ccanetwork

newsletter of the children's craniofacial association
Cher—national spokesperson
2016: Issue 2

inside

one day at a time

By Emily Merrill

Hello, I am **Emily Merrill**. I am 12 years old and live in Tinton Falls, NJ. My family includes my dad, **Gary**; mom, **Nancy**; 9-year-old sister **Abigail** and our two labradoodles, **Hank** and **Charlie**. My life has been full of challenges, but I have learned to just take one day at a time.

I was born on January 22, 2004, and was 6 lbs. 11 oz. and 19 inches long. My parents learned I had Tetralogy of Fallot when my Mom was pregnant. However, when I was born I also had skin tags around both of my ears, a high-arch palate in my mouth, a short retracted tongue and a severely retracted jaw. I was hospitalized in our local hospital's NICU for 3 weeks for feeding difficulties. I could not coordinate a suck and swallow to bottle feed, so I was fed through an NG tube. At 3 weeks I was transported to

see **merrill family**, page 16

message from the program director

I don't know about you, but I can't believe the retreat has already come and gone! The 26th Annual Family Retreat was held in Ft. Lauderdale, FL, June 23-26 and was one of our largest retreats to date! **One hundred six families** attended from 30 states as well as from Australia and Canada. Of the 106 families, 22 families were first-time attendees.

Our home for the weekend was the beautiful Hyatt Regency Pier 66. The hotel sits next to some amazing homes and yachts, and the views were spectacular!

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empowering and giving hope to individuals and families affected by facial differences

meet josie paugh

Josie Paugh is one busy kid. The 8-and-a-half-year-old from Indianola, Iowa, recently completed second grade. She likes school, particularly her math, reading and art classes, and is on her local YMCA swim team during the school year.

For now she's enjoying a summer filled with fun. Josie is super excited about camping with her family and friends, plus she has plans to go to the zoo and the water park, which should be a blast too. She is also playing softball this summer. And, of course, there's hanging out with twin brother, **Brooks**, and younger sister, **Amelia**. She's looking forward to long days with them at the pool, jumping on their trampoline and going for bike rides.

When she's not out and about, she likes to read, especially *Pony Pals* books, listen to country music, color, paint, add to her ever-growing Hello Kitty collection and watch *Fuller House* on Netflix. Her favorite movie at the moment is *The Boxcar Children*, but she has also seen *The Angry Birds Movie* and "kinda liked it." Josie also spends time with **Maggie**, her 5-and-a-half-year-old black Lab, as well **Jinx** and **Sissy**, her 15-year-old cats.

Josie couldn't make it to the CCA retreat this year, because she has a surgery scheduled for this summer. Her surgeries are usually scheduled in the summer, so she hasn't been able to attend a retreat yet, but she hopes to one day. She has some good advice for kids going through similar situations as hers. When it comes to surgeries and procedures, she said not to worry too much and that worrying will make a challenging situation even harder to go through. "Just be brave and it will go pretty easy," she said.

A Note from Erin, Josie's Mom:

"Thank you so much to CCA for shining a light on our brave girl, Josie! CCA has been such a friend to our family over the years, and we are so thankful for you! Also, I'd like to add that Josie's brother and sister have had to be just as brave during our trips for Josie's surgeries and procedures. So, for all the siblings, I'd like to say 'Thank you for being the unsung heroes!'"

ccateen

meet logan brown

hi, my name is **Logan Brown**. I am 14 years old and just finished up the eighth grade. We live in Fort Worth, Texas, which is about two hours away from Medical City Dallas Children's, the hospital where I have all my surgeries. I have Apert syndrome and have had 12 surgeries thus far.

I have a brother named **Landon** who is 11 years old, and a beagle dog named **Snoopy** who is 6 years old. We named him after the cartoon character from *Peanuts*.

My favorite things to do are: playing *Destiny* on my PS3 and watching funny YouTube videos.

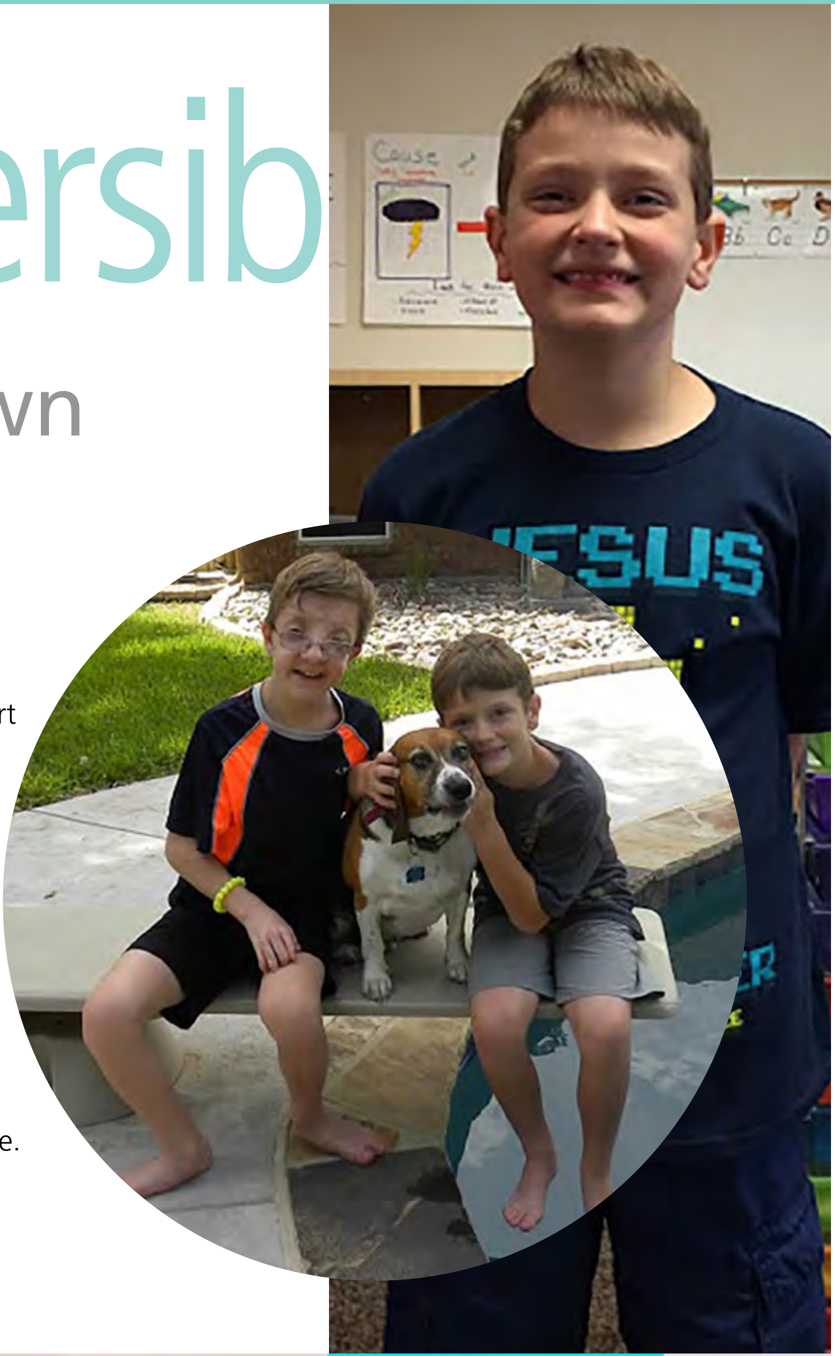
My interests are cars, cars, and more cars. I love all sports cars and hyper cars, like the Bugatti, Devel, Lamborghini, Pagini, Koenigsegg and Ferrari. Recently, I went to a car show in Dallas with my dad. I got to see and sit in a bunch of rare, expensive cars, which was pretty cool.

