charity in their will.

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.



# sponsors needed for cher's family retreat!

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

From time-to-time we've had T-shirt sponsors, but we are in need of more sponsors. This year we are offering named sponsorships for events like the ice cream social and farewell breakfast. If you know of anyone who might be interested in supporting this worthwhile program, please have them contact our office. Email [contact@ccakids.com](mailto:contact@ccakids.com) or call 800.535.3643.

## registration is now open for 2016 cher's annual family retreat

**June 23-June 26  
in Fort Lauderdale, Florida**

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

For more information,  
please contact Annie Reeves,

[ARees@ccakids.com](mailto:ARees@ccakids.com)

We hope to see you there!

**Registration ends May 13, 2016.** Register by May 1st to get the early bird price of \$100. Registration will increase to \$125 starting May 2nd.

### GO PAPERLESS and

view the newsletter

online in FULL COLOR!

Please sign up on the

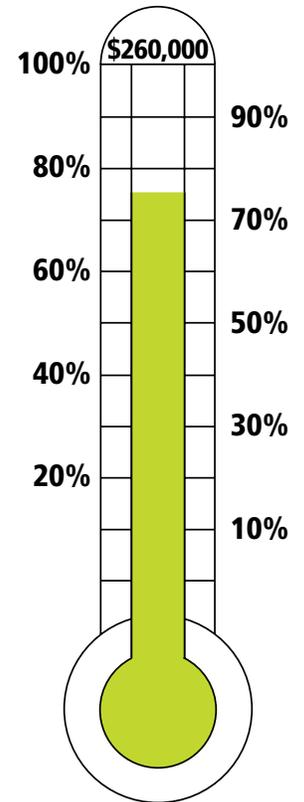
home page of our

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**environment and**

**save money for CCA.**

### 2015 FAMILY FUNDRAISER GOAL THERMOMETER



To see CCA's list of donors as of September 30, 2015, please go to our website. The list can be found at

[www.ccakids.org/donor-list.html](http://www.ccakids.org/donor-list.html)

## state assistance:

**d**id you know that many states offer **funding/small grants to individuals with disabilities and their family members to attend advocacy trainings, learning events and conferences?** The **CCA Annual Family 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](http://ccakids.org/state-funding.html)

# 8th annual links of love golf tournament

The 8th Annual Links of Love Golf Tournament took place on Friday morning, September 25, at Bear Creek Golf Club, Dallas, Texas, grossing **more than \$17,000**. Registration began with morning coffee and baked goods from **Starbucks** on **Inwood**, and golfers were fitted for gloves sponsored by **Credit Union of Texas**, who also handed out goodies like golf towels and ball markers along with cart sponsor, **FairLease**.

CCA Mom, **April Gorman**, said a few words about CCA before tee off, and we had two CCA kid golfers, **Levi Scroggin** and **John Gorman** as well as the many CCA kids and CCA adults represented on photo signs at each tee box beside sponsor signs. Our volunteer crew included **Judi Freeman** and **Susanne Archer**, who helped with auction setup, registration, on-the-course contests, post-tournament festivities and clean up. Golfers were treated to lunch afterward, catered by **Spring Creek Barbeque**, and enjoyed a door-prize raffle, awards and auctions.

Many thanks to all who helped make the 2015 Links of Love a success, our volunteers, participants and especially our 2015 8th Annual Links of Love Sponsors:

## Gold Sponsors

(\$1,000 or more in Monetary/Goods/ Services Sponsorship)

Dallas Labs  
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Spring Creek Barbeque  
Credit Union of Texas (Gloves)  
FairLease (Carts)

## Silver Sponsors

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Reverent Technologies  
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William Gorman, MD  
Hardt Group  
Paragon Sports Constructors

## Pin Flag Sponsors

Steven & Petty Weiss  
Vance & Judy Kemler  
RC & Sallye Rife

## Auction Sponsors

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Quentin D. Witherspoon Distillery  
Fuzzys Taco Shop  
Ken Kirchofer  
Starbucks

## Other Sponsors

Avid Golfer  
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Bob Guzzo  
Gecko True Value  
Bob Montgomery  
Top Golf  
Charles Schwab  
Williamson Creative Services





## donors in the spotlight

While ALL of our donors are special to us, we like to feature those who've given in many different ways because we know this is of interest and will inspire everyone. For that reason, our donors in the spotlight this year-end are **Larry Whitler** and **Robin MacBlane**.

Larry and Robin do a morning radio show on WOCA in Ocala, Florida, and are also known to many as "Robin and the Giant," a children's musical act, though they are known to entertain elsewhere too, wherever a smile is needed.

Their affinity for helping children goes without saying, but how they came to embrace CCA's cause happened in a roundabout way. One of their listeners told them they were in good company with **Cher**, another entertainer who cares for children, as she's the spokesperson for an organization that helps children with facial issues. They decided to see if they could get an interview with her to ask about their mutual passion for helping such causes.

They were unable to make that happen, but were introduced to Children's Craniofacial Association. Larry and Robin have since interviewed our executive director on the air over the years as well as other representatives, and we have recurring monthly online monetary gifts coming our way too!

But it goes beyond that. Their tweets and posts for awareness are regular, and they are on board with all of our campaigns. They launched their own "Queen's Wave" video for our CCA Kids and attended the Orlando CCA Craniofacial Acceptance Month picnic in their area!

Please listen and watch this original piece, a love song and video created by Larry and dedicated to our CCA kids: <https://www.facebook.com/video.php?v=10152752734803434>.

We're happy to have friends like Larry and Robin, our latest Donors in the Spotlight.

## matching gifts

Children's Craniofacial Association (CCA) provides support for patients and their families affected by facial differences resulting at birth, later in development, or from accident or disease. Support is provided through our programs and services at no charge so we rely heavily on your gifts to do this. We encourage you to consider maximizing the impact of your donations through your company's Matching Gifts program. Please contact your

Human Resources department to see if your company will match your donations to double your contributions for CCA!



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[ccakids-cardonations.org](http://ccakids-cardonations.org)

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their name and address.

## Issiah's lemonade stand for cca

by Jessica Eakright

At the Annual Family Retreat in June, Issiah set a goal of raising \$100 for CCA. We thought a lemonade stand would be his best bet for raising the money and decided to hold the lemonade stand in September during Craniofacial Acceptance Month.

We started a FirstGiving page a few weeks before the actual lemonade stand, and within the first few days it became apparent that we were going to need to raise our goal amount. We had Issiah's lemonade stand on September 20th and couldn't have asked for a more beautiful day! We had an information table with CCA buttons and bracelets, T-shirts and lots of lemonade! The lemonade stand raised a total of **\$1,594!** It was a huge success!

I wish we could name every single person who helped make this a success, however, that list would be quite long. So a special thanks to **Angela** and **Alisha Withered** for the awesome shirts! And to everyone who donated and helped Issiah reach his goal, know that we couldn't have done this without every one of you!

