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message from the development director

This year has been an exciting year full of opportunities for CCA and our families. We are thrilled to have more families fundraising in new and innovative ways. The most standout development of this year is the rise of social giving. We have seen social media, like Facebook and Twitter, recruit new followers to join us and support CCA Kids on Giving Days and through social media contests, viral videos, and the awesome Birthday Club, where kids and adults donate to CCA funds raised in honor of their birthdays.

ode to a superhero

By Amy Kern

Superheroes come in all shapes and sizes. They have special powers and secret identities, wearing masks and costumes. They are unique, brave, and battle supervillains.

I'll tell you a secret if you promise not to tell—a superhero lives in my house. He says his name is Batman, but we call him **Matthew**. Already at age 6 he has had to battle so much.

Matthew's extraordinary birth happened to two ordinary parents. I never went into labor and having polyhydramnios, too much amniotic fluid, my doctor did not want me to go past my due date. So at exactly forty weeks and one day, Ed and I settled into the hospital room for an induction. After forty long hours of chemically induced labor, I was not progressing and the decision was made to have a C-section.

see **superhero**, page 16

see **development director**, page 11





meet wyatt dearmond

ccakid

four-year-old **Wyatt DeArmond** is one smart preschooler. He counts to 100, knows his letters and likes to read. On top of that, he taught himself how to play the piano. Incredibly, he listens to a song, sings it to himself and then quickly figures out which keys make the right sounds. So far, he can play “Twinkle, Twinkle Little Star,” “Old MacDonald” and “Happy Birthday,” but I’m sure by the time we go to print, Wyatt has already taught himself a few more.

When he’s not playing the piano, he likes to play catch with his big brother, **Ethan**. Or they play football, pretending they’re Ohio State Buckeyes. There’s a whole lot of tackling and wrestling as well as a whole lot of giggling.

Whenever his brother has a sports game, Wyatt is right there, cheering Ethan on. And when he’s not playing football or cheering

in the stands, Wyatt and Ethan love watching their favorite TV show, *Paw Patrol*.

Wyatt enjoys painting and singing every Wednesday at his library’s Story and Music Time. He also loves the water, and swims any chance he can get. And he adores Thomas the Train. In fact, last summer he even got to ride on Thomas!

Wyatt and his family have been to a couple of retreats so far and have had a fantastic time at both. Wyatt has Goldenhar syndrome, and the retreats have given him a chance to be around other kids going through similar circumstances. He and his family loved meeting the other kids, siblings and families. They felt the atmosphere was great all weekend long, and they look forward to the next time they can go again.



ccaadult

meet genevieve desroches



my name is **Genevieve Desroches**. I'm 23 years old and from Queens, NY. I have five brothers and two sisters. I'm the oldest sister, but I'm younger than all of my brothers. I like watching my favorite TV shows, shopping and hanging out with my friends and family. I enjoy listening to music and love to dance. I have been dancing since I was 7 years old, and took ballet classes when I was in the sixth grade.

I was born prematurely on September 24, 1993, and was diagnosed with Pfeiffer syndrome. When I was born, I had trouble breathing and turned blue. The doctors fitted me with a trach tube, which saved my life. It helped me breathe better and, later on, helped me talk. I had a G-tube because I had trouble eating by mouth.

I also had a hearing aid and a shunt.

The hardest part about my childhood was being bullied every day at school. Kids called me "bug-eyes girl," "scary monster" and all sorts of other mean names. The kids didn't want to sit next to me in the lunchroom because of the way my face looked. I always came home crying to my mom, telling her I don't want to go back to school. But my mom always said to me, "What big eyes? They're beautiful eyes." Those words gave me confidence in myself and helped me ignore what people said to me.

The surgeries I've had throughout my life have been a painful struggle. Still, I feel blessed to be here. The doctors first told my mom I was never going to walk or talk. Well, I certainly proved them wrong.

When my mom first told me about the CCA retreat I was so happy. My mom couldn't go, so I went with my sister, **Alison**. When we finally got to Fort Lauderdale, I was really excited. The weather was so nice and beautiful during the retreat that I didn't want to leave.

What was nice about the retreat is that I met new friends, and we accepted each other for who we are. And it felt really good and inspiring to be around so many kids and adults going through situations similar to mine.

Thank you, **Annie Reeves**, for inviting us to the retreat. It was so nice to finally meet you. The whole weekend really did change my life! I'm looking forward to seeing you and the CCA crew again next year.

Genevieve (center) with new friends Cynthia (left) and Barbara (right) at the 2016 CCA Retreat and Educational Symposium.

ccasupersib

meet ethan dearmond

Ethan DeArmond is 7 years old and a first grader at the same school where mom teaches in Marysville, Ohio. He loves to play outdoors and has participated in baseball, soccer, and basketball throughout the year. Ethan also loves to watch football and is quite the

statistician when it comes to remembering the names and plays of his beloved Ohio State Buckeyes. He likes to tell jokes and is very competitive at board games. Ethan is a good helper and has two pet fish named Stripey and Zoom that he cares for each day. He is a loving older brother



to **Wyatt**, as well, and does a great job looking out for him. Wyatt adores playing catch with his big brother and giggles with delight when they do silly dances around the living room. Ethan can usually be found building elaborate

things out of blocks or train tracks; meanwhile, Wyatt is tagging along and knocking them down. Ethan thinks his little brother is cute and it doesn't matter that he is different. Ethan says, "It is fun to be me!"

cca benefits from coto de caza's charity classic

On Saturday, August 20, CCA was one of the beneficiaries of the Coto de Caza Charity Classic sponsored by ClubCorp. The event raised just over \$300,000, which will be split between all of the charities selected as this year's beneficiaries.

