THIS ISSUE OF THE E-NETWORK IS DEDICATED IN MEMORY OF **THE MANY CCA FRIENDS WE LOST THIS YEAR.**
see page 9 for more

ccae-network

e-newsletter of children's craniofacial association

2021: ISSUE 2

inside

Meet the McLaughlins

by Amy McLaughlin

We're the McLaughlin family, and our son **Teddy** is a "Golden" kid.

In spring of 2009, we had a beautiful 2 ½ year-old daughter named **Charlotte (Charlee).** I had a wonderful husband, **Doug,** and I was 36 weeks pregnant with our son. Because I am a Type I diabetic, my OB/GYN and I discussed for weeks when we were going to deliver the baby. I had a lot of ultrasounds and other testing but they had not identified anything "wrong" except some extra amniotic fluid and somewhat erratic blood pressure. At this point, it was decided that I would go to the hospital for monitored bed rest. It was a compromise between my doctors and me. We were just trying to let Teddy "cook" for a couple more weeks. Teddy's big sister, Charlee, had climbed into the hospital bed with me to watch cartoons, and Doug and my mom were chatting about plans for the next few weeks.

continued on: page 2

letter from the program director

2nd Virtual Retreat

After having to cancel our 2020 Retreat, we remained hopeful for an in-person Retreat in 2021, but unfortunately we had to make yet another difficult decision and go virtual for the second year in a row. Making this announcement wasn't easy but I feel like most of you expected and appreciated our decision. Thank you for that! So, once again, we reached out to our craniofacial community, and all joined together online. We had first-time families join us as well as families from all over the United States and even internationally

see virtual retreat, page 6

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

McLaughlins, from the cover continued

It was late afternoon when the nurse came in and said that no one should leave yet. My OB/GYN was on her way in, and there was a good chance I was going to have our baby that night because there was something she didn't like in my bloodwork. We knew that there was a chance Teddy's lungs may not be fully developed, but overall, we were excited to welcome our son. It was March 31st, and as they prepped me for a C-section, we started taking bets about whether we would have an April Fool's baby or not. We knew that either way we would have to spend some time the next day convincing everyone that Teddy had arrived, and it wasn't just an April Fool's Day joke. What we didn't know was that our lives were about to change in a way we never imagined.

Theodore (Teddy) was born at 11:17pm. They told me to kiss his cheek and whisked him away to the NICU. It was about 3:00am by the time they had Teddy stabilized and had me settled into a room. One of the neonatologists came in to see me. They let me know that Teddy was on a CPAP but was generally doing well. However, his ear was not formed on the right side (microtia and atresia), and his lower jaw was smaller than normal (micrognathia). At this point, there was no "diagnosis." He spent 10 days in the NICU gradually learning how to eat and regulate his body temperature. He had failed his hearing test. When we took him home right before Easter on an apnea monitor. They told us to feed him every three hours around the clock, and he would likely "grow out of" most of his issues. We were also to follow-up with the neonatologist, geneticist, our pediatrician, and an ENT for his hearing.

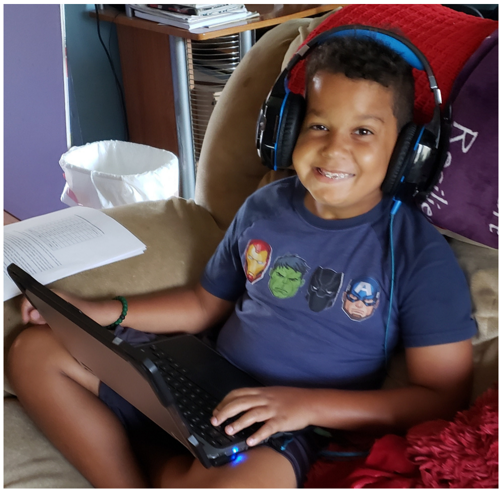
Teddy spent the next 1 ½ months struggling. When he was born, he weighed 6lbs 3oz , and we had no idea the amount of work it would take over the next several months to get him to 7lbs. He spent all his calories eating and breathing and wasn't gaining weight. He looked like a puppy who has yet to grow into his skin, and he had a light blue tint to him. We had an appointment scheduled with an ENT from the **Children's Hospital of Philadelphia (CHOP)** because of his hearing issues. What we didn't know at the time was that he happened to be one of the best airway doctors on the East Coast and was the blessing we needed. Up until that point, no one had really discussed with us the challenges Teddy was experiencing due to his small lower jaw. The first time that we saw **Dr. Jacobs**, he asked me a lot of questions that I didn't have answers to. Teddy still didn't have a diagnosis, and the neonatologist thought he was doing okay. You could tell Dr. Jacobs was frustrated, but he had us make another appointment for two weeks later. The second time we saw him, he was very concerned. He started to make a list of the tests that Teddy needed, but then he stopped and said, "I'm going to get him a bed at CHOP. Feed your baby, and call whoever you need to." Although it was scary when he told me to put Teddy

McLaughlins, from the cover continued

in the car and take him directly to CHOP, there was also some relief. Hopefully, I was finally going to get some of the answers that we craved and some help for my tiny Teddy. It was challenging getting appointments in the "real world," and Dr. Jacobs was the first to confirm what my "mommy sense" had been telling me all along - that more was wrong than what they were saying.

When we got to CHOP, Teddy saw just about every specialist in 3 days. (We often refer to CHOP as "one-stop shopping." They are great about coordinating appointments to minimize trips to Philadelphia and surgeries to minimize anesthesia. We would keep a running list of "things for next time.") They listened to my concerns and involved me in decision making. He was finally diagnosed with Goldenhar syndrome. He got an NG tube so that he would stop aspirating his food and didn't have to burn as many calories working to eat. He finally started to gain weight a few ounces at a time. **Dr. Jacobs, Dr. Bartlett** (Teddy's plastic surgeon), and the entire craniofacial team finally started giving us the answers that we were looking for since he was born.

About a week later, Teddy had a **tongue-lip adhesion (TLA)** in order to open his airway. Initially it seemed to be helping, but unfortunately, it became apparent around the 4th of July that it was not going to be the answer we were hoping for. We were told early on that kids with Teddy's condition usually responded well with TLA surgery, but some would need jaw surgery and rarely a tracheostomy. I'll never forget that night when I sat at the nurses' station with Teddy's plastic surgeon looking at his scans and talking about his options. His jaw was too small and fragile for distraction, and we would have to wait until his ribs were big enough for grafting. It was pretty clear that Teddy was going to be one of those rare kids who needed a trach. This was devastating to us initially, but we soon learned the doctors had a bigger plan for Teddy that would unfold over the next several years. This would be the first step to let him breath more easily, allow him to start putting on weight more easily and would eventually keep his airway safe as he learned to eat again, and most importantly let him stop struggling so much.