I have attended one retreat with my family in 2014 in St. Louis, Missouri. I met some other kids with Apert syndrome, and it was pretty nice. I felt good because I found out that I am not the only one—people in other states and countries have Apert syndrome like me.

I feel that no matter what syndrome you have, you can still enjoy life while you have it. And I know that God always protects me.

ccasupersib

meet landon brown



My name is **Landon Brown**. I am 11 years old and I have a good sense of humor. I am a Christian boy who loves going to church on Sundays.

I really like baseball, video games, chess, nerf guns, dogs, swimming and bunnies. My favorite sports team is the Texas Rangers! My favorite books to read are adventure, mysteries, survival and science fiction.

I play baseball, and my favorite positions are pitcher and second base. The name of my baseball team is the Texas Rangers too!

I like to play the alto saxophone as one of my hobbies, and I also like to put together engineering kits from Tinker Crate.

Before going to my first retreat, I was afraid I'd accidentally say something that would hurt their feelings. I thought I'd hurt someone's feelings just by asking questions. But once I was there, I realized I am not the only sibling that has a brother with Apert syndrome. Going to the retreat has changed my life, because now I don't feel scared anymore.

fourth annual all the way for cca

the Texas Moms held their 4th annual "All the Way for CCA" golf tournament, April 15, 2016, at Wildcat Golf course in Houston, Texas. Our Title Sponsor, **LBC Tank Terminals** and **Empowering Motivated Women** hosted this event, our largest ever.

A special thanks to **John Grimes** from LBC Tank Terminals, who helped us grow from 22 teams last year to 36 teams this year, raising more than **$70,000**! Through the consistent determination of Mr. Grimes, **Alisa Shelton** and **Lynna Mc Guyer**, we have exceeded last year's total money raised—in fact, it's almost doubled!

There are never enough words to express the kindness and generosity shown from our surrogate CCA Moms, Alisa and Lynna. Since the inception of this golf tournament four years ago, these ladies have committed their time, money, energy and love to raise awareness about craniofacial conditions and have worked diligently throughout the year to ensure the success of this event. They love knowing that they are able to help children attend retreats.

Our tournament day was full and included breakfast, games on the course with a Harley-Davidson on a hole-in-one, BBQ lunch, raffles, and silent and live auctions. Auction and raffle donations included fishing trips, airline tickets from **Southwest Airlines**, a shotgun, sports memorabilia, **Texans** and **Astros** game tickets, and so much more! CCA kids **Ashley Bock**, **Jakob Happ**, and **Wade White** were on hand for photo ops and handshakes. Also, thank you to our CCA Super Sibs **Destiny Carlisle**, **Antasia Hart**, **Jessica Bock**, and **Roberta Fernandez**—thank you for being such great support to this event!

Without the hard work of our volunteers we would be lost! Much gratitude to our photographer, **Carla Pike**, from **Dinna Fash Photography** for donating her time and talent for the second year in a row—we love you! We had some really cool volunteers this year: **Cathleen Carey** and **Dr. Rebecca Burke**, both from Texas Children's Hospital; **Tina Baukol**; **Heather Russ** (a BIG supporter all year long!); **Bri King** (friend to CCA sib, Antasia); **Jill Patterson** and **Erica Mossholder** from CCA; and so many more!

Along with our Title Sponsor and Empowering Motivated Women, our sponsors included **Alan Callaway** and **Maxcon, LLC**; **Patricia Bock**; **Roy & Celeste Craeger** with **F.I.R.S.T.**; **Dr. Payne** and **The Craniofacial & Plastic Surgery Center of Houston**; **J.J. Shelton** and **Shelton Services**; **The Women's Hospital of Texas Pediatric Center**; **Danny Boyer** and **Hufco**; **Mike Collins** (husband to **Sarah Collins**, our precious other surrogate CCA mom) and **FMC Technologies**; **Rilco**; **Triple B Services**; **Megan Latour** and **Homes by Meg**; **CRB**; **Dillon Environmental**; **John Nickens** and T**exas Children's Hospital**; **Epic Health Services**; **Republic International**; **Helfman River Oaks Chrysler, Jeep, Dodge and Ram**; and **Republic Harley-Davidson**. We want to express our gratitude to all of you for ensuring this organization can continue to aid families with craniofacial conditions.

Each and every year we are encouraged and renewed by the continued support and the way Southeast Texas really shows up for our cause. The mission of CCA is simple: to empower and give hope to individuals and families affected by facial differences. It's through this tournament that we, "Texas Moms" endeavor to do our part

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fifth annual morgan meck's match play

On April 27 and April 28, the Mecklenburg family hosted the fifth annual Morgan Meck Invitational benefitting the Children's Craniofacial Association. We had an amazing group of participants representing 10 states, along with two participants from London, including British aristocrat **Lord Hall**.

We are so grateful for our committed friends and neighbors who join us for this two-day event that continues to raise the bar each year. Morgan welcomed all participants and thanked them for their continuing support, encouraging them to "spend more money for her friends at CCA!"

Erica Mossholder along with CCA Dads **Tate Gorman** and **Darin Dankelson** truly moved the group with their personal accounts attesting to the amazing work CCA does. Erica emphasized the fact that thanks to donor generosity, CCA has committed to doubling the amount of financial assistance offered to families in 2016. Tate Gorman spoke about the amazing transformation his son, **John**, recently experienced after his major surgery, the mid-face advancement this past summer. Not only has John's health improved, but most noticeably his confidence has skyrocketed.