The funds CCA receives from this event will be used to bring *Wonder* to every 6th grade student in the **Capistrano Unified School District**, helping further the awareness and efforts in the area which have been spearheaded by the **Mecklenburg Family, Chris Jones, the CUSD faculty and staff, and the Dankelson Family** who have traveled to Southern California to present #ChooseKind assemblies.

We had four CCA families representing at Charity Classic: **Erica Mossholder, Nick Wiese, the Dysons, and the Mecklenburgs**, including **Morgan**. They all did a spectacular job in representing CCA as they engaged participants in a Par 3 competition on the 16th hole and met with participants throughout the day. **Morgan and Teresa** worked side-by-side selling a game of chance and charmed every person they met. No one refused to



Charity Recipients at Charity Classic

make a contribution to this dynamic duo! **Nick** was an incredible ambassador, meeting and chatting with the golfers on the course and that night he gave a very moving speech that impressed everyone at the dinner. CCA is so grateful that we were selected and included in this fantastic event and we are so excited to bring *Wonder* to all the CUSD students, as we pair them with CCA Kids to deepen and strengthen their pledges to Choose Kind!



The Dyson family



Morgan Mecklenburg and Teresa Joy Dyson

9th annual links of love golf tournament



Mike Willard

The 9th Annual Links of Love Golf Tournament took place last September at a new venue, Firewheel Golf Park, in Garland, TX, grossing almost **\$15,000!** Registration began with morning coffee and baked goods from **Starbucks on Inwood & Willow**. Then participants were fitted for gloves sponsored by **Credit Union of Texas** and ate or grabbed box lunches before boarding carts sponsored by **FairLease**.

CCA Executive Director, **Erica Mossholder**, said a few words before the 1:00 pm start. She also manned a fun putting contest to give away a new **TaylorMade** driver and a dozen balls to a lucky winner. CCA Kids and CCA Adults were represented on photo signs at each of the 18 tee boxes beside sponsor signs. Our volunteer crew included **Judi Freeman, Rich Thomas, Torey and Randy Harrah**, helping with auction set-up, registration,

on-the-course contests, and festivities following as well as clean up! This year we welcomed **Christian Ladimir** from **Diamonds In The Rough Auctions** to add some interesting sports memorabilia to our auction. Golfers enjoyed dinner afterward catered by our friends at **Spring Creek Barbeque**, with door prizes, raffles, awards and auctions.

Many thanks to everyone involved with the 2016 Links of Love: our volunteers, participants and especially our "9th Annual Links of Love" sponsors:

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

Ben E. Keith / Real Ale Brewing Company
Spring Creek Barbeque
Credit Union of Texas (Gloves)
FairLease (Carts)
Paragon Sports

Silver Sponsors (\$750 or more)

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Team Margaret
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Starbucks
Hyatt Regency Hill Country Resort & Spa



CCA staff



Team Hardt Group / Ebby



Team Lavender



Paragon Sports

Other Sponsors

Avid Golfer
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Bob Guzzo
Gecko True Value
Charles Schwab
Williamson Creative Services
Starbucks
Prime Living Magazine
BCBS Texas
TaylorMade



Volunteer Torey Harrah, left

CCA Volunteer

2016 miles for cca kids benefit ride

The 2016 Miles for CCA Kids Benefit Ride took place July 16, raising more than **\$6,000!** **Reverend Lewis Boykin** coordinated the event, and **Dickweed Motorcycle Club** (with president **Tommy Purtle** helping at our registration table) along with **Gen White, Katherine Jones, Imperfect Society, Sharon Screws, Robert Paige** and **Max Screws** helped with sponsors, prizes, vendors, registration and checkpoints for biker participants and throughout the day.

We would like to thank "Leaders of the Pack" sponsors, **Adkerson, Hauder & Bezney, The Law Offices of Stephen Blaine Smith, Laucius & Associates, Ekvall & Byrne, Cole Investigative Agency** and **BikerLawyer.com**.

We would also like to thank our "Road Captain" sponsors: **2nd Sunday Biker Church; Praise Hymn Fashions; American Eagle Harley-**



Davidson, Corinth, TX; Hula Hut, Little Elm; Lantern St. Grill & Tap House; Rock 101-Little Elm, TX; Nick's Bar & Grill-The Colony, TX; Il Brothers, Hank's Texas Grill, Hooters of Mesquite and Acacia Insurance Managers, LLC.

