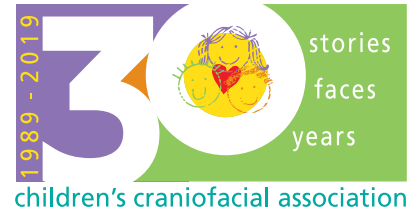


ccanetwork



newsletter of the children's craniofacial association

Cher—national spokesperson

2020: Issue 1

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new year's cheer from the director of development

For those of you I have not met yet, I am **Christine Andler** and have been with CCA for a year-and-a-half now serving as Director of Development. I feel so lucky to be a part of this organization, and the warmth I have felt by the countless families, board members and staff (past and present) who have welcomed me into the fold.

To say CCA is special, is an understatement! I am truly in awe of this community comprised of the most giving people I have ever encountered. The overwhelming amount of pride and heart our families

a journey worth taking—a warrior princess story

By Jennifer Cooper

Our lives have all been enriched by sharing them with our Warrior Princess, **Chloe**. I am pleased to share our story with you and hope that it offers the inspiration to your life that it has brought to my family, and the large circle of friends we have made along the way. Since the beginning, our journey has held many trials and tears, and also innumerable moments of joy and celebration.

When I became pregnant with Chloe, I was a mom to **Sierra**, age 5, and **Kadin**, age 3. The years have passed by quickly and Chloe is now 10 yrs. old, Kadin is 13 and Sierra is 15! Time does fly! Her grandmother has been present since the beginning and we now share our lives with our Warrior's soon-to-be stepdad, **Jeremy**.

see **chloe**, page 26

see **development** page 12





Eight-year-old **Max Molina** is a friendly, hardworking second grader from San Diego, who wants to be a police officer one day to “chase after bad guys.” An avid reader, Max enjoys the *Geronimo Stilton* book series. But ask him about school, and he’d tell you his favorite subject is recess. He likes his freedom, he says, perhaps to get in a couple more chapters of *Geronimo* and his friends’ latest adventures.

During the week, Max stays busy with an after-school program at his local YMCA. He’s been going about three days a week for the past year. The afternoons are filled with sports and games, and he has a lot of fun.

His go-to computer game is Roblox, but on Saturday mornings, Max sets gaming aside and heads to the beach with his father and siblings. He’s ready to go as early as 6:30 am to catch the best waves. He’s learning to surf, but, for

now, he’s perfecting his moves on his boogie board.

As for music, he loves Michael Jackson songs and is also a big fan of Queen and Coldplay. He doesn’t watch much TV, just a few Netflix shows and fun YouTube videos featuring shark puppets as well as ones featuring another puppet, Jeffy. Max loves the movie, *Cars 3* and is a Marvel Universe kid—*Avengers Endgame* is his favorite movie.

Max and his family enjoyed the CCA Retreat this past June in Scottsdale, AZ. He had the chance to make new friends and enjoy all the activities over the weekend. It was “boiling hot,” Max said, but he found the waterslide the perfect way to cool off.

Max was born with Treacher Collins syndrome and has had two major operations so far, one to repair a cleft palate when he was eight months old, and a cheekbone reconstruction when he was six years old. Both were successful. Next year, he will have ear reconstruction surgery.

Always one to laugh and have fun, and never one to be shy and quiet, Max smiles at everyone and says “Hi,” even if people at times are curious and stare. He has a lot of friends and is a very loving young man. He said if he knew anyone going through similar



situations as him, he would “be a friend. They could talk to me, and I would listen.”

ccasupersibs

meet isabella and emilio molina

Isabella Molina

my name is **Isabella Molina**, I am 12 years old, and in the 7th grade. I am enrolled in the Dual Immersion program at Eastlake Middle School in Chula Vista, CA. The other language I speak is Spanish. What I like most about school is I get to hang out with my friends, but what I like least about school is that sometimes the soap dispensers don't work.

After school I participate in cross country. I just started this year, and I enjoy it very much. I like it because it makes P.E. a breeze.

One of my hobbies is reading. I have read all the *Harry Potter* series, and one of my favorite authors is Kelly Barnhill. Sometimes I like to collect seashells, but 99% of the time they end up in the trash because I don't know what to do with them.

When I'm really bored I like to draw people and I also downloaded an app called Duolingo where I am learning Japanese.

The music I enjoy listening to is Billy Joel and the Beatles. My favorite song from Billy Joel is "Piano Man," and from the Beatles, it's **ALL** of them! I do not play video games because I care about my brain. I feel like they can be a big waste of time. I attended my first CCA retreat this summer in Scottsdale, AZ. It was nice to be around other kids whose sibling has facial differences like my little brother. My favorite part of the retreat was the food. I learned that my little brother is not the only one with a facial difference even if it sometimes feels like he is.

I don't know what I want to be when I grow up because I don't want to grow up.

Emilio Molina

my name is **Emilio Molina**, and I am 10 years old and in the 5th grade. I attend the Dual Immersion program at Liberty Elementary school studying in Spanish and English. What I like most about school is that I learn things. My favorite activity

is Biz Town where we get to pretend like we are grown-ups and do things like write checks, go to the bank and use credit cards. The thing I like least about school is homework. They give us too much in my opinion.

What I like to do for fun is play with my action figures and use my imagination. I also enjoy exercising. My dad is a Personal Trainer, so he helps me. On the weekends we go surfing. I would go every day if I could, but I can't. My favorite beach to surf at is La Jolla Shores in San Diego. I have an Al Merrick 5'6" surfboard.

My favorite band is Coldplay, they have unique music. My favorite song is "A Rush of Blood to the Head." I enjoy listening to Alternative the most.

I don't watch much TV, but when I do I enjoy watching surfing videos of John John Florence, Kelly Slater and Jamie O'Brien. They are my favorite surfers and they inspire me to get better.

I like watching Horror movies like "IT." Most kids my age are scared of those movies, but I am not. I also like action movies like "San Andreas." I liked all the

explosions and the thrills. Dwayne Johnson is a good actor. I also enjoy watching sports documentaries.

I attended my first ever CCA retreat this past summer in Scottsdale, AZ. I liked that they talked about differences, and how I got to meet kids from all over, and we did activities together. My favorite class was when we sat in a circle with other siblings and had great conversations. I learned that everybody is different, not just those with facial differences.

My favorite activity was the pool party with the huge water slide. It was so gnarly. The food was great; for breakfast I liked the muffins, eggs and bacon. For dinner, the chicken tenders and barbeque sauce, with the side of Caesar salad was the best.

When I grow up I want to be a professional surfer and study at the Scripps Institute of Oceanography. I love the ocean and want to learn a lot about it.