In addition, Darin Dankelson spoke about the powerful movement his sons, **Peter** and **Jacob**, are helping build through the CCA "Choose Kind" *Wonder* initiative. They regularly visit schools and Skype with classrooms to bring the book *Wonder* to life and help all students develop empathy and compassion for each other and those with facial differences. And **Chris Jones**, the head of the English Department at Ladera Ranch Middle School, announced that **Coto de Caza Golf and Racquet Club** has selected CCA to be one of the recipients of its annual Charity Classic tournament; the proceeds will provide copies of *Wonder*, which will be incorporated into the curriculum for the 3,761 sixth-grade students in the Capistrano Unified School District.

John Mahoney became the first two-time winner in the tournament; however, the true champions of the tournament were our CCA kids who inspired this small group of friends, corporate sponsors and auction participants to contribute more than **$90,000**. A special thank you goes out to our Platinum Level Sponsors: **Crum & Forster Insurance**, **EverGuard Insurance**, **Praxair**, **SES Insurance**, **Maria Amelio**, **Greg** and **Donna Bonnell**, and **Kevin** and **Jennifer Trapani**. A special thank you is also deserved for **Christine Condino-Mecklenburg**, **Shawn**

Craig and **Trina Conti** for providing incredible golf and hotel experiences for the auction along with **TaylorMade Golf** for allowing CCA to benefit from its Charity Purchase Program.

Coto de Caza Golf and Racquet Club was the host venue, and all out-of-town participants stayed at the **Laguna Cliffs Marriott Resort & Spa** in Dana Point, California. Private dinners were held at **Hanna's Restaurant and Bar** in Rancho Santa Margarita and at the **Vue Restaurant** overlooking the Pacific Ocean in Dana Point, and transportation was generously provided by **ACCESS Destination Services**.

CCA and the Mecklenburg family would like to thank all of the volunteers, participants, contributors and auction item donors who have made this a memorable and meaningful event.

donors and participants

Host Sponsor
Bill Mecklenburg & Christine Condino-Mecklenburg

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Crum and Forster
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Dale Meyer
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Darin Dankelson
Darren Bowden
Doug Tabbert
Drew Tabbert
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Four Seasons Resort Scottsdale at Troon North
Four Seasons San Francisco
Hanna's Restaurant and Bar
Laguna Cliffs Resort & Spa
Michael Dandini
Mission Hills Country Club
Montage Laguna Beach
Morgan Run Club & Resort
Morgan Winery
Pat Burke - former PGA Professional
Porter Valley Country Club
Rancho Valencia Resort and Spa
San Diego Marriott Gas Lamp District
Spring Valley Lake Country Club
Steven and Susan King
The Woodlands Resort

*wonder*ful guests at retreat

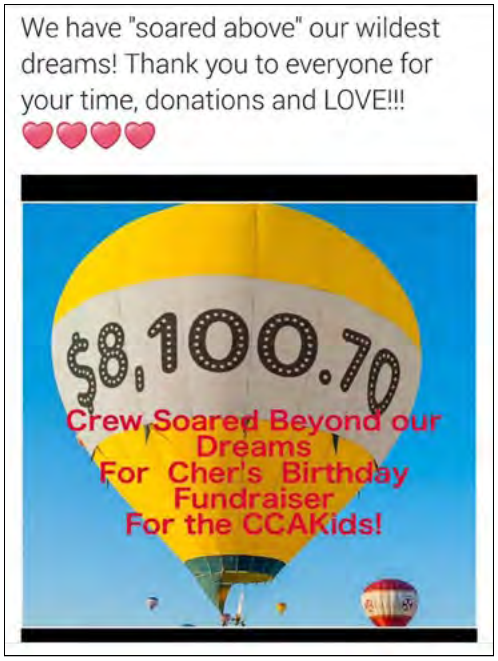
We are so grateful to our special guests who joined us at Retreat this year. Cast as Auggie Pullman, in the upcoming major motion picture hitting theatres April 2017, **Jacob Tremblay** and his entire family, including mom, **Christina**, dad, **Jason**, and sisters **Emma** and **Erica**, flew to sunny Ft. Lauderdale all the way from Vancouver, British Columbia to experience life like a CCA Family.

Since Jacob will be telling our story on the silver screen, CCA wanted him to know what it is really like to be a CCA Kid… and we think he got a pretty good idea at Retreat! Jacob, Emma, and Erica played in the sun all weekend along with other CCA Kids and their Super Sibs. Several special moments were shared and we know that when Jacob is filming the movie he'll draw inspiration from his time with our CCA Kids.

We were also fortunate to have one the producers of the film, **David Hoberman**, in attendance with his children, **Chloe**, **Charlie**, and **Hannah**, and their friend **Rachel Erickson**. Thank you for joining us at Retreat, Tremblays & Hobermans! We hope you all had the time of your lives. And, Jacob, break a leg! We're behind Team *Wonder* all the way!

Top photo: Peter Dankelson, Jacob Tremblay, Jacob Dankelson
Inset photo: Issaiah Eakright and Jacob Tremblay

cher's 70th birthday fundraiser



We have "soared above" our wildest dreams! Thank you to everyone for your time, donations and LOVE!!! ❤❤❤❤

The "**CherCrew**" held an amazing effort for Cher's 70th Birthday celebration throughout the month of May, to honor our spokesperson, **Cher**, benefitting CCA kids and families!

We are grateful to **Janet Novick**, **Doug Wemple**, **James Waters**, **Scott Clarke**, **James Lonsdale**, **Stacy Arrighi**, **Gloria Montgomery**, **Darla Kramer** and **Sue Dolby** who donated collectibles to be raffled for donors to win and to **Terry Hughes**, for her custom memes spreading the word throughout social media along with **Sue** and **Linda Marie**.

To everyone who shared our posts & retweeted the funder news and to our own Diva herself, for personally contributing 6 pieces of jewelry and 10 autographed photos to the raffle, sincere thanks! It ended with an incredible total of **$8,100.70** and donors had great fun watching to see who would win the valuable raffle prizes with the help of **Jesse**, who organized the prize line-up for CCA and **Dougie** who announced the winners (& also spearheaded the entire effort)! Thanks to all who donated items, funds, shared or participated in any way. CCA Kids love you all!