And we couldn't have done it without our participants, who patronized each stop and joined in with our raffles and all-around fun, helping our CCA kids and leaving knowing more about our cause.

Thank you one and all! We hope to see you at next year's Miles for CCA Kids Benefit Ride—Saturday, May 20, 2017.



Tommy Purtle & Rob Gorecki



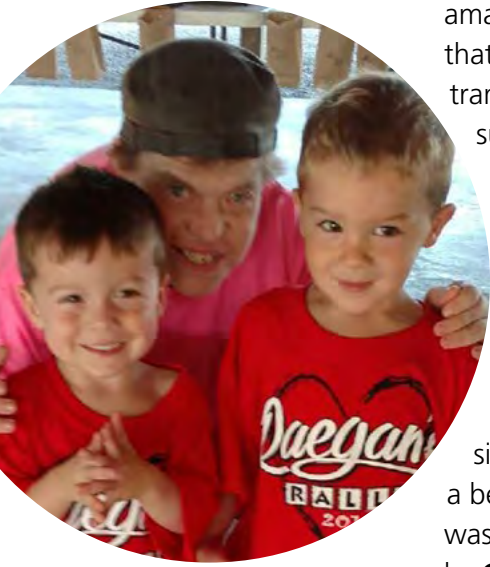
L-R Joann Boyett, Scott Reynolds, Shirley & Jack Holcomb



Ride Coordinator, Lewis Boykin

raegan's rally

by Ashley Daugherty



Raegan's Rally 2016 took place September 16 at Deerassic Park in Cambridge, OH, for the sixth consecutive year. As Raegan gets older, we try to make modifications to the activities to include her friends from school. This year Raegan picked a carnival theme. Thanks to the donations from **FK Rod Ends** and **Dirt on Dirt**, we were able to purchase wonderful games and prizes for the kiddos to win!

This year we were also fortunate to have volunteers from **Muskingum University** to assist in running the games! The kids played various games, winning tickets to cash in for various prizes. **Kasey Decker** brought her artistic talents to the event this year and provided some

amazing face paintings that were a huge hit! She transformed the kids into superheroes, princesses, and Buckeyes!

As always, we had wonderful donations to make the silent and white elephant auctions a huge success. In the silent auction we had a beautiful painting that was painted and donated by **Georgie Parsons**; an OSU lamp donated by Raegan's friend, **Josie Rome**, and family; many handcrafted, primitive wooden pieces made by **Nancy Arthurs**; and an OSU basket donated by **Carrie Matheny** CEO and president of **Shirley K's**. For the sixth consecutive year, we had a beautiful glass donation from **Mindy Hartley** with **Mosser Glass**. White Elephant auction items included a gymnastics session from **Zanesville Gymnastics**; many hunting items from **Gene Percy** with **Kansas Whitetail Adventures**; oil changes from **Dunning Motor Sales**; clothing items from **Cintas**; handmade blankets from Raegan's **Great Grandmother Ellen**; kids baskets donated by her **Grandma Michele** and **Grandma Cheryl**; a

"candy cake" donated by **Christi Smith**; **Columbus Zoo, Wilds**, and a real Ostrich egg donated by the **Canter family**; and many gift baskets donated by **Ann Lanzer**, **Galaxy Pizza**, **Jacqueline's Day Spa**, **Allana Decker**, **Cambridge Packaging**, **Central Station Steak and Ale**, **Nothing But Chocolate**, **Town House**, **Cindi Johnson** and many others.

Another hit at Raegan's Rally yearly is the snack area, and this year was no exception. Raegan's grandma, **Connie**, and **Joy Hannahs** made homemade noodles, **Haley McAfee** made many cupcakes (some even had icing on top!), and lots of delicious desserts were made by **Joy, Christi**, and **Michele**. **Conns Potato Chips** and **Appalachian Water** provided drinks and chips.

A ball drop was incorporated this year as well. One hundred numbered golf balls were sold prior to the Rally. This ball entered you for a chance to win one of the two following prizes: Ultimate Fan Package from the Coca Cola 600, donated by Raegan's uncle, **Matt Long**, with **Charlotte Motor Speedway** or \$500 cash. At the rally, the golf balls were loaded into the

bucket of a tractor and dropped. Two flags marked the winners on the ground. The winner of the \$500 cash donated the money back to the rally, which was a heartwarming moment.

We would like to give a special thanks to the staff of **Deerassic Park** for their continued support in Raegan's Rally. Without them it wouldn't be the success that it is. And we thank all of Raegan's grandparents who also donated their time in making this event run smoothly. Special thanks to family friends **Beth** and **Audrey** for all of their help. Raegan even had a special surprise with her **Aunt Amber** and cousin, **Madison**, joining us from North Carolina this year! And, as always, we thank her school family from **Pike Elementary**, who have become very close to us. We are so lucky to be surrounded by so many wonderful friends and families that take time out of their busy schedules to make this event such a success!





seth's stride

by Stacy Horne

Seth's Stride was held August 28, 2016. Once again, we joined **RunCanton** as part of the **Canton City Charity Chase**, a 5K and 10K walk/run highlighting local individuals and community charities. This year, Seth's Stride was one of five charities featured.