If I met another 10-year-old that had a little brother with Treacher Collins syndrome, I would advise him to always be there for him; to never doubt that somebody is going to bully them, so be on the lookout.

meet the featherstones



before my husband **Mark** and I got married, we briefly talked about how many children we wanted. I wanted four, Mark wanted three. We both got what we wanted... seven... plus two unexpected blessings a few years ago.

After having four biological children, Mark and I began our adoption journey. First **Anna**, followed by **Danny**, **Keriann**, **Andrew** and **Emerita (Emma)**. Our youngest four are all within

the age range of 13-17 years old now. Being a teenager with a Cleft Lip and Palate can be tough, but having each other has proved to be invaluable.

Fortunately, all of our children are seen at the **Children's Hospital of Philadelphia**. Through the years, many of our visits are noted as "Team Featherstone," as they all have treatments and visits at the same time as much as possible.

All four of our children were born with a Cleft Lip

and Palate and are uniquely different, but so much alike.

Danny is a 17-year-old Junior. He was adopted at age 2. He rows for the crew team and just completed his Eagle Scout. He loves anything about science and engineering.

Andrew, who was adopted at age 10, idolizes his older brother Danny. He is now 14 and is in 8th grade. He is also a Scout, and has tried—and enjoys—so many new sports including the swim team and sailing. Andrew

has continued his Chinese language, along with his sister Emma. They both go to Chinese school weekly.

Keriann is 14 and is in the 8th grade with Andrew. Keriann has also tried many sports, and has found her passion in long-distance running. She enjoys track, and cross country and has competed in a few 5k races.

Emerita is 13, in the 7th grade, and literally loves any sport or activity she is involved in. But in reality, her favorite thing to do is to bike, skateboard, hide-and-seek, stick baseball... you name it... with the neighborhood kids.

Danny came with me to China 4 years ago to bring home Andrew and Keriann, and 3 years ago to bring home Emerita. Despite a total language difference, they bonded, unmediated, because they knew they looked alike... Chinese and Cleft Lip and Palate. It was simply amazing.

Danny, Andrew, Keriann and Emerita have 5 older siblings. **Maggie, Thomas, Mark, John** and **Anna**, ages 19-24.

My older children have welcomed and embraced their siblings from the moment of the announcements of their adoption. They have comforted and empathized with them during their surgery recovery and have made many trips for milkshakes! We truly are amazingly blessed!

Mark and I could not have planned this family any better.



ccateens

it's the brooklyn way— michigan golf tournament



The 2nd Annual “Spreading the Love for CCA; it’s the Brooklyn Way” Golf Tournament was a day to be remembered! The weather, atmosphere and company couldn’t have been better! Thanks to the hard work, commitment, and love of so many individuals, we had an amazing day celebrating acceptance and awareness while raising a little over **\$20,000** for CCA! I couldn’t believe it.

The event was held on Saturday, August 10th at **Fox Creek Golf Course** in Livonia, Michigan. **Brian McCalister** of **8 Trax Musical Trivia** was the Master of Ceremonies, bringing just the right amount of humor and wit to the event. Each hole was

sponsored by a company or individual yielding \$100 per hole sponsorship. We had 43 various individuals or companies sponsor holes which was absolutely incredible! **Masri Orthodontics, Hinderliter Hearing Services, and Tre-Torri Construction** were just a handful of organizations that sponsored holes. New to the outing this year, was the variation in levels of sponsorship. We were incredibly fortunate to have Gold and Silver Sponsors. A Gold Sponsorship was \$1,000 and included hole signage, one team of four golfers, organization name listed on event T-shirts, and mentioned in social media publications. Silver Sponsorships were \$500

and included organization name on a hole sign, organization name listed on event T-shirts, and social media acknowledgment. Our Gold Sponsor was **Dave MacFarland** of **MacFarland and Company Home Sales**. Here’s what Dave had to say about the outing, “In a day and age where it seems like everyone has a charity or cause they’re fundraising for, it can be hard to tell which truly make a difference, and which are for PR and tax purposes. When you see the passion that Angela and everyone who organized the event has for the cause, the tireless hours they put in to be sure it’s a great event, and meeting the kids and families that are directly

impacted by the donations, it’s very clear this is not your average charity event. As someone who truly believes money is only as good as the good it can do, I feel very fortunate to know **Angela, Brent** and **Brooklyn** and have been able to meet some of the other families that are affected by a condition that I previously knew very little about. I’m a proud sponsor, and look forward to continuing my support.” Our Silver Sponsors included **Ryan Broderick** of **Shermco Industries**, **Gary Sinelli** of **Sinelli Charles and Sons**, **Mike Tomczyk** of **Paramount Appraisals** and **John MacFarland** of **MacFarland Painting**.

Huge thanks to all sponsors and donors!

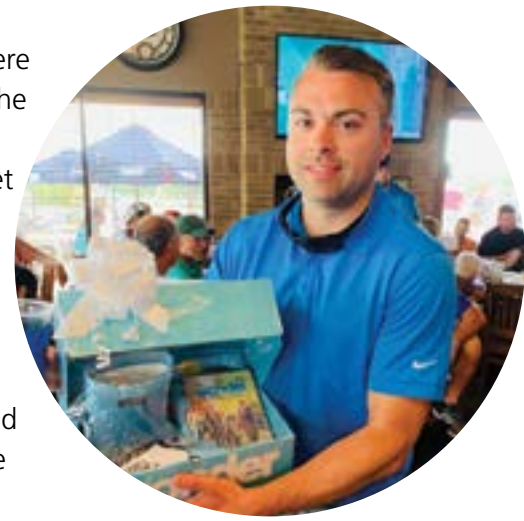
Players were greeted with welcome bags containing items from CCA, golf tees from **Carl's Golfland** in Plymouth, MI, delicious flavored popcorn from **Popcorn Paradise** in Marine City, MI, cup koozies donated from **Tito's Handmade Vodka**, Gift certificates for a free shake from **New 5 Nutrition** in Livonia, as well as **Core Nutrition, and Fitness** in Canton and T-shirts made by **Shane Merem of Mission Impossible Printing**.

Players also got their first peek at over 60 amazing raffle items and 25 silent auction items to bid on. There was a round of golf for four, including lunch, at the exclusive **Forest Lake Golf Club** in Bloomfield Hills, MI, donated by **Marty Gillespie, VIP Wine Tour at Chateau Chantal Winery** in Traverse City, Mi, a Shinola watch and purse and so much more! Players and guests repeatedly commented on the wide array of items

and how many there were to choose from! Family, friends, **Shelby Mies of Sprinkles, Rumi's Passion Bakery** in Plymouth, MI, and **National Honor Society of Stevenson High School** in Livonia created an absolute dream assortment of baked goods ranging from cookies, brownies, muffins, cupcakes, cake pops, etc., for players to take with them on the course or enjoy afterwards. On the course, there were fun challenges for the players to be a part of. Dave MacFarland of MacFarland and Company Home Sales led a longest drive competition on one of the Par 5's awarding prizes to the longest drive male and female. Madonna University golfer, **Jackie Green** raised over \$500 on a par 3 by challenging players to use her shot instead of their own. We had two "booze wagons" that were fan favorites. These wagons will filled with a wide variety of liquor and wine, and could be won if your lucky playing card was drawn. The winners were quite ecstatic! Players also loved seeing Brooklyn riding around and taking pics during the tournament! She truly was at the center of the planning, implementation, and overall spirit of the event. **Coach's Corner** is the restaurant/clubhouse

in which players were provided lunch at the turn, as well as a delicious BBQ buffet dinner. The staff of both Coach's Corner and Fox Creek couldn't have been more accommodating and helpful to make the event a success.