During this time, I moved into a room at the **Ronald McDonald House** in Philadelphia (another blessing). Not only did this provide me with a hot meal and a warm bed each night, but it also gave me an opportunity to spend time with Charlee and Doug outside of the hospital. We quickly formed a core group of friends who were also going through some of the same things. It was nice to have others who understood the ups and downs of NICU life. We all cried together during the rough times and celebrated together during the happy ones.

It rapidly became apparent that Teddy would rarely take the easy, straight-forward path. When he had a Nissen fundoplication to relieve his reflux and his G-tube placed, he ended up with dumping syndrome which required a special diet and careful monitoring of his blood sugar. In addition to his microtia and atresia on his right side, Teddy had a narrowed canal on the left side which also affected his hearing. We got him a traditional hearing aid on the left side early on, but he also ended up with several ear tubes placed in that ear to prevent the build-up of fluid which further affected his ability to hear.

In the days before Thanksgiving, we underwent all the

McLaughlins, from the cover continued

training needed to care for Teddy, so he was finally stable enough to take home with nursing care. At home he continued to have physical therapy (PT), speech, occupational therapy (OT), and a teacher of the deaf (TOD), but his best teacher was his big sister, Charlee. She would get down on the floor with him and get him to do things that nobody else could. She adores her little brother and she was so happy to have us all home as a family again. In the spring when Teddy turned one, we had a huge party. We wanted to thank all the people who helped us get to that point as there were definitely times during that first year we weren't sure we were going to make it.

When Teddy turned 2, he started in the **Ivy Nursery** at the **Lake Drive School in Mountain Lakes**. Around this time, Teddy also trialed a BAHA on a soft band. I was really impressed with how much his hearing seemed to improve. He would later have it implanted when he was older. While at Lake Drive, we knew that it was important to teach him total communication so that he would have options to make himself understood. When Teddy was younger, sign language really helped to keep him from getting frustrated while he was having intensive speech therapy and learning to speak. It also came in handy when he was 5 and finally had his rib graft jaw surgery, and his jaw was wired shut for a month. We had planned on this surgery opening his airway and realigning his jaw, but it turned out that it wasn't sufficient. Before he could be decannulated, he also needed to undergo jaw distraction, and before his stoma could be closed he had to have his adenoids removed again (yes – they can grow back). When he finally had a quiet, clean sleep study and could finally close his stoma, we were so excited.

Teddy went to school at **Lake Drive** through kindergarten before transitioning to **Wildwood in Mountain Lakes** and then elementary school in our home district. After spending years traveling over an hour each way to go to school, it was a novelty to only drive across town. He finally got to ride on a schoolbus for the first time! Our district provided Teddy with a teacher of the deaf in the classroom full time in elementary school to help with learning strategies, to learn to advocate for himself, and to act as extra support. Now, Teddy goes to the intermediate school in town (5th & 6th grades) which is right around the corner from our house. He is down to

minimal TOD support, and he is the primary person responsible for his hearing equipment.

When Teddy was eight, we had a discussion about his "little, closed ear" as he referred to it. This was a surgery that we had always intended to let him have a major say in. His inner ear had not formed on the right side, so opening his canal and recovering hearing was not an option. He went back and forth a couple of times before deciding to go forward with it. A couple of weeks after his ear reconstruction, we noticed that part of the graft didn't take. This resulted in a second surgery to have part of the graft replaced. Like a lot of things in Teddy's life, it turned out to be more complicated than was originally planned, but he's happy with the results, which is the most important thing.

We've always been open to talking about Teddy's condition. When he was little we made sure that Charlee and Teddy had age appropriate answers for questions that other kids inevitably had. "What happened to his ear? – It didn't grow right in my mommy's belly. The doctors will fix it when he's bigger." "What's that on his neck? (referring to his trach) – It helps him breath better." Most of the time, we would find that they were merely curious and would soon be off playing together.

Now that Teddy is older, we have done several presentations at schools, talking about his journey and the importance of kindness.