Thank you, RunCanton, for bringing Seth's Stride to the forefront of our community! Special thanks also goes to **Marathon Petroleum** for nine years of continued sponsorship, to our faithful gift basket donors **Lisa Chiavari/Nationwide Insurance, Steve and Jenifer Miller, Creekside Cottage Winery** and **Carol Minock**. Many thanks to



Chiavari's Bakery and Café for setting up at the race and donating half of your proceeds to Seth's Stride! To our faithful personal donors—we truly appreciate what you give each year. And to our volunteers and families, thank you for supporting our efforts as we continue to promote acceptance!



help host local wonder premieres in your hometown!

CCA wants you to host a local premiere of the movie *Wonder* in your town! We are currently in the planning stages with volunteers and educators across the country to organize event groups who will host a "local premiere" of *Wonder* in April 2017 at the theatre of your choice. Groups that can participate include schools and classrooms, libraries, hospitals and craniofacial teams, CCA families, civic and religious groups, and honor clubs.

The volunteer group will be responsible for selecting a date and location, inviting their friends, family, and local community, working with vendors to get a red carpet and "paparazzi banner," and inviting local media, photographers, and celebrities to the event.

CCA will help with your promotions and planning efforts. If you are interested in hosting a premiere in your area and being connected with others in your area, sign up at bit.ly/ccapremieres.

global genes



tirelessly, not focusing on what was, but setting their sights on what can and will be, in research, advocacy, treatment, and community building.

This year, as part of the celebration, **Peter Dankelson** was honored as the **Champion of Hope:**

Teen Advocacy for his work with CCA's #ChooseKIND Wonder Initiative. We could not be more proud of Peter and grateful that Global Genes honored him at their Tribute to Hope Gala on Saturday, September 24. Peter was recognized for his work speaking to students around the country and Skyping with classrooms weekly about the importance of choosing kindness to overcome hate, fear, isolation, and bullying. He spoke to over 4,000 students last year and has already booked speaking engagements that will reach over 3,000 more students this spring.

As part of this honor, Peter was given an amazing opportunity to address the crowd of 700 at the gala and was presented his prestigious award by two Navy SEALs, **Geoff Reeves** and **Travis Lively**, who honored Peter and his SuperSib, **Jacob**,

Each year, **Global Genes**, a national rare disease advocacy nonprofit, hosts its annual Tribute to Champions of Hope Summit and Gala, where they host rare disease champions, patients, researchers, experts, and community members from around the globe who are proving that great things can be accomplished by dreaming, planning, taking action, and believing in the hope for treatment and cures.

The results are quite inspiring, and this year was no different!

The purpose of the Tribute to Champions of Hope is to recognize those who are uniquely attacking the challenges they face in the fight against rare disease; those who are thinking outside of the box and working



Navy SEALs Travis Lively, Geoff Reeves, and Jacob and Peter Dankelson

with the Champion of Hope award and a huge box of SEALs goodies, including SEAL-issued boots!

In addition to these American Heroes in attendance to honor Peter, CCA invited celebrities to join us in the audience to celebrate Peter, including **Ed O'Neill** and his wife, **Cathy**, and daughter, **Sophia**, actors **Louise Barnes-Boraine** and **Nick Boraine**, and director **Edward Edwards** and his wife,

Louise Barnes-Boraine, Ed O'Neill, Peter Dankelson, Edward Edwards, and Nick Boraine

Liis. Also in attendance were **Darin, Dede**, and **Jacob Dankelson**, **Erica Mossholder**, and **Morgan Mecklenburg**. But without a doubt, Peter was the star of the show, and CCA could not be more proud of his hard work! We are grateful to the entire **Dankelson family** for their tireless efforts to widen the circle of acceptance. Thank you Global Genes for recognizing Peter and his incredible advocacy!



development director, from page 1

Two big “wins” for CCA from our social media community include a year-long ad campaign in *Prime Living magazine*, that featured a full-page spot for CCA in every issue, and the amazing **Ansell Nurse HERO award**, won by CCA Mom **Rebecca White**, for \$10,000 (see page 23)!

However, we have also seen an increase in financial assistance requests and applications from schools that want to participate in our Choose Kind *Wonder* program. CCA wants to keep up with the demand! We are funding medical travel, printing educator guides for classrooms, connecting with new families who want to attend Retreat, and shipping books at a growing rate. Now, more than ever, we are grateful to our monthly donors who’ve set up an auto-gift. **Truly, the gift that keeps on giving, recurring givers are the bedrock of CCA’s ability to serve families.**

We encourage you to pledge that in 2017, you will give a monthly gift. You can set it up on our website or through your bank or even through United Way. No amount is too small, and once you set it up, you will never forget to support CCA and

we will certainly not forget your generosity.

Our plans for 2017 include more ways to involve our communities and supporters. Through our outreach program with the Choose Kind Initiative, we will be bringing the message of acceptance to theatres in your hometown with the help of volunteers and educators. We are working tirelessly to help more students benefit from the Choose Kind message.