For me, the most special aspect of this year's outing was having numerous craniofacial families with whom we have connected (through CCA!) attend the event. This was the culmination for me and what I feel it's really all about. The connections that CCA has provided my family and I are immeasurable and are something I cherish. I would love to have even more families attend in the future! **Courtney Chavez** of Brighton, MI (mom to **Mila**, CCA Kid) had this to say, "Our family is so grateful for CCA, and the amazing work Angela has done with this outing. We were so happy and proud to be able to play and volunteer this year to support CCA." **Tricia Brusk** of Grand Rapids, MI (mom to **Amelia**, CCA Kid) shared this about the day, "It was amazing to see so much love for CCA. It's incredible to have the opportunity to participate in sharing and educating others on craniofacial differences."



My heart is full, and I have so many people to thank. I can only hope you all know who you are. This outing is my favorite day of the year. All the time, effort, and organization is completely worth it. I feel fortunate to be able to do this and have so many people who WANT to contribute. I was in absolute awe of pretty much everything the entire day. I have witnessed the kindness of so many people; from strangers to our closest friends and family who have shown that they believe and want to be a part of the vision of CCA; for all individuals to be accepted for who they are, not how they look. And above all, to CHOOSE KIND. An outing of this size and magnitude would not be possible without the help and support of so many. I am blessed with the tribe that my family has. It's the best feeling in the world. Mark your calendars for next year—**August 8th, 2020!** Hope to see you there!



3 cheers (and interns!) for volunteers!

by Khadija Moten,
Outreach Director



This year we partnered with the **Dallas Mayor's Intern Fellow Program** for the Summer of 2019. This program provides high school students an opportunity to gain hands-on experience in their desired fields, through an eight-

week paid summer internship. It is modeled after the White House Fellows. We were grateful to have **Dallas Independent School District** sponsor our Mayor's Internship Fellow, **Monica Martinez**. Monica played a role in CCA's #ChooseKind Initiative and Outreach activities this past summer. She assisted us in projects to widen our reach and spread awareness through creating marketing materials, contacting educators, filtering our database, assisting with proclamation requests and creating feedback surveys to improve future programming. Thank you, Monica, for your hard work and dedication, all the best in your future endeavors!

I would also like to take this opportunity to thank our hardworking volunteers: **Yiseul Park**, **Jasmine Amini**, and **Zoya Moten**, sister of **Khadija Moten**, CCA staffer.

Yiseul assisted us with archiving documents and photographs we have collected over the past 30 years. She was also involved in preparing event material and assisting with our #ChooseKind



Initiative. Yiseul shared some words of reflection from her time:

"I am a student at **Richland College**. I had the opportunity to volunteer at CCA during my summer vacation. Before I volunteered at CCA, I did not know much about craniofacial conditions. I thought they might not be real.

However, after being a volunteer at CCA, my mind changed. I realized that there are so many people affected by craniofacial conditions and they are "suffering" from the eyes of people on the outside.

However, after volunteering I was allowed to think about how to treat people who are affected with craniofacial conditions through the educational materials provided by CCA, and it was an opportunity to inform people around me about craniofacial conditions.

I now think that people with craniofacial conditions are just different. Just like your and my looks are different."

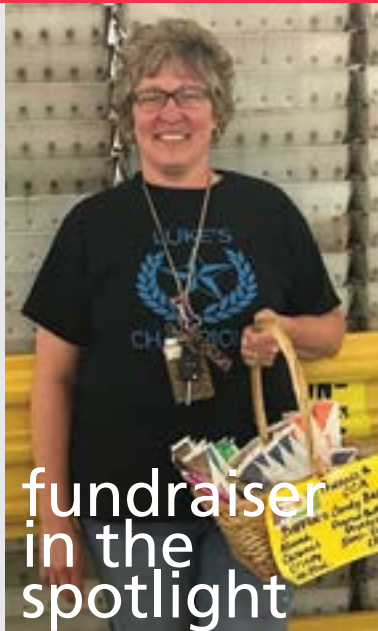
~ Yiseul Park, College Student

Jasmine has been volunteering with us for the past several years and we are so very grateful. I am sure you have seen her name in a previous newsletter or blog post. Thank you Jasmine for your continuous support and for assisting us in organizing our 30 years-worth of documentation and user profiles this summer!

Educator packet requests did not stop just because school was out for the summer. Thank you **Zoya**, for assisting us in assembling packets and sending them off to educators across the nation. Your efforts reach thousands!

CCA is always so humbled by the willingness from the community to help. We are who we are because of you. Thank you to our volunteers, interns, and supporters over the years. It is because of you all that we are able to serve for the past 30 years. Thank you!





fundraiser in the spotlight

a BIG thank you to **Lisa Bowers** for her candy bar hustle!

Lisa came to us with the idea to sell **Daffin's Candy Bars** at her local CAM Picnic in September. Well, she got a head start and started selling the candy bars in her office. Over the course of about three months she sold over 1,500 candy bars alone... even before the picnic! At the picnic and back at work she sold an additional 1,000 candy bars...totaling a whopping 2,500+ bars!

Lisa also raised \$400 in donations at the picnic they hosted. Our candy bar queen in total raised **\$2,500** from her fundraiser!

WOW! Your friends' and family's sweet tooth for CCA is better than a sugar rush to our annual fundraising efforts. Thank you so much to Lisa for her dedication, creativity, and heart for CCA!



thank you, tc team!

We received a call in August from **Melanie Mannon** who explained that for the last three years, her daughter, **Madison**, her friend, **Gretchen**, and a group of their friends, had been raising money for CCA after reading the book *Wonder* in their classroom. The book inspired the girls to do something and create a group for kids who wanted to #choosekind and give back. They cleverly coined the name **TC Team** in honor of Auggie's Teacher

Collins syndrome depicted in the book.

For over the past three years, TC Team has done various lemonade stands, bake sales, and created homemade goods such as: dog biscuits, air fresheners, and stress balls all to raise money and awareness for CCA. The group has even helped us brighten our care packages for us with handwritten and crafted cards of encouragement when our kids go into one of their countless surgeries.