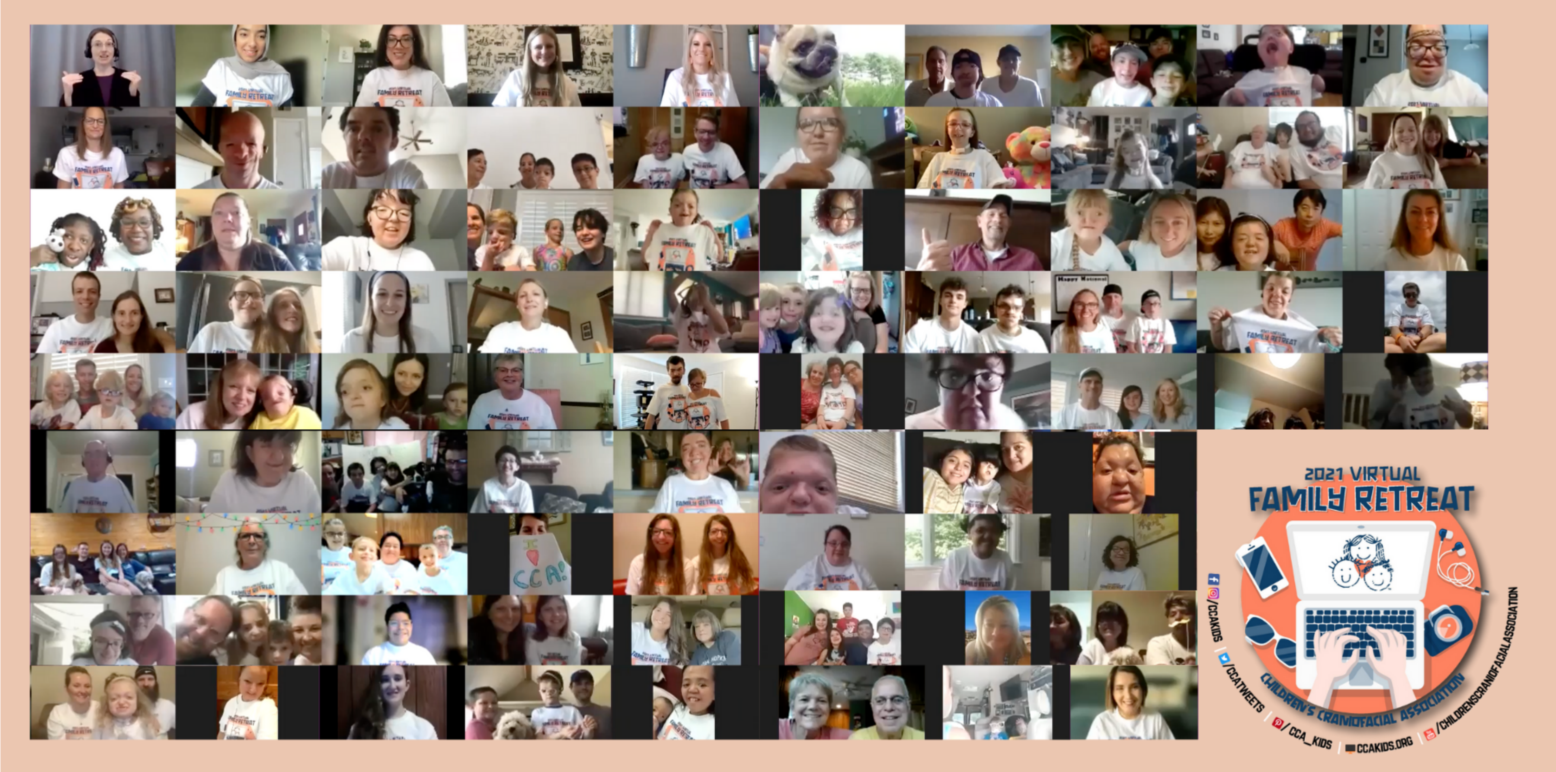
Our first CCA Retreat was in Virginia in 2017. **Diana Sweeney** from CHOP called me and said that she wanted to send our family on Retreat! I wasn't entirely sure what to expect, but when we walked into the lobby of the hotel, Teddy declared, "Mommy! These kids are all just like me!!" I instantly knew that we were in the right place. There was a group of boys who are all the same age as Teddy that quickly became friends. Charlee made new friends as well. Everyone was warm and welcoming. These were siblings and parents and kids that truly "got it." When we arrived in Salt Lake City for our 2nd Retreat, we were greeted with hugs and happy tears. It felt like not a day had passed, and we picked up right where we left off. Teddy is now a charming and amazingly resilient 12-year-old who dances (hip hop, tap, and jazz) and sings ("Hamilton" is a favorite) his way through life. He loves the beach, football and Minecraft. He's come a long way, but there are still a few things in progress.

He's on his third round of braces, trying to align his teeth and improve his bite. He still needs at least one more major jaw surgery at some point in the future. He's still figuring out the right level of "sharing" with his new friends at the intermediate school. Most of them have no idea of how much he's been through, just that the "box" on the side of his head helps him hear better.

To them, he's just Teddy.

To us, he's so much more.

2nd virtual retreat , from the cover continued



which makes our hearts so happy! We had 191 families sign up, and our largest single events (Group Photo and Dinner/Dance) both had 80 families logged in at once!

Although it still wasn't quite the same as "in-person" Retreat, we had three fun-filled days of laughter, smiles, tears, and learning. This year's Retreat went so smoothly and you could sense a feeling of calmness, happiness, and unity among our families. It was quite amazing to witness, especially after all of the unknowns from last year.

We kicked off our Virtual Retreat on Friday with Virtual Exhibit halls hosted by our sponsors and enjoyed Educational Symposium sessions. Both carried over into Saturday morning. CCA is so fortunate to have expert speakers volunteer their time to host these sessions for our families and we couldn't do it without their generosity. We would like to thank the following teams and volunteers: **Belong Ministry at Highland Park United Methodist Church, ConnectMed International, Children's Hospital of San Antonio, MED-EL, Nationwide Children's Hospital, and Stryker**. The speakers were **Liz Irwin, CTRS; Josh Espinosa; Rita Albert, JD; Cashel Gaffey, MSW; Sara G. Seth, MPH, CGC; Dr. Scott McLean; Lynn Stephenson, Ph.D.; Kevin Vukovich; Gregory Pearson, MD, FAAP, FACS; Ibrahim Khansa, MD; Annie Drapeau, MD; Canice E. Crerand, PhD.;**

Ana M. Mercado, DMD, Ph.D; and **Dina Leone Frank.**

This year's topics included Choosing a Hearing Aid Solution, CARE (Communication, Anxiety Management, Resources, Empowerment) for Patient Parents, Addressing Bullying throughout the Lifespan, Orthodontics, Siblings Support, and more!

We truly appreciate our speakers' time, expertise, and dedication to ensure our families had an enriching learning experience.

We would also like to thank our Motivational Speakers, Presenters and Panel Members: **Rose Seitz; Joel Brusk; Jason & Liz Cox; Greg & Abby Daniels; Karen Foley; Laurel Sanborn; Vanessa Acero, PsyD, M.S., APCC.; Lexi Sorbara, LMFT-A, ATR-P, CYT-200, EMDR-Trained; Priscilla Batres; Abbey Merrill; Quinn Stevens; Patricia Simon, R.N. (CCA Board Member); Courtney Vysocky (CCA Board Member); Josh Daniel; and David Roche** for sharing their personal experiences with us, offering advice, entertaining us, and serving as trusted mentors and role models.

Friday also had a couple of events for the whole family, including an educational show from the **Indianapolis Zoo** on their **Simon Skjodt International Orangutan Center.** Then we held one of our most popular events, "CCA's Got Talent!" We had 21 performers this year. Let me tell you, they brought some serious talent! There was singing, instrument playing, dancing, artwork, a magic trick, a Tai Chi Fan performance and a baton routine! For the second year in a row, **Chelsea Buyalos** was our emcee. And, just like last year, she brought her "A" game! We love Chelsea's commentary and her bright personality; she is a true performer! Plus, she debuted not only one…but two bows this year, complete with a costume change!

Although she doesn't know this, I will be asking her to emcee again next year, because, YES, she's that good!