We hope that more families will contact us to continue to grow CCA through fundraising. We appreciate all of our families who donate their sales commissions, all of the teachers who host school drives, and everyone who has started up an online fundraiser. YOU make the vision of a kinder world a reality for our children and their families, and we are so grateful.

As we celebrate this holiday season, the season of giving, we ask for your generosity once again during our year-end appeal. We sincerely thank you for your support throughout this incredible year. Happy holidays and many blessings to you and yours!

Jill Patterson
CCA’s Development
Director



donor in the spotlight

my wife, **JoLana’s**, pregnancy with **Vienna** was complicated from the start. We lost Vienna’s twin a few weeks in. As the pregnancy progressed, we found out Vienna only had two vessel cords, instead of three. Everything progressed normally otherwise and on March 9 she was born with a condition we had no knowledge about. She was beautiful but her right ear and jaw were underdeveloped. We received a possible diagnosis of Goldenhar syndrome from a pediatric ENT when she was a week old.

We started doing research and I wanted to help others going through the same condition. I am a teacher and a bartender and love craft beer. The local brewery in Berlin, Maryland, had guest bartenders on Monday nights who would work for charity. When I was chosen to guest bartend, I decided to do it for Vienna’s condition and decided a great organization supporting that was CCA. We earned over **\$800** from sales, tips and a Chinese auction.

Vienna does have perfect hearing on the left side and we will get a Baha for her very soon. Her middle name, **Mirai**, means miracle, and she’s been proving to be a true miracle. Even the hole in her heart has grown shut! She is beautiful and developing ahead of her age group. She is joined in the family by her brother, **Preston**, who is four. We are a blessed family.

Greg Caldwell (and JoLana)

craniofacial acceptance month

This year marked the 12th 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 promote acceptance. Our theme this year has been “Different is Cool!” to remind us to celebrate each and every person’s uniqueness.

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. We mailed out more than 100 Craniofacial Acceptance Month packets to 29 states! And, for the ninth year, CCA held National Picnic Day in September as part of Craniofacial Acceptance Month. CCA families across the nation held picnics in California (2), Delaware, Georgia, Michigan (2) and New Jersey. We would like to thank all of our amazing families and friends who held picnics. A special shout-out to the New Jersey area picnic hosted by the **Merrill Family**, which had over 100 attendees. Wow!

CCA thanks everyone for all of their hard



ANN ARBOR, MICHIGAN

work in making Craniofacial Acceptance Month another great success!



ANN ARBOR, MICHIGAN



GEORGIA

LIVONIA, MICHIGAN



LIVONIA, MICHIGAN



LIVONIA, MICHIGAN

NEW JERSEY



NEW JERSEY

CALIFORNIA



CALIFORNIA



paint nite to benefit cca

In honor of Craniofacial Acceptance Month, the **Dyson** family sponsored a "Paint Nite" Fundraiser at the **Summit Bar and Grill** in San Jose, California. Deena Dyson chose the painting "Dare To Be Different," and the artists did not disappoint! Door prizes included copies of *Wonder*, and everyone went home with plenty of information about CCA in their "Choose Kind" gift bags. Many thanks to all who came out to celebrate the beauty in difference! The Dysons met their fundraising goal of **\$1,000** through this special event!

Thank you **Deena, Daryl, and Teresa Joy Dyson** and everyone who supported and/or participated!



Thank You,
Coto de Caza!



Your generosity shines through and we are so grateful for your support of our #ChooseKind Wonder program!



**COTO DE CAZA
GOLF & RACQUET CLUB**
A Member of the ClubCorp Family

BIG NEWS!
We got a challenge grant!
please **DONATE**
Now until Dec. 31,
every gift of \$500
or more will be matched
- dollar for dollar -
up to \$25,000!

more
fundraising
news




CCA Mom, **Dorina Watkins** designed and sold pins and keychains for CAM and sent CCA a check for proceeds of **\$103!**



Join the CCA
Birthday Club

If you donate your birthday, we'll send you a special prize, plus recognize your gift online & at Retreat!

Empowering & giving hope to individuals & families affected by facial differences ... since 1989.



fearless holiday cards

fearless is an inspiring collection of poems and illustrations created for children with craniofacial challenges. Originally published in 2001 by Children's Craniofacial Association, the small regional release was immediately embraced by children and families affected by facial differences. A 10th anniversary edition was redesigned as an ebook and continues to inspire families around the country.

Now the dynamic duo that created this original book of poetry for CCA Kids have done it again and

created a set of beautiful holiday cards with stories in poetry form that will inspire you and warm your heart ... all while spreading the message of acceptance to your friends, families, and colleagues. There are three new stories: *Christmas*

Kite, *A Fearless Carol*, *Esme Moody Brings You Tidings of Great Joy*, and a revised classic, *Crooked Smile*.

Please order a set (or several) today and they will arrive to you in time for holiday card mailing. Each set is \$25 (plus shipping)

and you get 20 cards (4 versions, 5 each) and 21 envelopes. The proceeds from these cards will further the mission of CCA.