Madison's mom, Melanie, said "While the group began as a way to help

others, it also was a way to help the kids think outside themselves, spread awareness, and create a special connection between kids and families living with craniofacial differences."

We are so grateful for Melanie, Madison, Gretchen and the entire TC team!



ILLINOIS



cca celebrates camp amigo

This September, the **Fogelson Plastic and Craniofacial Surgery Center at Children's Health** celebrated acceptance and community with their annual **Camp Amigo** for children with facial differences from ages 6 – 16.

Even though a scheduling conflict had our DFW #CAM Picnic on the same weekend as Camp Amigo, we wanted to help celebrate acceptance with the campers. Craniofacial Coordinator (and resident superhero), **Sally Derrick, BSN, RN, CPN**, picked up 48 special bags to bring to the campers from CCA Kids. Each camper got a *Wonder* shirt, book, and a #ChooseKind backpack wrap! We hope that this goody bag made the thrilling weekend just a little more special. Sally

says, "The swag bags were a GIANT hit with the Camp Amigo campers! I heard kids say things like 'I have always wanted to read *Wonder*' and 'My sister stole my copy and now I have my own!' The bracelets could be seen on the wrists of the campers all weekend long." We love this response!

In addition to making new friends, fishing, boating, sports and swimming were all a part of the activity-filled experience enjoyed by children at Camp Amigo. Camp Amigo was designed to give children with craniofacial conditions a chance to enjoy the wonders of the out-of-doors and to try new activities in an environment based on support and trust.

This camping adventure offers the campers a

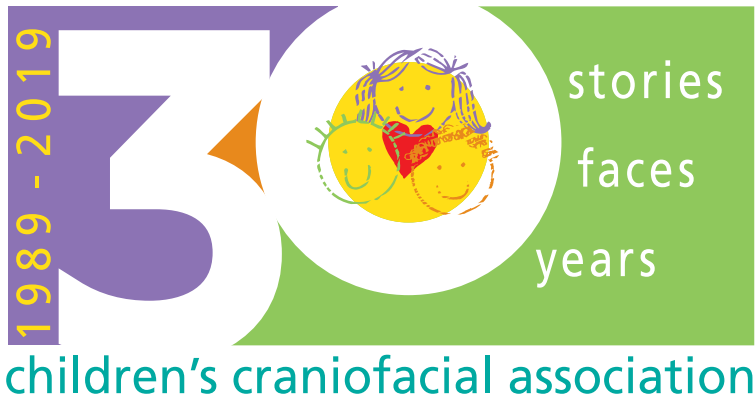


combination of challenges and interactions that leave them feeling good about themselves. The staff consists of Craniofacial Team members who

volunteer their time to serve as counselors.

Thank you to Sally and the entire team at Children's Health for offering this special weekend to area kids.





my name is **Emerald**. I have Crouzon syndrome, and I'm 24 years old. My first CCA retreat was in 2003, when I was 8

years old. Since then, I've gone to as many as I've been able. Every year is full of moments that change

the way I view myself and the world.

To me, CCA means hope. It's a chance for worried children and parents to see real-life success stories. It's a chance to meet others who understand some of the special circumstances we live through. It's a chance to feel just like every other person in the room. Yes, we're all different, but we're all drawn together in one massive family that welcomes others with open arms and smiling faces.

I love that I'm able to be a role model and an example of success. I want to give hope to parents and kids that having a craniofacial condition doesn't have to be a limit. I'm constantly pushing myself to do things that challenge me, and even if I don't succeed, I'm able to bounce back, and find another way to accomplish my goals. CCA allows us all to celebrate these successes.



I also get to see examples of what my future can hold. At CCA, I see people with great careers, spouses, and families. I see people following their passion in hundreds of different ways and it normalizes everything for me. It shows that even though we have craniofacial differences, that doesn't mean we all need to follow one path.

CCA is about sharing our successes and blazing trails for each other. It's about helping each other and sharing common experiences. Of course, we help each other through sadness and fear, but we always return to the good. CCA is a source of positivity and light that we all need.



development,
continued from pg 1

have for CCA is not short of amazing. We give the biggest thanks to each and every one of you who created, cultivated, and have grown some of our most successful fundraising efforts in this last year. I would especially like to highlight the **Wojtyniak Family**, who raised **over \$20,000** and had so many CCA families join with them in Livonia, MI, for the **2nd Annual Spreading the Love for CCA; it's the Brooklyn Way** golf outing!

In 2019, we spent this monumental year celebrating 30 years as an organization! You have probably noticed our 30 Faces, 30 Stories, 30 Years marketing campaign and appeal. We are proud to say **we raised over \$60,000 from our anniversary appeal** alone. A special thank you to the **Anto Family**, whose gorgeous **Grace** was featured in our Spring appeal, which helped us generate many of these matching funds! Thank you to all of you who contributed with stories, fundraising efforts, matching gifts and promotions.

We continue to see an uptick in our family and individual fundraisers. Our most standout fundraising

efforts has come from the relatively simple Facebook Fundraisers. So many of you have donated your birthdays in 2019 to the tune north of **\$100,000...** WOW! We, as a staff, are blown away by all of your generosity and applaud you for these efforts. A big bonus, to which some of you may not be aware, is the fact that Facebook does not take any fees for donations made through their online platform; meaning every dollar you give or solicit goes straight to CCA. Keep up the great work!

Our plan for 2020 is to celebrate the milestone year of our 30th Annual Family Retreat & Symposium with a party the size of Texas! We aim to give more families the opportunity to attend and benefit from our most special program. Increasing our financial assistance fund for medical travel will also be top priority. The ways we plan to increase our giving efforts will come strongly in the form of corporate sponsorships for Retreat plus directed grants for scholarships and financial assistance. We can always use your help in identifying corporations for corporate grants, and I encourage you to email me if you have any leads.

Another ask we make is if you have connections for auction items such as:

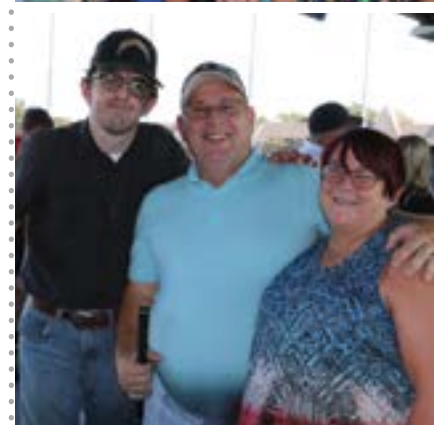
plane tickets to lunches with local celebrities or athletes in your area. These items generate a huge "buzz" in our online auctions on CharityBuzz.com. We can auction off virtually anything with a value of \$1,000+. The most popular items are always meet-and-greets with well-known people of all kinds...know a famous news anchor? Wrestler? Musician? These are the folks that people outside our community will bid to see.