Saturday morning kicked off with Breakfast with the Beasts of the **Fort Worth Zoo**, followed by an Animal Adventures Program by the **Dallas Zoo**! Families came dressed in animal print and asked wonderful questions. Then, we all met up for our Annual Group Photo. It was so nice to see everyone in their Retreat t-shirts, which were designed by CCA Adult, **Jennifer Johnson.** Following the photo, we held Group Meet-Ups, which we changed this year, having two groups that were a "Get to Know You" group and others that covered topics such as Navigating Parenthood, Hearing Aids /Devices, Genetics, & Orthodontics. Though they were short, it was an interesting way to connect and meet people interested in the same topics.

Following the Group Meet-Ups, we all gathered to watch one of the coolest things I've ever seen! If you haven't heard of **Spheres Bubble Show: A Fusion of Art, Science, and Magic,** by **Blaise Ryndes,** you need to Google it. **Erica Klauber** and myself were fortunate enough to meet Blaise and his Dad in January of 2020 at the **CCA Mini Retreat** in St. Petersburg, FL. He told us about his Bubble Show and showed us some clips from when Blaise was on Season 13 of **America's Got Talent** and we were blown away (no bubble pun intended). I can tell you that by the look on some of your faces that you were blown away as well!

Saturday evening, everyone turned to Facebook to watch CCA Dad and amazing musician, **Josh Daniel**, jam and serenade us. By the look of the comments, I'd say everyone thoroughly enjoyed his concert and is hoping for an appearance at the 2022 Retreat!

After being wowed by Josh's talent, we all came together for our signature event of the Retreat …the **Dinner/Dance**! This year we asked everyone who wanted to participate to dress up from their favorite decade which brought another level of fun to our signature event! **DJ Neil Turner** kept the party hopping and played all of our favorites. Seeing the glow sticks, your amazing set-up's and dance moves was so much fun! Thank you for your participation and yes, we all agree that dancing on the same dance floor will be the most amazing feeling ever next year.

Sunday morning always comes way too fast with both the virtual and in-person Retreat!

(continued...)

Subscribe to our YouTube channel to view short retreat highlights in the coming weeks.

Subscribe

American Cleft Palate–Craniofacial Association

2nd Virtual Retreat, from the cover continued

They say time flies when you're having fun, and I'd say this phrase is spot on. We were fortunate to have **David Roche** speak during our **Farewell Breakfast** again this year. David has such an amazing personality, a kind heart, an openness that invites you to connect, and the ability to tell a story like no other. Even if you don't know him, the moment he starts talking, you feel like you've known him your entire life. We laughed, we cried, we learned, and most importantly, we expressed gratitude for this strong community called CCA.

We would like to thank our sponsors who have supported us through a pandemic and beyond. Without your generosity, we wouldn't have been able make this year's Virtual Retreat possible. We want to thank **MED-EL, Nationwide Children's Hospital, Stryker, KLS Martin, Libra Group, ConnectMed International, Children's Hospital of San Antonio, UF Health, ACPA, myFace, DePuy Synthes,** and **Orthomerica.**

Thank you all so much for attending and for being absolutely wonderful! Seeing all of you during our Retreat was just what I needed!

It was a reminder of how truly blessed I am because of all of you. Let the countdown begin to our next in person **Retreat in Dallas, Texas, June 23-26, 2022 at the Sheraton Dallas Hotel.** It's going to be the best reunion ever! See y'all next year!

Thank you,

Annie Reeves

Annie Reeves
CCA's Program Director

Thank you to our 2021 Virtual Retreat Sponsors!

In memory of:

Our August 2021 E-Network is dedicated in memory of:

- **Robert Opdyke**
    - Father of CCA Adult, **Shannon Sesa** and husband of **Roseann "Rosie" Opdyke** (see pg.12)
- **Cathy Evans**
    - Former CCA Board Member and Mom to CCA Adult, **Jennifer Smith**
- **Paul Dexter "Doze" Sanders**
    - Father of CCA Adults, **M.E.** and **Wesley Sanders**
- **Martha Jane Colley**
    - Grandmother of CCA Mom, **Melissa McGowan**
- **Nick Walker**
    - SuperSib of CCA Kid, **Lily Walker**
- **Paul George Morgan**
    - Uncle of CCA Mom, **Kristine Dale**
- **Audrey C. Sinelli**
    - Grandmother of CCA Mom, **Angela Wojtyniak**

We would like to recognize the passing of our dear friend, Cathy Evans. Cathy was involved with CCA since our inception in 1989. She served on the CCA Board of Directors from 1991 to 1996 and then became CCA's Business Manager through 2008. Cathy's youngest daughter, Jennifer, was born with a cleft lip and palate and both Jennifer and Cathy's older daughter, Nicole, were involved with the organization. Both of them worked for a time in the CCA front office. We truly value their whole family's commitment to CCA, as well as their dear friendship. Cathy was a genuinely kind person and will be sorely missed.

Legacy Giving

Simply put, planned giving enables you to make a meaningful gift to CCA that reflects your beliefs and values while leaving a unique legacy to memorialize those values and beliefs by supporting CCA Kids during your lifetime and beyond.

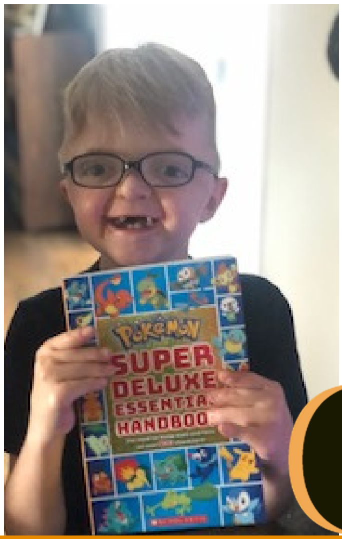
To learn more about how to leave your mark on the world through supporting CCA Kids and Families, visit: ccakids.org/legacy-planned-giving/ or email **Christine** at candler@ccakids.com

meet knox

My name is **Knox Cloes,** and I am 8 years old (but can't wait to be 9). I have **Apert syndrome** and have had many surgeries, some minor and some pretty big ones - my mom lost count! I am going to be in 3rd grade. My favorite things in school are recess and Chromebook time on Friday, because we can pick a game. My favorite subject is art, but I also want to learn to sew, too. Writing is my least favorite because it is hard for me to hold the pencil and it takes me a long time. I like when my mom reads to me. Right now, we are reading "The Action Bible" and I want to start reading the "Harry Potter" series.