You can read an exclusive interview with the creators, **Bradley Harding** and **Dan Gremminger**, on our blog.



Holiday Wishes

Order CCA Holiday cards in the webstore. Send holiday wishes and share kindness!

only \$25
for a set of 20 cards & 21 envelopes

superhero, from page 1



Excitement rushed over me as I finally heard our baby cry for the first time. Ed went over to cut the cord and take the first picture. Anxiously, I waited for my baby to be placed on my chest. As I waited, I heard the NICU being paged, the word “syndrome” being whispered, and the room getting really busy, really fast. “What is going on?” I asked Ed. At that moment, a nurse said “Mom, meet your son,” as a blur of little baby nestled in a blanket was rushed past me in an isolette incubator headed to the NICU.

Lying in an oxygen hood, IV in his belly button, and an oral-gastric tube taped to his cheek was how we first met Matthew. He seemed so tiny, yet fighting so hard. Beeping monitors and tiny babies surrounded us as we were informed by the neonatologist of

Matthew’s condition. He was born with a pneumothorax (which is the collection of air or gas in the space inside the chest around the lungs, which leads to a lung collapse), a PDA or patent ductus arteriosus, a cleft palate, and a rare syndrome called Treacher Collins syndrome.

The cleft in his soft palate led to feeding issues. He could not create enough suction for breastfeeding or for a normal bottle nipple. He was fed via IV until we found a way to bottle feed him. I never knew there were so many options. We finally found the Haberman nipple. He could do it, he could finally take a bottle! Reluctantly, the staff pulled his IV, but he had to stay in the NICU until he gained weight. He was moved to the “grower/feeder” side



of the NICU for a couple of days. When he started eating and gaining weight, they released us. Finally, after 7 days in the NICU, we took our new baby boy, our Haberman nipples, and our fear and excitement home to start our life as a new family.

Being a new family was exciting. The love we felt for this baby was like nothing either of us had ever experienced before. We knew we would do anything for this child. Matthew was a happy baby, hitting all of his milestones just as he was supposed to. We are fortunate to live close to the Children’s Hospital of Philadelphia (CHOP) and it was there we met our craniofacial team. Fumbling along from room to room with a three month old in tow, a stroller that was too big for any examination room, a diaper bag complete with diapers, wipes, bottles, burp cloths, an extra outfit (that was needed), and toys to keep him entertained, we met all of our doctors and specialists. It was an incredibly informative but exhausting day. At this clinic, we learned about Matthew’s TCS and what we needed to do medically to care for him.

Part of this process was learning about Matthew’s hearing loss. Matthew was born with microtia on left side and a cupped ear with a minuscule canal on the right. Due to this, he has conductive hearing loss; sound cannot pass from the ear canals to the inner ear. To allow sound to pass, a processor or Baha was needed. At five months old, Matthew got his first Baha. I will never forget the day it was first placed on his head. I looked him in the eyes and said gently “Hi, Matthew.” And he screamed. And screamed. And screamed. It took a couple of months for Matthew to get adjusted to wearing it. Until he got use to this new sense, we took it slow and gave him breaks from wearing it. He finally realized being able to hear opened up a whole new world to him and the Baha was the reason for that. These days, he can be overheard proudly telling people, “this is my Baha, it’s how I hear.”

Our next big step was his cleft palate surgery. It was 4 a.m. on Matthew’s first birthday. In the quiet stillness of early morning, Ed and I woke our sleeping baby. We gently placed him in his car seat, double checked that we had everything we needed,



and headed out on the now familiar trek to CHOP. Cleft palate surgery is a relatively routine surgery that **Dr. Bartlett**, his plastic surgeon, has performed numerous times. However, nothing is routine when it's *your* child. One of the hardest things I've ever had to do was hand my one-year-old over to the nurse that carried him to the OR. Slowly Ed and I turned away and walked through the double doors to the surgical waiting room. There we see the comforting faces of our parents that have come to support us during this difficult time. We spent the next three hours in idle conversation and watching TV, anything to distract our minds and keep our eyes off the

clock. Finally, we were paged to the phone in the waiting room. We stand listening as Dr. Bartlett informs us the procedure was successful, however, the anesthesiologists were walking a fine line between pain control and airway management. If they gave him too much pain medication, his oxygen saturation would drop so they erred of the side of less medicine. When Matthew awoke, he was in so much pain he bore down and blood oozed. They almost lost his airway. A nasal trumpet was placed to secure the airway and he was sent to ICU for monitoring. Our "routine surgery" extended to three days in ICU. Three days of Ed and me not leaving that ICU room. Three

days of sleeping on the floor or in a rocking chair. Three days of keeping our eyes glued to Matthew's monitor to ensure his oxygen saturation was not dropping. Three days of Matthew, without tears or fussing, enduring pain, catheterizations, and Velcro arm bands holding his arms straight so they could not get into his mouth. Three days of Matthew being incredibly brave.

The cleft palate repair was necessary, but a difficulty arose from it. Closing part of Matthew's tiny airway has caused obstructive

sleep apnea. Matthew experienced his first of many sleep studies at one-and-a-half years old. He stopped breathing twenty-seven times in one hour. We were told anything over three for a child is considered severe. We then went through the gamut of seeing every specialist to see what they could do for Matthew.