As we look forward to the new year, we cannot wait to see the new fundraisers our families dream up for CCA. We stand ready to help you promote and organize your event. We also look back on the incredible year we had, and thank each and every one of you for all you have done for CCA.

For 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 30th year and upcoming 30th Retreat.

Happiest of holidays to each and every one of you!

Christine Andler
Director of Development



12th annual links of love tournament



CCA had a wonderful turnout for its **12th annual Links of Love** tournament hosted this year at **TopGolf Park Lane** on Thursday, September 12th, 2019. About 50 people gathered, golfed in groups, and mingled with other CCA families, donors, and staff!

We could not be more grateful for our loyal Links of Love sponsors, **Team Impact (Tommy Reeves, of Texas, and Tom Reeves, of California)** and **Team Hickerson, from Hickerson Mechanical**, who come back year after year to this signature event to benefit CCA Kids.

The biggest thank you of all goes to our standout Board Member, **Steven Weiss** and his wife, **Petty**, who have raised over **\$14,000** and counting for our kids for Links of Love. It has been truly amazing to see their network give so much to CCA on behalf of them! Thank you for your hard work!

Our generous donors and sponsors helped three families take part in the evening event. Our raffle packages are always impressive thanks to donations collected and made towards our extravagant raffle packages. Many thanks to donations collected and made towards our extravagant raffle packages. Many thanks to **Zack Albritton, Karen Allbritton, and Brad Boatner**. This family hit the streets collecting many of

the donation prizes in our basket!

Thank you to our raffle donors including: **Grimaldi's Pizza, Pie Tap, Village Burger Bar, In-N-Out Burger, Raising Canes, Fleming's, Hard Eight BBQ, Whataburger, Cheddars, Chuy's, Red Lobster, Buffalo Wild Wings, Gaylord Texan, Medieval Times, Asian Mint, Alamo Draft House, Toys Unique, International Scuba, Castle Hills Taekwondo America, Fossil, Belk's, Lily Pulitzer, Diptiques, Kendra Scott, Alex and Ani, St. Bernard's Sports, Nixon golf, Trader Joes, Western Sons Vodka, the Peace Family and the Andler Family.**

A special thank you to **Chirrisse Owens**, our volunteer photographer, who did a fantastic job making sure to capture the evening!

The raffle winners for our 2019 baskets were:

- Hole in One: **Greg Johnson**, Texas
- Family Fun: **Brittany Brown**, Texas
- Kitchen Shutdown: **Kim Gerard**, Florida
- Queen for a Day: **Tom Reeves**, California
- Whataburger for a Year: **Kevin Winter**, Texas
- Yeti to Party: **Kyle Anderson**, Texas



17th annual coto for the cure tennis pro-am—benefiting cca

By Bill Mecklenburg // Photos by Don Franco



anxiety while creating self-confidence, showcasing their unique talents and being embraced by a community that will support them for life at the 2020 CCA Retreat.

A portion of the funds will also be dedicated to ensuring that over 5,000 students in South Orange County will annually read the book *Wonder* as part of their English curriculum, helping to create a culture of kindness and inclusion as the students enter their critical teenage years.

Vicki Hanna, Val Laguatan, David Page and **Michael Olds** organized the incredible night and weekend. Over **\$160,000** was raised for **Children's Craniofacial Association**, thanks to the community's overwhelming generosity and the lead sponsorships of **Kaiser Permanente, Karma,**

There are several communities that demonstrate empathy for others, but there are very few communities that step up to the challenge to cure those in need. Coto de Caza's Tennis Community is one of those rare exceptions. For 17 straight years, this community has sought out a non-profit to fund with a substantial contribution for providing a cure for the individuals the non-profit serves. On November 8th and 9th over 200 people came out in force to embrace children with craniofacial differences and fund their most critical needs. The **17th Annual Coto for the Cure Tennis Pro-Am** shattered all fundraising expectations. These funds will be used to cure hundreds of CCA (Children's Craniofacial Association) Kids of social



Alliant Insurance Services, and Haynie & Company. The

weekend kicked off with a spectacular event at the beautiful home of **Nick and Vicki Hanna.**

The evening was catered by some of Southern California's finest restaurants including:

Harley Laguna Beach, Hanna's Restaurant & Bar, Piccolino Ristorante, Philly's Best, Kenji Private Chef and Handel's Homemade Ice Cream. The Derek Bordeaux Band rocked the night for the 200+

guests in attendance. **Jono Lancaster** returned from Great Britain to address the crowd before **Ben Kjar** delivered an inspirational testimonial on our need to prevail as victors rather than victims, that culminated with grown adults shouting

their commitment to **"step up and be a force for good."** The guests also had the pleasure of meeting adorable CCA Kids **Keegan Strogatz, Lily Walker, PJ Reynafarje** and **Madeleine Daniels. David Page** masterfully worked



the crowd during the "fund the cure" and live auction, while drawing on **Morgan Mecklenburg** and **Madeleine Daniels** to encourage the crowd to dig deep for this important cause.

On Saturday morning, sixteen amateurs and sixteen professional tennis players competed for the highly coveted Pro-Am Championship. The talent and tenacity was beyond compare for a local event that drew legendary players, including **Michael Chang** and **Rick Leach. Zack Maline** and **Tanner Smith** captured the championship in a highly contested match with **Giovanni Vaglietti** and **Nick Borchenko.**





topgolf tournament in alabama



On a sunny October afternoon, CCA friends and family came together to celebrate acceptance and play a **TopGolf** tournament to raise funds for our programs and services. What always amazes our staff team is how the families themselves turn up and give generously to raise

support for an organization we all love.

At the start of the event, **Erica Mossholder, Executive Director**, offered a warm welcome to her hometown supporters, and introduced **Mindi Stowe**, CCA Mom, who gave a moving speech about her family's first Retreat experience this year. Mindi described



how her family, including husband **Jeremy**, CCA Kid, **Carter**, and SuperSibs **Wesley** and **Jackson**, drove literally across the country from Decatur, AL to Scottsdale, AZ and the impact of meeting a hotel full of families like theirs made on their lives. Many of us welled up with tears at Mindi's candidness and earnestness. But before we could reminisce too long about our own journeys, **TopGolf Pro, Jonathan Lynch** took over and said it was time to get playing! He explained the rules as food was served, and teams went out to their bays to warm up.