I love spending time on our Nintendo Switch. My favorite games are the “NBA 2K” basketball game and “Lego City.” I could play on it all day! I also like to take apart and build things. I like to say that I am the "handyman of the family!” For my last birthday, I got a drill and tools and made a dolly. My brother, **Ryder**, and I like to lay on our bellies and ride on them.

My favorite movie is "Harry Potter," the first and second one. I also like playing basketball, archery, and jiujitsu. I was sad when I had to stop because of the COVID-19 pandemic. I love listening to music with my big brother Ryder. My favorite songs are, “I’m Still Standing,” “Old Town Road,” and “Lightning and the Thunder.” We also have some sweet dance moves, too!



Two years ago, my brother and I won first place in our school talent show for dancing to “What Does The Fox Say.” All our family and friends were cheering us on! I love playing with my brother and sister. Some of my favorite things to do with them are build Legos, play basketball, ride bikes, and jump on the trampoline. My favorite thing about Ryder is he plays with me all day. My favorite thing about my sister, **Helena Blaine**, is that she will play catch with me and let me hold her.

One of my favorite vacations with my family was when we went to the beach and the San Diego Zoo. I love playing in the sand with my dad and watching the monkeys at the zoo. I want to go on more trips with my family.

Our family went to two Retreats, one in Newport Beach that I don’t remember but my mom said I had so much fun running all around, and then last year's Virtual Retreat. I liked when we danced and saw the zoo animals. Ryder and I are going to have our own zoo together one day, just like the one in Texas.

I don’t like the smell of the hospital at all. I had to go into the hospital this year and didn’t feel good. They told me I have too much fluid in my head. I was supposed to have surgery to help me, but it was too dangerous. I was so happy I didn’t have surgery and now I take a medicine every day to help my head. We are still waiting to see if this helps. I get scared when I am at the hospital, but it helps me when I have my stuffed animals with me.

One thing I wish people would know about me is that I love music and when my eyes go down, I can still see. I wish people wouldn’t stare at me but one thing I say to them is, “That’s how I was made, and God made me - born unique and special.”

PLAY CONNECT THRIVE

CAMP COSMOS
2021 SUMMER CAMP WEEKEND

OUR 2021 CAMP COSMOS IS GOING ***HYBRID*** THIS SUMMER WITH VIRTUAL & IN-PERSON OPTIONS!
THE THEME IS...

"SPEAK UP AND REACH OUT"!

Empowering attendees to share their experiences, open up conversations that counteract negative stereotypes, and advocate for themselves!

VIRTUAL EVENT:
SATURDAY, JULY 31 - 10:00 AM - 1:00/1:30PM PST

HERE'S WHAT TO EXPECT:

- Hear from our special guest speaker, Phyllida Swift (@phyllidaswift) - an appearance activist and CEO of Face Equality International
- Interactive games like "In It To Win It", an Escape Room activity & more!
- Receive an Activity Kit with supplies and surprises that will be mailed to your house!

IN-PERSON EVENT:
SUNDAY, AUGUST 1ST - 10 AM-1PM PST

HERE'S WHAT TO EXPECT:

- Beach and lawn games at Kellogg Park in La Jolla Shores
- Optional kayaking lessons
- LOTS of Dough Momma pizza!

Register for one or both events - REGISTRATION IS NOW OPEN at https://connectmed.org/camp-cosmos-application/
If you have any questions, email info@connectmed.org

ccasupersibs

meet helena

Helena Blaine is a 5-year-old little girl that loves to create and invent anything and everything. Helena Blaine loves to invent with her Magna Tiles, marbles, and Legos. She loves playing with her friends at school and playing pretend. She likes everything in school. She is starting Kindergarten this fall and is a little scared but excited to meet new friends and learn to read like her big brothers. Her favorite things to do are play Barbies, dance, and create art projects.

She is a huge fan of all the princesses and wants to be a "builder" when she gets bigger. She also wants to join dance or gymnastics and learn new twirly tricks. She also knows how to have a great time playing in the mud and creating big dirt castles or digging for bugs. When she is not finding bugs or picking flowers, she loves to cuddle our dog **Rip**, trying to ride him like a pony.

She has the sweetest personality, but sure can boss her brothers around. She has the nickname "Boss Lady" because boy will she put those brothers in place. She is a great combination of sweet and sassy. She is able to hang with those boys in any wresting or Nerf gun battle that goes on all while wearing a pretty skirt or dress.

One of the funniest things we witnessed was Helena Blaine wrestling **Knoxie** to the ground to get a football. As she was getting up and running to get the ball, she was pulling up her skirt that was falling down - not even phased that she had her skirt halfway down, or that she just tackled her big brother. As she ran and picked up the ball, she also pulled up her skirt and got the touchdown. She then began her happy dance!

She loves to eat pizza, In & Out hamburgers, and macaroni and cheese. Her favorite place to go is Disneyland and she misses it so much. One of her favorite memories was when she met princesses, Anna and Elsa. She said it was the best day ever! Her favorite movies are "Frozen" and "The Little Mermaid." She loves to listen to all of the songs from the movies. We love to go on Mommy and me dates with the kids, and when it is Helena Blaine's turn she gets to listen to her favorite stations and always picks "Frozen" or "The Little Mermaid."

She does not like to play baseball, but will cheer on big brother, **Ryder**! Her favorite thing about her brother, Knoxie, is that he will play kitchen with her and he is nice to her. She loves Knox so much. She gets sad when he is in the hospital or gone too long because she says he is the best brother ever and misses playing with him. She loves drawing and painting with Knox. When he is away, she will make him the sweetest pictures.

meet ryder

My name is **Ryder Cloes**, and I am almost 10 years old and going into 4th grade. My favorite thing to do is play sports! My favorites are football, baseball, and soccer. I am playing travel baseball right now on the Squires team. My favorite position is pitcher. I am working hard to get better and better at it. I like when Knox plays catch with me. When I grow up, I want to be a professional football player on the Steelers and a zoologist after I am done playing football. I love helping animals. My favorite animal is a sloth. I also love music, too! My favorites are Post Malone and NF. I am pretty good at dancing, too!

I like going to school to learn about history and science. I like that I am learning about all the

meet ryder, continued from supersibs

the states and countries. I also like learning about how things work with science experiments. My favorite experiment that I have done is putting Mentos in coke and making a huge explosion! In school, we have to read a lot, but I don't mind because I get to read the "Percy Jackson" books. If we read a lot of books, we get prizes, so I always try to win.