Cher
@cher

Want 2Thank Everyone Who Donated 2CCA In Honor Of My 17th 🎂DAY🎉
My Crew Rocks Out Loud !!

7:22 PM 31 May 16

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Thanks to the Internet and social media, many of our new families and those who had not attended previous retreats became friends on Facebook and through CCA's Yahoo Group during the past year. That meant the initial "get-to-know-you" period was taken care of before the retreat even started. Family members were glad to finally meet in person and immediately made connections.

This year, we had some amazing speakers who generously gave of their time and expertise to conduct the 8th Annual Craniofacial Symposium. We would like to thank the following team members and volunteers from **Joe DiMaggio Children's Hospital**: **Eric Stelnicki, MD**; **Roman Yusupov, MD**; **Marnie Laratro, Psy.D**;**Dina Weiss, LCSW**; **Sam Ostrower, MD**; **Kristen De Luca, CCC/SLP**; **Bianca Gomez Castro, AuD, CCC-A**; **Helena Urrea-Feldsberg, DDS, MDS**; **Katie Torres, CCLS**; **Michelle Pasqua, CCLS**; **Kelly Hall, CCLS**; **Bobby Brasher, ARNP**; **Margaret Grell, MD**; **Ann Lindahl**; and **Arien Tripp**.

We would also like to thank **Debra Harrington** and **Jessica Gianos** from Broward County Schools and CCA family members, **Jacob Dankelson**, **Antasia Hart**, **Quinn Stevens**, **Tom Moore**, **Rose Seitz** and **Becky White** for being panel members for the Sibling and Parent Discussions. Presenters discussed topics including genetics, how to be a friend/choosing kindness, a safer selfie, teeth and more!

And last but not least, a big thanks goes out to the following members of our Adults and Alums committee for volunteering their time during the symposium and registration: **Frederick Seitz**, **David** and **Meg Storie**, **Casey Deakins**, **Christine Clinton**, **Jill Laufbaum**, **Torey Harrah**, **Joe Brooks** and **Jaci Samhammer**! Thanks to all for a very informative, productive day.

We kicked the retreat off Thursday evening at the Ice Cream Social. Families were entertained by **Magic Jack Maxwell**, who had quite a few tricks up his sleeve—literally! The kids instantly gathered around him and started developing friendships, while the parents were also getting to know one another.

Also during the Ice Cream Social, renowned photographer, **Rick Guidotti** of **Positive Exposure** and collaborator **Bieke Kreps**, spoke about their mission to show the beauty in appearance diversity. They each gave a short presentation and inspired everyone with their work.

Rick used to be a fashion photographer, who worked with supermodels and fashion icons. After meeting a stunning woman with albinism several years ago and working with her, he decided to change his life's work and now exclusively photographs people with differences and exhibits his art in cities around the globe.

We are truly grateful that the Positive Exposure team volunteered their time and talent at the CCA Retreat, and we are grateful for craniofacial surgeon, **Dr. Richard Kirschner, M.D., F.A.C.S, F.A.A.P**, from **Nationwide Children's Hospital** in Columbus, OH, and his wife **LoriAnn**, who connected us with Rick, Bieke and the entire team.

Friday morning kicked off with an outdoor breakfast on the terrace, and the CCA Kids, Teens and Adults got together for a big group shot, which was taken by volunteer photographer, **Traci Seitz** of **Tracie Burke Photography**. Everyone

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put on their biggest smiles and wrapped up the photo with a big thank you video for the **#CherCrew**, who are always promoting CCA Kids during the year through their social media efforts.

Following breakfast, the families gathered around the pool for a fun-filled afternoon of swimming! The Hyatt provided us with a bounce house and lawn games, while our volunteer photographers, Traci and Rick snapped candid shots and portraits to capture the memories of the "time of our lives."

Friday evening, we held the traditional Family Night and Teen Party.

Once again, families from across the United States and beyond brought baskets of goodies from their areas for CCA to raffle! These baskets held everything from sports souvenirs and memorabilia to local food specialties and everything in between. The generosity of our families never ceases to amaze us.

While parents were buying raffle tickets and stuffing them in the raffle bags, the teens were mingling by the pool and making new friends. Teen night wouldn't be possible without the help of our chaperones each year. Thank you **Carolyn Johnson**, **Jennifer Johnson** and **Harlena Morton** for helping us this year!

Family Night is always made more fun with the presence of therapy dogs, and this year we had two—big thank you to **Lindsay Condefer**, who brought **Sprout** this year and to the **Kirschners**, who brought their dog, a sweet little Cavapoo, named **Zuzu**. And, as an added bonus, we also had **Hank**, who belongs to the Merrill family.

Saturday, the families gathered for a beach pool party on the shores of the Atlantic Ocean! Families loved the nice warm water and played in the ocean for hours. You can't beat seeing the oceans from coast to coast with your extended CCA Family!

After getting plenty of sun, everyone gathered in the Hyatt Ballroom for Saturday evening's Dinner/ Dance, which is a family favorite! But before the festivities began, we honored our very own **Char Smith** with a surprise retirement celebration. **Nick Wiese** gave a heartfelt speech and presented Char with a cake from the Adults & Alums committee. CCA's board chair, **Bill Mecklenburg**, then presented Char with

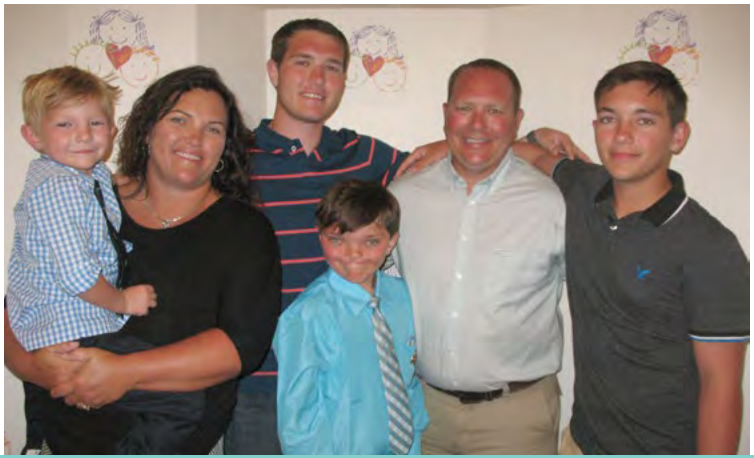
another heartfelt speech and presented her with a lovely gift from the board and staff—he announced a new retreat scholarship program in her name, the **Char Smith Starfish Scholarship**!