There were several family teams, which we sincerely appreciate! **Laura, Heath**, and CCA Kid, **Beth Wilson** came out from Boaz, AL and brought their



family with them to play. **Nathosa Click** and her parents (we missed Dad, **Justin**, and SuperSibs due to scheduling conflicts), came from New Hope to enjoy food and fellowship

where her CCA Kid, **Taylor**, learned he is an amazing driver! New to CCA, the **Damron family**, with CCA Kid **Luke**, and SuperSibs, **Spencer** and **Paul**, joined us and finally experienced what so many of us often say, "I feel like I know you from Facebook, but it's so much better to meet in person!" We are so glad they drove all the way from Tuscaloosa to meet their friends "IRL—in real life!"

The tournament heated up as the teams vied for first and second place, but in the end, **The Rammer Jammers**, took top spot, with team member **Oscar Brown** winning the top spot for the Men's Individual Award, too! Also from this team, the Women's Individual Award went to **Dede Allen**. The Nerds, a team put together by volunteer, **Eric Klauber**, and his dedicated coworkers from **BASF**,

took home the second place prize. Finally, our Golf Pro, **Jonathan**, wanted the kids in attendance to take a swing at a quick competition, too, and so the juniors played a round

and **Spencer Damron** took home the prize of pizza! To close us all out, CCA Adult, **Casey Deakins**, who drove all the way from Atlanta, GA, sent us away with a heartfelt thanks and testament to the work that CCA has done for 30 years—as one of the earliest CCA Kids, Casey described her “aha!” moment when she attended Retreat and found a friend who looked just like her. Now, no matter where she goes—from the grocery store to her work at Kennesaw State University, stares and comments don’t get her down. Instead, she greets the world with the confidence of having her CCA family behind her.

One of the coolest stories from the event, however, was upon getting to know our energetic



and enthusiastic Golf Pro, Jonathan, we found out he too is a CCA SuperSib! Jonathan has a brother, **Nick**, who has Goldenhar syndrome. We found this story especially touching, because sometimes you never know the true reaches of your community until you open up and share your own story.

We must also thank our amazing volunteers who made this event a success! Thank you to our speakers, Mindi Stowe and Casey Deakins, as previously mentioned, and **Eric Klauber**, who assisted with preparation, setup, and fundraising. Finally, **Andy Yarbrough**, CCA Dad, collected hundreds of dollars of goodies for our raffle, which truly made the fundraiser a success for our kids. Altogether, we netted over \$1,500 for CCA!

- **Ainsley Bowen and @ Homes Realty Group**
- **Pump it Up, Parties and Bounce Houses**



- **Tate Farms**
- **Fantasy Playhouse Children’s Theater and Academy**
- **ZOOM Indoor Cycling**
- **MisterWash Car Wash**
- **St. Nick’s Knives**
- **Kendra Scott Bridge Street**
- **Jen Robinson Lash Design**
- **TopGolf Huntsville**
- **Mike Foreman**
- **Panera Bread**
- **Brickhouse Sports Cafe**
- **Bravo Cucina Italiana**
- **Connor’s Steak & Seafood**
- **BJ’s Brewhouse**
- **Cheddar’s Scratch Kitchen**

- **Drake’s**
- **Lawler’s BBQ**
- **Chuy’s Tex Mex**
- **Chick-Fil-A Meal (Madison, AL)**
- **I Love Sushi**
- **Tropical Smoothie Cafe**
- **Earth & Stone Pizza**
- **Tazikis Mediterranean Cafe**
- **Another Broken Egg**
- **Mellow Mushroom**
- **Shrimp Basket**
- **Phil Sandoval’s Mexican Restaurant**
- **Ol’ Heidelberg German Restaurant**
- **ModPizza**
- **Metro Diner**





COLORADO PICNIC

craniofacial acceptance month 2019

This year marked the 15th 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.

Several of our amazing CCA families were able to get their local newspapers to feature them in the paper, and a couple were even featured on their local news stations! We mailed out around 75 Craniofacial Acceptance Month packets to over 20 states. It's always fun to see pictures of our CAM posters hanging in

local libraries, schools, churches, restaurants, etc... Thank you to everyone who requested a packet and/or posters! And, for the twelfth year, CCA held National Picnic Day in September as part of Craniofacial Acceptance Month. CCA families across the nation held picnics in **California, Colorado, Idaho, Illinois, Michigan, New Mexico, Ohio, Pennsylvania, South Carolina, Texas** and **Utah**. For the third year in a row, **The Craniofacial Center and International Craniofacial Institute** joined us and invited their

patients for our local DFW picnic here in Texas.

CCA would like to send out a special thank you to the following families for hosting picnics!

- **Watkins Family**
- **Vysocky Family**
- **Scamehorn Family**
- **Hollingshead Family**
- **Harrold Family**
- **Dowd Family**
- **Clements Family**
- **Seitz Family**
- **Bowers Family**
- **Children's Hospital of Georgia**
- **Sutton Family**

We would also like to thank **Spring Creek BBQ** and the **Carroll**



CALIFORNIA PICNIC

Family, for your continued generosity, and for supporting CCA year after year, as well as all of the CCA families who attended the picnics!



CALIFORNIA PICNIC



CALIFORNIA PICNIC



CALIFORNIA PICNIC



CALIFORNIA PICNIC



CALIFORNIA PICNIC



NEW MEXICO PICNIC



NEW MEXICO PICNIC



OHIO PICNIC



OHIO PICNIC



OHIO PICNIC



OHIO PICNIC



UTAH PICNIC



UTAH PICNIC



OHIO PICNIC

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IDAHO PICNIC



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PENNSYLVANIA PICNIC





PENNSYLVANIA PICNIC



TEXAS PICNIC



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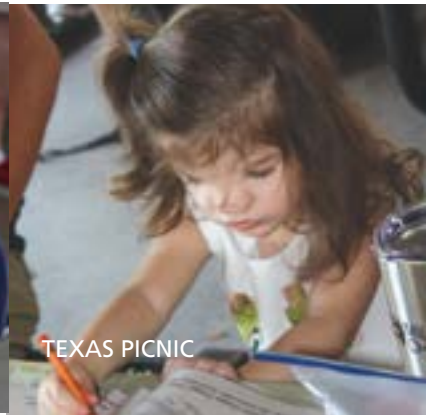
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chloe, from page 1

From the very first, I knew that Chloe's birth was expected to hold risks, but the unforeseen obstacles and physical complications were yet to be determined. These started to become apparent at about 11 weeks when the ultrasounds began showing a "a small jaw." That, in itself, was quite concerning to me, as you can imagine. I had many emotional ups and downs, some normal as any pregnant mom experiences, some just especially worrisome. All along I held strong to my beliefs, knowing that God would carry us through all things seen and unseen.