First stop ENT—a scope determined Matthew's adenoids and tonsils were small and therefore did not need removing. Second stop: Dr. Bartlett—he determined that Matthew's

see **superhero**, page 18



superhero, from page 17

jaw lined up and no jaw distraction was needed. Third stop pulmonary—our pulmonologist decided the best thing for Matthew at the time was CPAP. We found a mask that fit his petite face and got our machine.

This has not been an easy road. It is difficult to get a child to wear a mask and understand that the air blowing in his face helps them breathe. To this day, it is still a struggle, not with wearing the mask, but with keeping it on all night. Matthew's sleep studies have gotten better as he's grown older. With the results of the last one showing his breathing stopped only four times in an hour. We are seeing improvement and for that we are thankful. Hopefully, one day he will outgrow

the need for the CPAP altogether, but for now, we do the best we can with it.

Nowadays, Matthew loves disguises and costumes but I hope he doesn't ever feel the need to hide behind them. The sideways glances, downcast eyes, and stares are all part of Matthew's everyday life. I'm not sure if he notices them yet but seems to hold his head high regardless. When he encounters a mean kid or a hurtful comment, a look of misunderstanding comes over his face. It is like he doesn't understand why a kid would be saying something like this to him, because in his mind, he is pretty cool. When a kid runs away from him on the playground, he just shrugs and finds someone else to play with. My instinct is to leave the playground, protect him from this.

Matthew's is to stay and just find someone else that does want to play with him. In this aspect, I have learned a lot from my son.

Every place can't be like the protective bubble of home or a CCA retreat.

Every year at craniofacial clinic at CHOP, **Diana**



Sweeney tells us about the wonderful CCA retreat. A couple of years ago, we finally decided to go. We landed in St. Louis with no idea what to expect. What we found was a group of caring, accepting, and understanding people.

If I had to use one word to describe this group, it would be family. It is getting to talk with a group of moms about the latest model of Baha instead of describing what the Baha is. It is a conversation comparing notes on CPAPs and feeding tubes and jaw distractions and night nurses. The atmosphere is one of empathy, not sympathy and pity. It is finally getting to meet the mom in person that gave you life-saving advice on Facebook and hug her.

Every superhero needs superfriends. That is exactly what Matthew found in

St. Louis when he met Nathan and Will. Three blonde boys, all the same age, all with TCS, all super. Matthew got to meet peers that were fun to play with. I saw a bond being formed between three boys that will be there forever. Now, Matthew has superfriends to call when he faces villains and slays foes. That is what CCA has given us, superfriends.

These days our caped crusader is enjoying the first grade. When not fighting crime, you can find him playing Minecraft on his iPad, riding his bike, or playing with his sidekick, Buttercup, our Golden Retriever. He had abutment surgeries over the summer and is enjoying life without a softband. Matthew is a unique, confident, brave kid that Ed and I find, well... super.



prime living opportunity

Thank you, **Prime Living**, for the generous donation of a year-long ad campaign in your magazine! *Prime Living* is the luxury lifestyle magazine of Texas. They have been so generous to CCA this year, helping us promote and advertise our mission and events. Now, they are boosting their donation by partnering with CCA so that for each new subscriber who orders the Digital & Print subscription (\$40), *Prime Living* will donate \$20 to CCA! Please subscribe using the code **CCA2016** at prime-living.com/subscribe.

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annie's birthday fundraiser

CCA Program Director **Annie Reeve's** birthday wish came true big time again this year. She rallied her friends and family to help her beat last year's total of \$1,615 with a tally for 2016 up to **\$1,700!** Thank you, Annie, and everyone who holds a Birthday Wish campaign on Facebook for CCA throughout the year! You inspire others to join the CCA Birthday Club by donating their birthday to benefit our CCA Kids!

caring for cca kids

CCA has been sending surgery care packages for several years, as funds allowed and as we had supplies donated. Thanks to an incredible care package fundraiser, hosted by **Steven and Petty Weiss** (with contributions from the **Watkins and Chiavari** families as well) we now are able to continue to

serve our families because of our donors' generosity!

If your child is having an upcoming surgery, you can sign up for a get well card, a phone call, and/or care package online at: bit.ly/ccasurgery. CCA will continue this service as long as we can, thanks to your support. We love to make our CCA kids smile!

calendar of events

date event contact

2016

Dec 3 **CCA Holiday Party—Midwest** JPatterson@ccakids.com
11:30A-2:30P Brat Stop/Parkway Chateau 214.570.9099
Kenosha, WI 800.535.3643

Dec 10 **CCA Holiday Party—Dallas** AReeses@ccakids.com
10A-Noon TBD 214.570.9099
800.535.3643

2017

May 20 **2017 "Miles for CCA Kids" Benefit Ride** lewisboykin55@gmail.com

Jun 29-Jul 2 **27th Annual Cher's Family Retreat** AReeses@ccakids.com
214.570.9099
Hyatt Regency Reston 800.535.3643
Reston, VA

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!