After everyone thanked Char, the dancing began and continued long into the night! We were thrilled to have **DJ Jim Moore** as our DJ this year. He just so happens to be the uncle of CCA Teen, **Katie**, and her older sister, **Anne**. Thank you, Jim. You rocked the party for us!

Sunday morning is always bittersweet. There were lots of hugs, promises of staying in touch and, as always, a few tears. We really enjoyed meeting all of the new families and catching up with old friends. We hope everyone had the TIME OF THEIR LIVES!

You too can get in on the fun next year! Don't delay, registration is officially open for the 2017 Reston, VA, retreat, and we hope to see you all there!

And be sure to read about a first-time retreat attendee, **Charity Falk**, and her family's experience.



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to ensure the continued advancement of this mission. Thank you, CCA, for letting us be a part of it!

—**Becky White**,
Lisa Bock, and
Jennifer Kilmer

chance raffle

The "Chance Raffle," held during this year's Annual Family Retreat in Ft. Lauderdale raised **$2,974**. Great items for raffle included gift baskets, goodies and other parcels from hometowns, states and even other countries provided by retreat attendees along with miscellaneous goodies other donors including Cher fan, **Cyndi Morgan**, who contributed kids' gifts for the second year in a row. Tickets were purchased in strips of 20 for $5 and dropped into the drawing for whichever prize one wished to win. Drawings were held during Friday's "Family Night" festivities. Thank you CCA retreat families all, for raising funds for CCA, for one another. We truly are "Family"!

cca retreat: a first-timer's perspective

Hi, my name is **Charity Falk**. My daughters, **Cadee** and **Emma**, and I had the privilege to attend the 26th annual Cher's Family Retreat in Fort Lauderdale, Florida. This was our very first retreat and, gosh, was it life changing!

My daughter Cadee has Goldenhar syndrome and was very nervous to go to the retreat. (Heck, we all were.) She made every excuse possible to try and get out of it, but Annie and I eventually got her to go! You see, Cadee is an extremely shy person. Meeting new people and, honestly, sometimes just going to the store, is extremely difficult for her, so she was very apprehensive about going.

Once we got to the retreat and started meeting all the wonderful and welcoming families there, our nerves started to go away, and talking to each new person got easier and easier. Everyone welcomed us as if we had known them for years.

On our first day both girls attended several symposium sessions. Cadee went to one session about "Becoming My Independent Self," Emma attended a session for siblings called "Hey, Don't Forget About Me," and they both attended a session called "10-18 Year Olds with a Facial Difference and Siblings: How to Be a Friend and Choose Kindness." Again, Cadee was very nervous about going and did not want to be called on during the sessions, but she came out with confidence and a smile. Emma told me that I would have been very proud at how much Cadee opened up and participated.

After the symposiums and dinner we went to the ice cream social and had the opportunity to meet some very special people who we have stayed connected with since the retreat!

We had tons of fun! There was so much to do at the hotel that we decided to stay at the hotel almost the entire time. We took a walk down to the pier and got to see a very well-known country music singer's yacht/boat. We went to the pool, played on the swings, laid on the hammock and played ping pong. One day we had an outing to the beach, and it was absolutely beautiful! It was so very different than the beaches we are used to in Louisiana.

That night was the dinner/dance. During the dance, Cadee told me that she never wanted the retreat to end. She was one of the first kids to get on the dancefloor, and she even did the conga line! Her favorite part of the night was dancing with all the little kids.

That night I cried, not because I was sad, but because I saw my daughter not once worry if someone was looking at her or if someone was staring at her face.

The whole retreat I watched her blossom, but that night she was carefree. In 13 years I've never seen her let her guard down around people she had just met a few days before. Her happiness was infectious, and all I wanted to do was smile and stop time. We took tons of pictures, exchanged phone numbers and emails, and became Facebook friends with so many new friends. I am overwhelmed at how welcoming, caring and accepting everyone was.

On our last day we had to say a fast farewell, because we had an early flight. We took more pictures with everyone, but one of our favorite pictures was with Cadee's fellow Goldenhar kids! This was the first time she has ever met someone with the exact same syndrome as her, and getting that opportunity was priceless! They are all now friends and she has stayed in contact with some of them since the retreat.

It took us a lot of years to get us to go to the retreat, and now we wish that we had gone many years ago—it was the absolute best weekend! I would just like to thank everyone who made this opportunity possible for us!

serving kindness on a bun

On May 12th, CCA held a "Give Back Night" at the popular Dallas restaurant chain, **Liberty Burger**. The Forest Lane location opened their doors and welcomed CCA supporters to "Dine and Dish for CCA" all day, and they donated a portion of the day's proceeds to CCA.

Not only was General Manager, **James Browning**, accommodating and enthusiastic, but he also told us we had an amazing turnout as CCA friends and families filled the restaurant three times: at lunch and two dinner rushes. Because of the excellent turnout from our supporters, including the **Gorman**, **Weiss**, **Harrah**, **Dalton**, and **Bono** families, plus the **Highland Lakes** and **Parkland Hospital** communities, CCA earned the honor of being featured as one of LB's "Give Back" Burgers.

This means that the chef-inspired burger for July came with a $1 donation to CCA for every burger ordered! We are so thrilled for this opportunity to raise awareness in our home base and for the opportunity to raise funds with Liberty Burger. Thank you to everyone who came out this summer to support our efforts!

Finally, we offer our special thanks to **Mariel** and **Marco Street**, the Liberty Burger ownership team who helped CCA secure this opportunity, created a great chef burger for the month, and shared the #GiveBackBurger on their social media to raise even more awareness for CCA.

children's craniofacial association

Empowering and giving hope to individuals and families affected by facial differences

Choosing Kind never tasted so good!

THURSDAY

MAY 12

11 am - 9 pm

Liberty Burger

5211 Forest Ln. | Dallas, TX 75244

Have a great meal and mention Children's Craniofacial Association and a donation will be made to help kids with facial differences

Visit CCA: www.CCAKids.org

wonder funders

South Edgecombe Middle School

by Lisa Pellegrino

The 7th grade ELA classes at **South Edgecombe Middle School** in Pinetops, North Carolina raffled off baskets of goodies, sold wristbands and put on a spirit week to raise over **$1,400** for CCA after reading the book, *Wonder*. The kids had a blast and the money will make a big difference in the lives of our CCA kids.

McKamy Middle School Book Club

by Librarian Katie Cox

Children's Craniofacial Association received a check for **$160** from the **McKamy Middle School Book Club** students who sold wristbands with the slogan, "McKamy Chooses Kind," in order to raise money to assist families with children who have facial differences. McKamy Middle School is located in Flower Mound, Texas.