I love hanging with Knox and watching funny movies. My favorite movie on Netflix is called "The Sleepover." It makes me laugh a lot. Knox and I also like to have Nerf gun wars with my dad. My dad likes to take us to our gym and creates fun workouts for us to do together. It is fun to cheer each other on when we are working out. My favorite thing about Knox is he always makes me laugh. He inspires me because he never gives up, even if he can't do something. I love that he always wants to play with me, especially when he asks to play Pokémon. I wish people would see how kind and nice Knox is. Even if kids stare at him, he still wants to go and give them a chance to play. He is amazing!

When Knox goes into the hospital, it makes me feel sad and nervous. I like to pray for him and try to FaceTime with him, if I can. We make funny faces with the emojis on the phone. I know that the hospital is a good place for him to go, so I am happy he is getting help. Knox having Apert syndrome teaches me just because you are different on the outside doesn't mean you are different on the inside. He shows me how to be brave and selfless when I am scared to do something. I hope that I can always show kindness to others the way Knox does. I am thankful he is my brother because he is my best friend.

In memory of Robert (Bob) Opdyke

by Rosie Opdyke

My husband, **Robert**, and I became involved with CCA, because of our now 45-year-old daughter, who was born with craniosynostosis and was a patient at **CHOP (Children's Hospital of Philadelphia)**. A dear friend of mine, who worked at CHOP, held several events for the kids as well as attended the CCA Retreat each year. She asked us if we wanted to help assist families attend the Retreat, and we were happy to help!

The first time I attended a CCA Retreat, I was overwhelmed by all of the families present. I loved hearing about their unique experiences and challenges. I was able to see firsthand the impact on these kids, teens, adults, and their families. It was so important for all of us to be able to attend the Annual Family Retreat.

Over the last 20+ years, my husband and I have been blessed to send more than 100 families to the CCA Retreat! I'm so proud we were able to do this, because it is such an important event for the entire family!

Sadly, my husband passed away in May of this year and we were all heartbroken. My family chose CCA as the suggested charitable donation in memory of Robert. It warms our hearts to know that each donation honored the most generous, loving, kind man we have ever met. He would have been so touched and honored by all the contributions that were made by our family and friends, especially knowing how important this Retreat is to all of us!

meet mariana

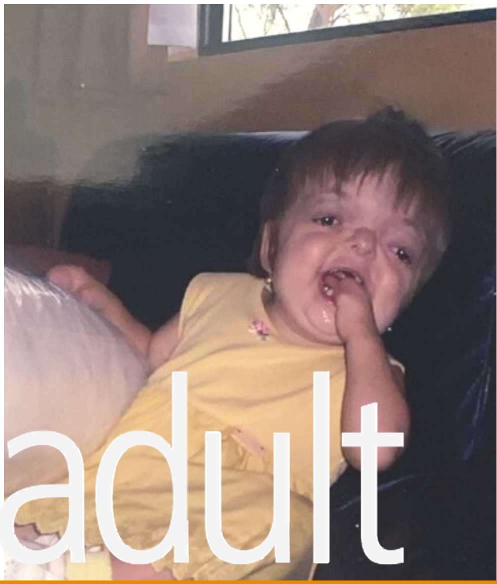
Hi, my name is **Marina Isaacs-Tallafigo**. I am from Arizona. I was born with **Apert syndrome**. I have had over 30 surgeries as a kid. Most of the surgeries were on my midface. A lot of people make assumptions about me before meeting me. Growing up, I was in special needs classes, but I fought my parents to get me out of it. In third grade, I was finally taken out of it. I was a stubborn person, and I still am. Growing up, I never let my syndrome define me or stop me from doing something. My parents were amazed with me because every obstacle I came across, I learned to adapt and come up with a solution that fit me. People would offer me accommodations, but I would refuse them.

Growing up, I wanted to be a lawyer or a nurse like my mom.

I did not know what I wanted to go to college for until I was in my junior year of high school. One story that I like telling from high school happened during my freshman year when we were registering for sophomore year classes. I chose almost all honors classes. One of my teachers at the time and my mom were hesitant about me doing honors, but I still did it and ended up with all A's and B's. When taking my placement exams before starting at **Pima High School**, I actually scored really well in reading and was offered to take the honors course, but I needed one more point on my writing exam to be eligible.

When I was a junior in high school, I started taking psychology classes. At my school it was called behavioral health. I got really interested in helping people and trying to understand the mind. Growing up, I loved watching the CSI shows, mainly ones based on real stories. I would watch "Investigation Discovery" a lot, too. It was interesting to learn about different types of serial killers, sociopaths, psychopaths, and so on. I decided after taking behavioral health I really wanted to help others around me. I applied to college and started my degree, and will be transferring to the university in my hometown this fall. I went into college thinking of being a therapist of some sort, because I loved giving people advice, and helping them. I am not entirely sure what I want to do now with my degree. I am taking different courses that are psychology classes to see what is out there.

One thing I do not like about my syndrome is not being able to wear nice shoes. My feet fit a teens size 3. I always had a hard time finding shoes that fit and looked appropriate for my age. A lot of the options in that size have bright colors and glitter. I cannot wear sandals, or any other shoes besides



mariana , from the cca adult

tennis shoes for the most part.

I started driving back in 2017. I was kind of late to getting to my permit and driver's license. I was first using my mom's car to practice in because my dad's car was a truck, which was way too big for me since I am just about 5 feet tall. My parents got me my first car for my 17th birthday. It was a gray 2015 Nissan Rogue. I needed my own car because I needed pedal extenders put in my car. They were hard to take on and off in my Mom's car which really hindered my ability to practice. Other than the pedal extenders and a small cushion on my seat to make the seat feel higher, I am able to drive just like any other person.

In my free time, I like to binge new series on Netflix, sleep, or watch “Friends” on TV. Right now I am finishing “Grey's Anatomy.” I am more of an introvert. I have slight social anxiety which makes me extremely shy. I do not have a ton of friends, but the ones I do have are the best. I like to keep my circle of friends small. My longest friendship is about ten years with my childhood best friend since sixth grade. We grew up together and lived about a half a mile away from each other. I consider her family. We act like we are siblings.