Donate Your Vehicle

Easy Process.
Free Pickup.
Tax Deductible.



Have an old car taking up space in your driveway? Donate it to Children's Craniofacial Association!

SUPPORT US TODAY!
Just Call 877-570-4222
ccakids-cardonations.org

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.

Welcome our newest CCA Legacy Society member:
Jane M. Franklin of Shelton, WA.



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,
AReves@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.

Attention SHOPPERS

Did you know...



that by 2020, online shoppers will spend **\$530 BILLION** each year?! Help CCA earn a portion of those funds while you shop! Shop through these links every time you shop online and CCA will receive a donation at no cost to you. Shoppers have raised **\$232.19** so far this year!



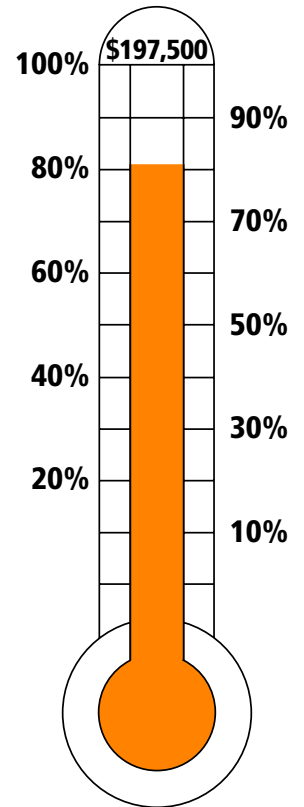
Smile.Amazon.com

iGive.com

SIGN UP FOR OUR MONTHLY E-NEWSLETTER!

Please sign up on the home page of our website!

2016 FAMILY FUNDRAISER GOAL THERMOMETER



To see CCA's list of 2016 donors through September 30, please go to our website. The list can be found at

www.ccakids.org/donor-list.html

challenge match grant

a generous donor has pledged **\$25,000** to help CCA meet our 2016 funding needs. **For every individual contribution of \$500 or more, the donation will be matched dollar-for-dollar.** Now more than ever, we ask you to open your hearts and make a major gift to CCA. If your employer matches your gift, that match will also be matched, thereby **QUADRUPLING your donation.** All gifts are tax deductible and make an immediate impact on children's lives. Ends 12/31.

WINTER SALE!

cozy shirts available in the **cca** webstore



Save \$5-\$10 on Long-Sleeve Black Logo Tees
ALL SIZES are \$15 (+shipping)

While They Last!
Available in Unisex Adult, Youth and Ladies

Sizes Limited.

Check out CCA's new "Different is Cool! Wristbands!
Order your wristbands online today in Adult 8" or Youth 7" - \$1 each



get one, give one!
New CCA Edition of *Wonder*
- newly updated Resource List for educators
- with a foreword from Dede Dankelson & Dr. Francis Smith
- includes a letter from author, RJ Palacio, for CCA Kids



ORDER ONLINE

stickers

Get the sticker set for only \$5!

- "We Are Family," **Jennifer Johnson**, Graphic Designer & CCA Adult
- "Different is Cool," **Bindy James**, Australian Illustrator & Designer
- "Kindness Matters," **Dana Wilson**, Graphic Artist & Animator

Order yours online while they last! Start your collection and share them with your friends.





Becky White, Alisa Shelton, Erica Mossholder



Friends from Texas Children's Hospital



Patty Taylor, Ansell's V.P. Professional Education and Clinical Affairs with Becky White



Chapman Elementary School in Rockwood, MI held a drive for **Anderson brothers, Owen** and CCA kid, **Nathan**, to recycle all these ink cartridges for CCA!

Save your used **INK CARTRIDGES** for CCA!

Once you've saved up a box, contact the office & we'll email you a FREE shipping label. Get your school, office, and church involved! CCA gets about \$1 for every cartridge you send. Our goal is to send a family to Retreat on ink cartridges alone and you can help!

RECYCLE TO DONATE!



Congratulations, **Becky White!** Thank you to **AnsellCARES** and our Houston community of supporters for helping us celebrate.

good news

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If you know of someone who would like to be placed on the mailing list please forward to us their name and address.

“testimonial



hello, as most of you already know, my name is **Genny**. I've been involved with Children's Craniofacial Association (CCA) since about 2004. Before CCA, I had very low self-confidence and was

unable to travel to Texas for 8 years to see my doctors. In those 8 years, my facial structure changed, but the size of my prosthetic eye stayed the same causing me to need two critical surgeries to correct the problem

I made several friends through CCA while attending the Retreats and being able to participate in the golf tournament and annual picnics. I have even had an opportunity to assist the CCA office staff in making *Wonder* packets

and preparing the items for the golf tournament.

Driving to Texas was a financial struggle before I was involved with CCA. In the time I've been involved with them, it has gotten much easier. CCA's assistance with travel and lodging expenses has allowed me to get the quality healthcare not available in Florida. The ability to get to Texas for needed medical care has improved my self image, expanded my confidence, and encouraged me to explore new ideas and new opportunities.”