At 33 weeks into my pregnancy I was expanding a centimeter larger than normal due to amniotic fluid building up. This was occurring due to the fetus having no lower jaw, therefore having no ability to swallow and recycle the amniotic fluid. I had around 5 amniocentesis procedures done, each removing over 6 liters of fluid. During the last procedure, the tech said to me, "Has anyone ever said anything about the ears?" and then would say no more. It didn't take long for much of the picture to be made clear. At 37 weeks, three days before my scheduled c-section with the at-risk delivery team in Denver, my

water broke. I was rushed to our local hospital and from there taken by Flight for Life to the hospital in Denver where a Step 3 NICU was waiting. The c-section was hurried but successful and our little Warrior weighed in at a healthy 5.7 pounds.

From that moment on, everything we learned was shocking and terrifying. Chloe was born with multiple physical defects, including Microtia, no lower jaw, two holes in her heart, multiple fused vertebrae, a tethered spinal cord, immaturely developed kidneys and stomach, and many other serious issues. A tracheotomy was placed soon after birth and every day held new anxieties. An ethics board determined that due to the level of care needed, our beautiful Chloe's life was not viable. That was the wrong thing to tell us, because we had already decided that God was our co-pilot and her life was in His hands. We moved her to **Denver Children's Hospital**, where every life-saving measure available was put into place. She was placed on the ventilator there and would be solely dependent on it for breathing for the next 2 ½ years.

At 12 weeks, our Princess underwent open-heart surgery, and the holes in her heart were repaired; her heart rate



was regulated and she came through it just like a Warrior does! A lot of stress was alleviated as vitals began to normalize some. Due to the missing jaw, and the inability to swallow, a g-tube was permanently placed at 3 months. She remains 100% tube fed to this day.

After 7 months of residency at Children's Hospital, Chloe was released and we were prepped to go home with 24/7 nursing care. No amount of preparation prevented my heart from almost stopping, when on

several occasions Chloe decannulated, among other things, requiring me to literally save my daughter's life as we waited for the EMTs to arrive. Those were some horrifying moments! As the years go by, we require less at home nursing, mostly evenings, and a full-time nurse who accompanies Chloe to school.

Chloe has been quite the mystery to medical professionals. The closest diagnosis to hers is Goldenhar syndrome, which has the most

consistent traits, although Treacher Collins syndrome has always been part of the conversation. She really is just Chloe, full of unique differences that get dealt with as we go along. Many doctors and teams have seen her and done their part in both Colorado and Ohio; all have offered something to improve her quality of life in the 35 surgeries to date. At 2 ½ years, our Warrior was ready to get mobile! The spinal cord surgery was done successfully and in a short time she was crawling and walking. We've never been a family to sit still for long, and Sierra and Kadin had her dancing before we knew it. Her craniofacial doctor in Ohio was able to do a free flap surgery using grafted bone from her scapula, in two separate surgeries,

to create a jaw which expanded her airway when she was 3 and 3 ½ years old. She was eventually able to be weaned off of the ventilator because of that cutting-edge procedure, which gave us all great peace-of-mind. As time went by, the Warrior Princess endured 4 jaw distractions using the RED device in hopes of creating a stable, open airway to allow permanent removal of the tracheotomy. Unfortunately, although she does have an airway now big enough to make some sound, the goal to remove the trach has been unsuccessful. The older she gets the harder it gets to watch Chloe endure the pain and her last one was done in 2017. She now faces additional problems as the mandible has fused to the skull, making it

impossible for her to open and close her mouth. The path forward is leading us to **Seattle Children's Hospital** where we will meet their craniofacial team and determine what they believe to be our best next steps. Our greatest goal is still to be able to find a way for Chloe to eat orally and have the tracheotomy removed. Time will tell.

As our Warrior Princess grows older, we continue to gauge what is needed for the best life possible and often give Chloe some of the decision-making power; I feel that doing this empowers her. She has bi-lateral hearing loss and bi-lateral microtia (lack of ears), and has always used bone-conducted hearing aids. Most recently, Chloe had a surgical procedure to implant her Baha aids using the Attract System. Now her hearing aids are magnetically attached, making hearing much more effective and efficient. During that particular surgery, Chloe asked for her ears, which formed cute little tags on her face, to be pierced. Her plastic surgeon gave the go ahead, and that made her one happy little Princess! Issues with vision have led to 2 strabismus repairs to aid the eyes tracking together, one of which was done recently alongside the Baha and ear-piercing

surgery. We do try to minimize time spent under anesthesia.

Chloe emits a bright light and is the heroine of her own story. She has been a fighter since day one and the sky's the limit for what we believe is possible for her. She is well known in our small town, and has many friends and followers around the United States—even globally. She is fluent in sign language due to her lack of verbal communication. She loves to use her imagination in play, loves dancing, spending time with good friends, loves learning, and does quite well academically. She is active in school clubs, including Battle of the Books, Lego Club, Card Club, Sign Choir, and hopes to do even more this year in 4th grade. She also participates in the **Colorado Angel Pageant** each year which celebrates children with special needs and their talent, uniqueness, and beauty. We are getting more involved with the craniofacial community, and helping to spread awareness in our area. Chloe, Warrior Princess, has been a true gift to our family. Every day with her is a blessing, and we hope all of you enjoy her beauty and spirit knowing a bit of her story. #WarriorPrincessChloe.





calendar of events

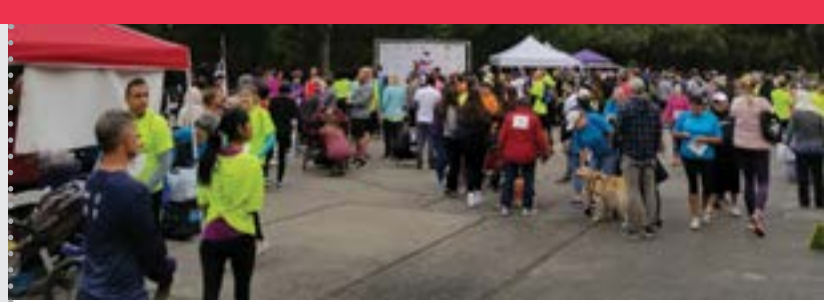
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2020

Jan 18 8am - 4pm	CCA's First Ever Mini Retreat & Educational Symposium All Children's Hospital, St. Petersburg, FL and St. Petersburg Country Club ARees@ccakids.com Join the Florida Cleft Palate Craniofacial Association for a morning educational symposium, and then an afternoon of food, fun, and friendship at the St. Pete Country Club. Food and entertainment provided. Free, but registration required.
Feb 28	Hemifacial Microsomia Family Symposium Boston Children's Hospital EMossholder@ccakids.com Boston, MA
Apr 6-8	2020 Face Equality International Forum National Fire Protection Association Headquarters and Conference Center EMossholder@ccakids.com Quincy, MA Join members of the Face Equality International Group to discuss "creating a world where everyone is treated fairly whatever their face looks like." Face Equality International is an alliance of Non-Governmental Organisations (NGOs), charities and support groups which are working at national, regional or international levels to promote the campaign for 'face equality.'
Apr 18	Monopoly Tournament – "Megaopoly" for CCAKids Gather a team and sign up for a tag team tournament at Megaopoly.net CAnder@ccakids.com Denton Event Center, Denton TX
Jun 25-28	30th Annual Family Retreat ARees@ccakids.com 214.570.9099 Austin, TX 800.535.3643
September	16th Annual Craniofacial Acceptance Month (CAM) ARees@ccakids.com 214.570.9099 Nationwide 800.535.3643