Right now with COVID-19, I am doing school online and trying to stay safe. I stay accompanied by my four dogs. I am not sure how I will do my classes next semester with everything going on. I would like to return to in-person classes, if possible. One thing that I have always stuck by was not letting my syndrome define me. I had to put more effort into certain things because of my limitations, but I try not to let my syndrome stop me.

craniofacial acceptance month (CAM): 2021

This year's theme is:

I ACCEPT ME.
i accept you.

This important statement is so timely as we all are finding our own self-acceptance and self-love, throughout our lives. We want our community to model acceptance towards others who are different from us, too. By celebrating and embracing others' differences, we are making the world a better place. Get to know someone different than you. Practice empathy, respectfully ask questions, and read books and personal stories to educate yourself on racial, cultural, and religious experiences different than yours. If you do this, you are quite literally changing the world one act of kindness at a time!

Group Photo

We are better together! Join us for the popular online group photo! Wear your favorite yellow attire (the bolder, the better) and jump in a very quick Zoom to record a snapshot of our families all "together." The Group Photo will be **Thursday, September 16 at 6pm CT (7pm ET, 5pm MT, 4pm PT)** and the zoom link will be updated here and sent via email a few days prior to the event.

Yard Signs from Sticker Mule

Last year, awareness yard signs were a popular feature we added to celebrate CAM! This year, we are not doing a fundraiser but many of you said you still wanted customizable yard signs. We researched some options, and we think the best price and features can be found by ordering via Sticker Mule, one of our favorite vendors. If you want your child's photo embedded on your CAM sign and need some help, just let us know. We're happy to create that file for you to upload and order.

While these do not raise money for CCA, if you shop though our link, we'll get $10 in credits to print more stickers that we include in financial assistance requests, care packages, and to teachers using our #ChooseKind curriculum.

Shop here:
https://www.stickermule.com/
Go to **More > Yard Signs.**
Only $60 for 10 signs with stakes and free shipping!

Order Resources

Want to share information with your school or neighborhood? We have booklets, brochures, and curriculum available for free. Just visit: http://bit.ly/CCAResources to request the resources you need to share acceptance near and far. Want to order books and curriculum? Visit: https://ccakids.org/choosekind-initiative-new/ to see what is available.

Host a CAM Funder

The possibilities are endless: from a lemonade stand, a school supply sale in your classroom, or holding a 5K run – bringing people together for awareness and fundraising makes a true impact for all of our families.

One of the easiest ways to raise funds during CAM is on your **Facebook or Instagram!** These platforms make it a breeze to share and invite friends and they charge no fees at all! As a special incentive, if start your own funder online and raise $750 or more, we will send you a special CCA Yeti Mug as a CAM Thank You! Here's one way to set this up: https://www.facebook.com/fund/ccakids/
(For step by step instructions visit the last page of this e-Network.)

Contact the Local Media

One of the most important goals of CCA is to promote social acceptance of children and adults with

craniofacial acceptance month, continued

facial differences. It usually only takes one conversation to help someone understand that we are more alike than different.

We believe that in order for the general public to accept facial, physical, and other differences, they must see and understand them. Furthermore, is important to see positive role models with facial differences in the media.

We encourage our families and friends to contact their local TV and radio stations, plus podcasters and bloggers you follow, to schedule interviews and awareness stories in your local communities. Here's a handy guide on how to pitch your story.

Plus, you can share the CCA PSA videos on YouTube and contact us if you'd like a custom press release for your event or story.

Plan a Picnic

See our article on planning a picnic to make your CAM celebration a huge success! Or attend an existing CAM picnic, listed on the last page.

CAM PICNIC HOSTING TIPS

September is Craniofacial Acceptance Month! Here are some suggestions for planning and hosting a top-notch event to raise awareness and celebrate our craniofacial families.

1. Location

- a local park
- beach pavilion
- own backyard
- state or city parks
- playground

CONSIDER:
- # of people you estimate to join
- space needed for activities
- amenities (grill, tables, restrooms)
- necessary permits/deposits/fees

2. Date

Choose the date that works best for you and your community

Avoid:
- Federal, local, and religious holidays
- Fall School Events

3. Food

What works for you?
- BYOLunch (guests bring their own)
- Snacks (savory, sweet, variety)
- Potluck Style
- Donation/sponsorship from restaurants

Don't forget to have someone bring utensils, plates, and napkins

*Consider:
- dietary needs and food sensitivities
- ask the location or look for signs about bringing food to your picnic place and cleanup and disposal

4. Activities

- Music
- Crafting
- Sports
- Kindness Rocks
- Painting
- DJ
- Face Painting

Invite Special Guests:
- Local celebrities
- Local Gov Representation
- First Responders

5. Party Favors

Make sure your guests leave informed about CAM and craniofacial differences

CCA offers complimentary resources:
- Newsletters
- Signage
- Brochures
- Posters
- Syndrome Booklets
- Educator Curriculum

We also offer bulk discounting on products from our webstore!

children's craniofacial association

#CAM2021

YOU'VE GOT THIS!

Let us know about your planned picnic by contacting Annie, areeves@ccakids.com.

We would love to hear about your event and share any pictures you may take from the day!

ccakids.com | IG/FB:@ccakids

View the next page for detailed CAM Picnic Hosting tips and resources.

CAM Picnic Hosting Tips

by Kara Jackman

Believe it or not, as you're soaking up the summer sun, we are preparing for September! Craniofacial Acceptance Month is just a couple months away. Planning a successful CAM picnic should start now. Here are some suggestions for planning and hosting a top-notch event to raise awareness and celebrate our craniofacial families.

Find a Cool Location & Create Your Guest List

Location location location! As important for a party as looking for a new home, we suggest you find a great space. Consider a local park, beach pavilion, or set up in your own backyard. After a year and some change inside, everyone wants to spread out in the sunshine, so be sure there are plenty of spots for all your guests. It is wise to base the amount of space you will need on the number of people you plan to invite.

State or city parks are great because many are free to use, and provide cool amenities like grills, picnic tables, pavilions, and bathrooms. A playground for the kids is always a crowd pleaser. Be sure to check with your local municipality or recreation department to make a reservation (if that is required and/or allowed), get a permit, and/or pay a reasonable deposit or fee. If it is first come, first serve, you may want a volunteer to go early in the day and stake out the location with some signage and decorations to hold your spot. If possible, include a map and detailed instructions on your invitation, and include a day-of contact number, so people can reach you if they are lost or have something come up.