Northwestern Local School District

In the **Northwestern Local School District** of West Salem, Ohio, students put together a "Kisses for Kindness" effort that raised **$304** for CCA Kids!

Terrace Community Middle School

The **Terrace Community Middle School** of Thonotosassa, Florida held a symposium and also sent proceeds of **$304** for CCA Kids!

Thanks to ALL of these "*Wonder*"ful fundraising efforts for our cause!

merrill family, from page 1

Children's Hospital of Philadelphia ("CHOP") because I was failing to thrive.

At CHOP I was examined by the craniofacial team and genetics group where I was diagnosed with both Goldenhar syndrome and 47 XXX, (a genetic disorder) in addition to the Tetralogy of Fallot.

However, to me, these are just labels and don't mean anything. I don't even think about them because they don't change who I am today and the challenges I am working so hard to overcome every day of my life.

At 2 months, I had open-heart surgery at CHOP to repair my Tetrology of Fallot. Finally, after 66 days in the hospital, I was able to come home for the first time in my life. After my open-heart surgery, I continued to be NG tube fed 100 percent of the time. About this time I also developed severe reflux and was also diagnosed with dairy, soy and tree nut allergies. Out of all the challenges I have, these food-related allergies are the most frustrating to me, even today.

In August 2005, I finally got rid of my NG tube and had a G-tube placed. (I still rely on my G-tube today, but later on I will tell you how determined I am to learn how to eat.) With my Tetralogy of Fallot repaired and my nutrition concerns resolved with a G-tube, my life has been affected by my treatment and adaptions to address my mandible/jaw, tongue and arch anomalies. Over the past 10 years, I have consistently had occupational, physical, feeding and speech therapies as my facial structure changed from the numerous mandible surgeries.

My first mandible surgery was bi-lateral rib grafts when I was about 3-and-a-half years old. They used two of my ribs to create my missing jaw bone, plus I had to have a tracheotomy. The rib bones used to reconstruct my mandible really improved by breathing and also allowed me to swallow "baby food" for the first time. That next summer I was accepted into the Richmond Children's Feeding Program. Mom, Abigail and I lived in Richmond for three months for this aggressive feeding program that helped me learn how to drink and eat. Dad stayed back in New Jersey to work and visited us every weekend. In Richmond, I also met one of my best friends, **Sarah**, who I still text with almost every day.

For the next two-and-a-half years, I kept working hard to keep up with my therapies and school.

Unfortunately, the rib grafts used to reconstruct my mandible were failing, and in February 2012 I had my left rib graft replaced with my right leg fibula bone. My Mom and Dad were hopeful that the other rib graft could be salvaged, so some of the excess fibula bone was also used to reinforce my right rib graft. This was a complex surgery because the fibula bone graft was vascularized to bring blood flow to my new left mandible. What I remember most about this surgery was that I had to use a wheelchair and walker as I went through extensive physical therapy to learn to walk again.

While my newly recreated left mandible was healing great, by December 2012 it was clear the rib graft used for my right mandible was still brittle. So, I went through an iliac crest (my hip) bone graft to make one last effort to avoid another vascularized fibula graft on my right mandible. I remember when I came home to recover all I wanted to do was to dance, laugh hysterically to the point of hiccups, scream "oh yeah," and jump into my parents arms with giant bear hugs. They seem like simple things but that is what I liked to do back then.

Looking back, I have missed a lot of school with all the surgeries I have had.

I think I have missed more days of school than I have actually attended the last few years. Good thing my Mom was an elementary school teacher before I was born. I also have the best home instruction teacher that teaches me when I can't go to school and helps me catch-up during the summer. It is so hard to balance recovery, therapies and school at the same time. My teacher has been coming to my house for many years and he really "gets" me. Sometimes I get frustrated and act silly when he is teaching me, but he is so awesome keeping me on track.

One of the best days of my life was in September 2013 when I came home from school to a big a surprise. We got a labradoodle puppy! We named him Hank. My dad spent about two years training Hank to be my service dog. Hank now goes everywhere with me. He is amazing!

I remember the first day Hank arrived I was a little scared of him as he was only a 2-month-old puppy. Now, Hank is the first thing I look for in the morning and when I leave the house he is by my side for school, doctor appointments, therapies or anywhere else we go.

When Hank is not working with me he is just a dog who loves to play. However, when I put on his vest he knows his job is to help me. When Hank and I are out, people don't treat me differently. Instead they look at Hank and ask me questions about my dog. Hank brings a calmness to my life that I can't imagine being without.

During one of my follow-up craniofacial appointments in early 2014, my surgeon told my mom and dad that he recommended we do a complete replacement of the right mandible as the past efforts to strengthen it would not withstand a jaw distraction. My parents recently told me that

making the choice to do a second vascularized fibula graft to create my mandible made them question all of the facial reconstruction I had up to that time. All they could do was rely on faith, hope and skilled surgeons to help me have a better quality of life. However, the fear of the unknown and risk made May 5, 2014 one of the toughest days our family ever experienced.

We think I am the first kid to have both mandibles replaced with vascularized fibula grafts in the United States. All I knew was I had months of physical, occupational and speech therapies ahead of me once again. I remember telling my dad, "Another lost summer spent healing instead of swimming, playing and just being an ordinary 10-year-old kid."

I was very frustrated during the recovery period, but my mom, dad, sister, labradoodles, cousins, Grammy, Poppy, GiGi and Grampy helped me so much during recovery times. On warm sunny days I remember my cousins sitting inside with me, while I knew all they really wanted to do was swim or go to the beach. I have an amazing family!

Even though my family helps me, sometimes I don't always want to talk to them about how different I feel. After all, I am a 12-year-old girl! People treat me differently because of the way I look. That makes me upset and frustrated. I have learned that I need somebody I can talk to and tell them anything. For me, that is my therapist. She really helps me understand why I feel the way I do and gives me strategies to deal with things.

see **merrill family**, page 18

more fundraising news

On June 27th and 29th, family and friends of **Angela Wojtyniak** gathered with her in an effort to raise money for the Children's Craniofacial Association. Her friend, **Jill Gerne Allevato** who is affiliated with the **Life Expressions** organization, generously donated 15% of each product purchased. This was her 3rd fundraiser and she is proud to say that they raised **$1,000** for CCA! Thank you to everyone who was a part of this!

merrill family, from page 17

In March of last year, we made another great family decision—we got another labradoodle puppy! We named him Charlie. Others could not understand why we would take on another puppy with everything we had going on. But, we fully understood that adding another doodle would bring our family even more joy and peace. We spend a lot of time at home, and just hanging out with our doodles makes everything that much more fun. We are not training Charlie as a service dog. It is amazing how attached my sister, Abigail, is to Charlie and to see the joy he brings her just like Hank brings to me!