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6th annual cleftstrong 5k

CCA was proud to take part in the 6th annual **CleftStrong 5K** presented by the **Children's Hospital of San Antonio!** Our hearts are happy to announce that alongside hitting a registration record this year, a little over 500 people gathered Saturday, October 12, 2019 at **Los Patios** in San Antonio, Texas to support those born with cleft lip, cleft palate, and other craniofacial conditions and celebrate amazing victories! The same strong smiles, and unique, inspiring moments took place both on site and throughout the race course, but unlike years past in San Antonio, TX, Disney characters and cooler temperatures filled the trail and air! It was a welcome surprise.

We are grateful to our CCA Board member, **Jim Brookshier**, and his children James and Laura for

attending the event and setting up an exhibit table at the event to let more families know about the programs and services CCA provides. At CCA, we believe we are better together, and we were happy to collaborate with these great organizations to promote awareness and acceptance across our communities.



6 testimonial



my little warrior **Malakai** was born on February 2nd, 2017 in California. He had a very traumatic birth in which he lost oxygen. He spent 54 days in the NICU where it was confirmed

that he had a rare form of Craniosynostosis, which they refer to as Mercedes Benz type because of the way that the lambdoid and sagittal sutures closed in the back of his skull. He had his first cranial

surgery when he was only 4 months old in which he had distractors put in. A month after that, he got a serious infection on one of the distractors and he had to go into immediate surgery to have it removed. Then four months later he had the last distractor taken out. At this point he had already gone through four surgeries and three of them were on his head. We thought we were done and that this nightmare was all over. But a year after his last surgery we were told he needed another surgery. This time we decided to seek a second opinion and this is when we found **Dr. Jeffrey Fearon** in Dallas, Texas. After meeting him, my husband and I agreed that we wanted him for what could be Malakai's last cranial surgery. Malakai was not his first patient with this type of rare Craniosynostosis, so that made us feel even more comfortable because he already had experience with it. Since this surgery was out of state both our insurances denied my son the right to have his surgery where it was more beneficial to him. At this point we decided to try and raise the money

because we weren't going to let financial status be the reason why our son couldn't have what he needed. So we started a gofundme, held a fundraising dinner and a Workout fundraiser. But the donations really started pouring in, when Malakai's story was featured on the local news. So we managed to raise the surgery money, but we did not have any money to put towards travel and lodging. This is when I got in contact with CCA and I spoke to **Annie**, she was so nice and patient with us. CCA helped us pay for our hotel stay during Malakai's surgery, and covered food costs as well. I am so grateful for CCA because they truly helped us in a time of need. As a parent, I never imagined I would have to be raising money for my son to have a life-saving surgery, but it's organizations like CCA that truly make a difference in the lives of families in need. We also need more people like Annie in this world—truly kind, loving, and caring people. Thank you CCA for what you did for our family; we truly appreciate you!

— **Segura-Rodriguez**
Family

surviving a sleepover

tips for hosting and attending a sleepover

Cashel Gaffey, MSW • ConnectMed International
and Children's Craniofacial Association

For the Host

- Talk to parents before the sleepover so they can alert you of any concerns/medical information for their child
- Have a notebook ready where parents can leave any relevant information necessary for their child (names, phone numbers, allergies, triggers, etc.)
- Clearly communicate rules on electronics to parents beforehand
- Offer parents the option of coming before bedtime to pick up their child

Set Rules

- Make a clear plan for the sleepover with activities *everyone* can enjoy—but be flexible!
- Set/agree upon a bedtime once all kids arrive, and communicate bedtime with parents and kids
- Let the children know where you will be if they need to find you (if you are not in the same area of the house as the kids)

Double Check

- Make sure if there are any medical devices that they are charged/have batteries!
- If hosting, educate your child about any special instructions regarding medical instruments that guests may have (CPAP, feeding tubes, hearing aids, etc.).
- Use the Buddy System! To ensure that no child is left out or isolated during the night, assign buddies with stickers or colored party favors. Encourage them to check in on each other and if their buddy is missing to make sure they are found and invited to participate in activities.

Is Your Child Ready for a Sleepover?

Ask yourself these five simple questions before packing your kid's sleeping bag:

1. Is s/he mostly independent at bedtime, or does she still rely on you for special cuddles and tuck-ins?
2. Has s/he slept over at a relative's home? Staying with grandparents or cousins can be a useful dry run.
3. Is your child comfortable with the other family? For a first sleepover, she'll do better staying with a close friend, rather than a casual pal.
4. Does your child separate from you with ease? With those who stress out in new situations, there's a high likelihood you'll get a middle-of-the-night "I want to come home" distress call. Be ready and discuss options in advance.
5. Can your child survive on very little sleep? Some kids cope better than others. Important to keep in mind if there are any activities planned for the day after!

Have Fun!

- Sleepovers are FUN! Sometimes stress during a sleepover can distract from the main reason these friends got together in the first place—to HAVE FUN! This should remain a focus for the host parents throughout the night, when making sure things are running smoothly. For parents of the guests, keep this in mind, too. Try not to transfer any anxieties you have onto your child. You communicating how fun a sleepover can be will reassure them that they can do it!
- Sleepovers are also a wonderful way of promoting independence. A night at a friend's house, often with other friends, is a gentle way to introduce them to their own individual autonomy and self reliance.

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Cher

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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.

care packages

did you know CCA has a Care Package program and you can request to receive one on our website? Care packages bring comfort to those who are having surgeries, going through a rough time, or just simply need some "cheer" in their lives. As the demand for these care packages increases, so does the need for care package supplies. We have created an Amazon Wish List and truly appreciate

everyone who has been ordering from our list, and those of you who are collecting items. Without your help, CCA wouldn't be able to provide Care Packages to our families.

We would like to thank the following people for their contributions:

Sharon Allbright

Dede & Peter Dankelson

Girl Scouts

Go Back for the Children

Irene Jacobs

Lake Zurich Middle School North

Crystal Florian Lindquist

Tim Lydia

Steven & Petty Weiss

And, everyone who has anonymously sent us items from our Amazon Wish List!

If you would like to check out our list, please visit: ccakids.org/amazon-wishlist/

To request a CCA Care Package, please visit: ccakids.org/carepackagerequest