Over the past few years, I have learned to accept that my craniofacial surgeon, Dr. B, is a huge part of my life. Mom and Dad are forever grateful for everything Dr. B has done for me. One day, I want to find a way to express this to him. However, now when I see Dr. B, the first thing I do is usually stick my tongue out at him. Once in a while he returns the favor and sticks his tongue out at me or tells me a funny joke. Yes, this is silly, but humor and distraction work for me!

Since my second fibula graft in 2014 I have also had a jaw distraction to lengthen my reconstructed mandible. Mom and Dad had to turn pins to length my jaw. I screamed and hated it! This January I had a jaw ankylosis surgery to unlock my mandible that had fused to my skull (side effect of my fibula grafts) and created a TMJ joint. Now I can open and close my jaw for the very first time! I am finally learning how to do things like drink from a straw, close my jaw, eat more types of soft foods and even talk more clearly without having to repeat myself.

Finally, after 12 years and too many surgeries to count, I have a jaw and mandible. I know I still have a long road ahead, but my parents tell me to take it slow. That is so tough to do, as I want it all NOW!

Many people tell me I am brave and a hero. I agree because I don't know any other way. Despite these challenges, I am so thankful for everybody, especially my family and friends, who have helped me become the girl I am today. I am so excited to be a teenager next year, but Mom and Dad always remind me to take it "one day at a time."

hutto *wonder* 5k fun run

On Saturday, April 16, 2016, the **Hutto Independent School District** libraries hosted a *Wonder* 5K Fun Run, Walk or Sleep In. The race was part of our One Book-One Community Initiative in the district. Since January all campuses shared copies of *Wonder* by **R.J. Palacio**. After reading the book and "meeting" the character Auggie, we talked with students about sponsoring a race to raise money for Children's Craniofacial Association, they overwhelmingly chose to raise money for the "kids like Auggie." All proceeds from race registrations benefited Children's Craniofacial Association in Dallas with the funds going toward sending CCA families to the Annual Family Retreat. Our race raised enough money to send four entire families!

Almost 400 people registered to race and the Executive Director of Children's Craniofacial Association, **Erica Mossholder**, participated in the event with us. The race festivities included a photo booth, shave iced from **Kona Ice** and live music by **Stephen Daly**. By offering an option to "sleep in" during the race, we increased the number of registrations. People with prior plans or those who didn't want to get out early on a Saturday morning still got the race T-shirt and supported a great cause. Thanks to R.J. Palacio for giving us permission to use the book cover image on the race t-shirts. We also thank **Random House** for sending *Wonder* bookmarks and journal pens for the race bags.

Volunteers who showed up before dawn on a Saturday morning were **cheerleaders**, members of **National Junior Honor Society**, **Student Council**, **JROTC**, **City of Hutto employees**, **parents** and **teachers**, **coaches** and **community members**. We are grateful to **Dr. Douglass Killian**, HISD superintendent, for supporting our big idea, the **Hutto Education Foundation** for awarding a grant for the One Book-One Community project, **Hutto Hampton Inn and Suites** for donating a room for Ms. Mossholder, **Walgreens** for donating cases of water and **Home Depot** for donating a BBQ grill for the silent auction. Thanks also to the **City of Hutto** for their help in planning the route and for waiving park usage fees. It took all of us to make the 5K happen.

calendar of events

date 2016	event	contact
Aug 20	**Charity Classic** Coto de Caza	Erica Mossholder emossholder@ccakids.com
Aug 28	**Seth's Stride** Canton, OH	Stacy Horne stacykhorne@gmail.com
September	**12th Annual Craniofacial Acceptance Month** Nationwide	AReeves@ccakids.com 214.570.9099 800.535.3643
Sep 3 3-8P	**California Picnic** Jon's Luau Family BBQ River Reflections RV Campground off Hwy 70 Oroville, CA	Sweetangeljen2017@gmail.com
Sep 9	**9th Annual Links of Love Golf Tournament** Firewheel Golf Park Garland, TX (Dallas area)	JPatterson@ccakids.com 214.570.9099 800.535.3643
Sep 10 11A-1P	**9th Annual National Picnic Day** Sandy Lake Amusement Park Carrollton, TX	AReeves@ccakids.com 214.570.9099 800.535.3643
Sep 10 1P	**New Jersey Picnic** The Merrill Family's Home 16 Gallant Fox Road Tinton Falls, NJ 07724	Gary Merrill gmerrill@commvault.com
September 10	**Raegan's Rally/Walk for CCA** Deerasic Park Cambridge, OH	Ashley Daugherty ashleyddaugherty@gmail.com
Sep 11 Noon-3P	**Michigan Picnic** Mott's Children's Hospital Marsh View Meadows Park Pavilion 300 E. Textile Rd. Ann Arbor, MI 48108	Coreen Abston cabston@med.umich.edu
Sep 17 10A	**California Picnic** Alpine Woods Lodge 939 Alpenweg Drive Big Bear, CA 92314	Courtney Vysocky cvysocky@gmail.com facebook.com/groups/SoCalCranioKids/
Sep 18 2P	**Delaware Picnic** Carpenter Recreation Area at The White Clay Creek State Park 880 New London Rd. Newark, DE	Gretchen Emery gretchen.emery@yahoo.com
Sep 18 6P	**Paint Nite to Benefit CCA** Summit Steak House (Four Points Sheraton) San Jose, CA	Deena Dyson deenstrick@aol.com
Sep 24 1-4P	**Michigan Picnic** Ben Celani Pavilion at Bicentennial Park 35400 7 Mile Road Livonia, MI 48152	Kellie Dowd kdowd22@gmail.com
Sep 24 2P	**Georgia Picnic** Cloudland Canyon State Park Picnic Shelter #2 122 Cloudland Canyon Park Rd. Rising Fawn, GA	Casey Deakins caseydeakins@gmail.com
Dec 3 11:30A-2:30P	**CCA Holiday Party–Midwest** Brat Stop/Parkway Chateau Kenosha, WI	JPatterson@ccakids.com 214.570.9099 800.535.3643
Dec 10 10A-Noon	**CCA Holiday Party–Dallas** TBD	AReeves@ccakids.com 214.570.9099 800.535.3643

knightgrams college funder

by Steven Petryk

My roommate, **Andrew Hamon**, and I launched a candygram service for UCF (University of Central Florida) students called "KnightGrams" for Valentine's Day. It wound up being unprecedentedly successful. We decided early on that we wanted to donate the profits to charity. A few semesters ago, I actually did a project in speech class involving CCA. I was in the class with **Anne Moore** (Anne is a CCA Supersib, sister of CCA teen, **Katie Moore**), so I knew quite a bit about Children's Craniofacial Association. I suggested CCA to my roommate as a donee and he was totally on board with it. We wish we had a higher profit margin, but hopefully this **$400** is still helpful. Happy Valentine's Day.

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.

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 or call 800.535.3643.

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,
AReeves@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!

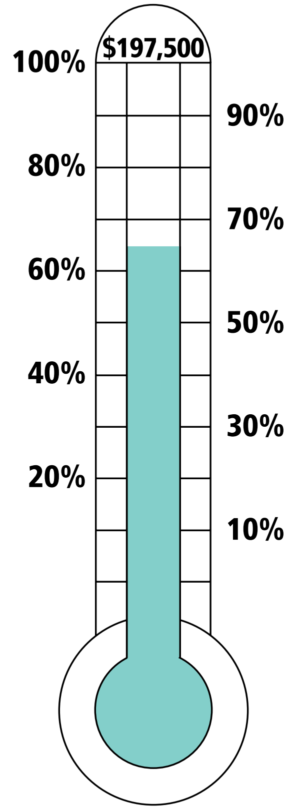
Smile.Amazon.com

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 June 30, please go to our website. The list can be found at

www.ccakids.org/donor-list.html

state assistance:

Did 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

artists volunteer for cca

Three Artists kick off the CCA sticker series with unique, limited edition designs.

Get the sticker set for only $5!

Check out the CCAKidsBlog.com to read interviews with the three artists and how they came up with their designs:

- "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.

Links of Love

BENEFITING
CHILDREN'S CRANIOFACIAL ASSOCIATION

Join us on September 9, 2016 at Firewheel Golf Park in Garland, TX for the 9th Annual Links of Love Golf Tournament Don't miss the fun!

Register, sponsor or donate now at bit.ly/ccalinks

BUY A CRANIOFACIAL ACCEPTANCE MONTH T-SHIRT! GO TO WWW.CCAKIDS.ORG/SHOP-WEBSTORE.HTML

$15 all sizes – While they last!

Colors Available:

■	□	🟨
Black	**White**	**Yellow** (Men and Youth sizes only)

Buy and/or sell "Beyond the Face is a Heart" wristbands for Craniofacial Acceptance Month

good news

CCA Mom and nurse (RN), **Rebecca "Becky" White**, was nominated for a service award, recognizing her dedication and drive in the career of nursing. The award, the "**Ansell CARES Inspirational Nurse HERO**" was determined by a social media vote on the Ansell website between May 13th and June 12th. You guessed it, the winner was Becky by a landslide, with **12,743** votes!

AnsellCARES
H.E.R.O.
NURSE SERVICE AWARD 2016

Part of the contest and award, was the offer that Ansell would donate a dollar for every vote cast up to **$10,000** to the charity of the winner's choosing. Becky chose CCA as her charity and stumped for votes, rallying several communities behind her. She came from behind initially, but maintained first place nearly the entire competition thanks to voters who kept her there even as she passed the 10,000 votes! We are so appreciative to everyone who voted daily, shared, and recruited friends to vote. We are extremely grateful to Becky for naming CCA as her cause and to everyone who sent her sailing through the finish line. This award is a true testament to her heroism and the award is well deserved. Now, CCA Kids will benefit from this incredible donation.

We're all overwhelmed by the outpouring of support and sharing on social media to gain votes. Becky asked us to especially thank "all my coworkers at **Texas Children's Hospital**, **Dr. Darcy** and **Texas A&M School of Public Health** and all of my former classmates, my local special needs moms, the **CherCrew** (especially **Leda** on Facebook and **Annie** on Twitter & all the "**Chickadees**" who helped her retweet, and all my new twitter followers), **Paulette** and **Cher**, of course the **CCA community** and a special shout out to a group in my tribe, you know who you are, who have been my support for more than eleven years. Thank you for teaching me the characteristics of love and helping us win this contest for CCA! Last and most importantly, I'd like to thank **Ansell CARES**, for being an advocate and a great support to nursing!"

birthday club

We want to thank all of our friends, who generously donated their birthdays to pay the celebration forward, so that more kids can attend Retreat and experience "the time of our lives!"

2016 Birthday Club – THANK YOU!

1. Cher (May 20)
2. Char Smith (January 14)
3. Lentil Bean (February 2)
4. Jackson Pond in honor of his sister, Victoria (December 30)
5. Torey Harrah (February 18)
6. Jakob Graudons (February 23)
7. Meg Storie (February 27)
8. Olivia Rae Vargas (February 11)
9. Francis Smith (April 25)
10. Annie Reeves (September 22)
11. Hayden Broin (October 10)
12. Joe Brooks (October 24)

Several of you have been donating your birthday for years, and we are so grateful that we decided to make it a club! If you sign up for the Birthday Club, you'll get a special surprise and recognized at Retreat. Don't worry, we don't have to tell them how old you are!

children's craniofacial association
13140 Coit Road, Suite 517 • Dallas, TX 75240

testimonial

We are beyond grateful for the assistance and support that CCA has provided to us. As many parents will agree, each child deserves the best possible medical care that is available. For us that meant traveling to Dallas, Texas, for surgery with **Dr. Fearon** and **Dr. Sacco**. With the help from CCA, we were able to afford the costs associated with travel and rest more easily as we prepared for surgery.

My son, **Reed**, was born with craniosynostosis, specifically metopic with trigonocephaly. Reed underwent his first surgery at 7 months old in Chicago. Unfortunately, he suffered great blood loss and the outcome of surgery was less than favorable.

When it came time to choose a surgeon for his necessary second surgery, I knew that going out of state was our best chance for a safe, successful outcome. I also knew that the costs would be much greater. CCA has been a great well of support. Without the assistance we've received, this journey would have been far more difficult to bear.

We are happy to announce that Reed's second surgery was a huge success. He required no transfusions this time around, and the overall outcome is exceeding our expectations. We are so very blessed and thankful to CCA for being an amazing part of our beautiful journey.

Love, Katie and Reed

children's craniofacial association

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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.