Invite Your Friends and Ours: Publicizing Your Picnic

CCA is happy to share your picnic location and details with friends in your area. Our database is filled with families you may or may not know. Let us help invite people and publicize your picnic. We are here to help! For instance, if you require RSVPs, you can count on 85-90% of your "Yes" RSVPs to show up. If you do not require RSVPs, it will be harder to estimate a headcount, but the rule of thumb is that roughly only 30-50% of your total invite list will most likely be there on that beautiful day in September.

Pick a Day That Works For All

Some say the date may be just as important as the location. Choose a day that avoids federal, local, and religious holidays. September is also back-to-school month, so be mindful of fall school events, too. For instance, CCA has selected **September 11, 2021**, as our region's official picnic day. We chose this day as it works best for us. However, you can choose the date that works best for you and your community. Since our headquarters will be celebrating on a day of national remembrance for many across the country, we will write "thank you" notes for first responders, followed by a moment of silence for everyone who was impacted on September 11, 2001, 20 years ago. If your picnic falls on that date, we encourage you to do the same.

Forage for Food

Food - It can make or break a party! You have a few options here. For years, we had our picnickers bring their own brown bag lunches. It's the easiest way to make sure everyone's needs are accommodated, but you have to notify guests to BYOLunch on your invitation.

If you plan to provide food, first, thank you for your generosity! Make sure you have a wide variety


Texas | 2019


California | 2019


Colorado | 2019

CAM hosting tips, continued


Idaho | 2019


Michigan | 2019

of snacks from the savory to the sweet to keep your guests' mouths watering. Variety also allows your guests to decide what works best for their dietary needs and food sensitivities. (Just make sure you ask the location or look for signs that state what their policies are about bringing food to your picnic place! At the very least, you must assume you're responsible for proper cleanup and disposal of all food and paper products.)

Another option is to have each family bring food in a potluck style. If you go this route, we suggest you create a Facebook event or Google form for your attendees to sign up for things to bring. You don't want a party with 15 dips, and no chips! Don't forget to have someone bring disposable cutlery, plates, and napkins!

Finally, many CCA families have had great luck contacting local eateries and supermarkets to see if they are willing to donate food from their stores. Bottled water is a popular donation item and will keep your guests hydrated on hot days. Many local BBQ restaurants are often amenable to this type of donation.

(CCA can provide our tax exempt letter for charitable donations and sample request letters. Contact us for more information.)

Organize Entertainment & Activities

Entertainment is vital for a poppin' party. From music and crafting to sports and games. Pick what works best for your family and friends. Wiffle ball, an acoustic concert, a talent show, cookie decorating, face painters, a DJ, or painting "Kindness Rocks" are fabulous ways to keep your guests engaged.

In past CAM picnics, friends invited special guests to their events. A local celebrity (sports figure, local TV news personality, high school mascot), or local government representative (mayor, councilman, state senator), first responders (firefighters, police, and EMTs) could really give your CAM picnic the draw it needs to make a bigger impact.

Invite the press using our CAM press release, and don't be shy! We encourage you to tell your story. Posters filled with pictures and definitions created by your family about craniofacial conditions will showcase your journey. For an added bonus, share how CCA was able to help your family embrace the craniofacial journey.

Party Favors

Contact **Annie Reeves** for CCA brochures, signage, posters, and other printed material that we can mail to you, free of charge. Folks will be able to bring them home to peruse throughout the year and share with their own teachers and librarians. Craniofacial Acceptance Month does not end in September. If you leave an enduring impression with your picnic, these resources will increase compassion and reduce the amount of teasing and questions in the years to come.

You can also shop our webstore for low cost party favors like stickers, vinyls, pencils, and bookmarks with our #ChooseKind slogan on them to share with your guests, too. If you contact us directly, we always give CCA families a bulk discount. Purchase higher price items for silent auctions or raffles -- these might include our logo silicone glasses or New Balance pullover.

You've Got This!

Have a great time! Take as many photos as possible or consider asking a photographer to volunteer their time for the day! After the big event, please email Annie (areeves@ccakids.com) with a short description of the day's events, exciting special guests, the yummy food you served, and a few (or all) photos you took, so we can publish them in our next E-Network newsletter, and watch our CCA family advocate acceptance in action.

Cher Crew Celebrates Cher's 75th Birthday to Honor CCA Kids

by Doug Wemple

I first became aware of children who lived with craniofacial differences after watching the 1985 movie **"Mask,"** starring **Cher**. I've been a huge Cher fan since I was 12 years old (1970!), so of course I went to see "Mask." I love Cher not only for her amazing talent and enormous heart but also, I felt I could relate and take inspiration from her because Cher always felt that she didn't fit in and was an outsider. Despite that, she fought hard and worked hard to find success and make a name for herself, so far as to be one of the most recognized and respected women in the world.

As a child in 1970's Montana, I was just coming to terms that I was gay (even though I really didn't know what that meant) and didn't fit in anywhere. Not at home. Not at school. And certainly not in Montana. I was constantly bullied, belittled, and told I was "not normal." Cher literally saved my life because she helped me not give up. She gave me the hope I needed to survive.

So as a diehard fan, I of course flew to Las Vegas in 2002 to attend the **CHER CONVENTION** benefiting CCA! There I met many CCA families including **Jill Patterson, Robbie Gorecki, and Scott Guzzo**! Everyone was so free, happy, and having a blast! There was no judgement from anyone – just love and acceptance!

Cher fans have been doing fundraiser benefiting CCA for many years. In 2015, the **Cher Crew** (Cher's name for us!) ran a funder benefiting CCA in honor of Cher's 69th birthday. There were some issues with leadership and I stepped in to help Jill Patterson guide operations until the funder was over. I then made a promise to Jill that I would gladly take on the role and organize the Cher Birthday funders each year thereafter. And here we are seven years later celebrating Cher's 75th birthday! Can you believe it?! The Cher Crew had an amazing funder this year! We all came together and through the magic of social media spent many, many, hours sharing, retweeting, and doing what we could to promote our CCA funder to the world! I brought many talents together, from fabulous and talented artists to social media experts, all to really give our funder an edge. Our goal was to showcase the wonderful children at CCA, Cher, our love, admiration, and how much they mean to us all! All this talent, determination and love raised **$7,878.75** for CCA while celebrating Cher's big day!

I especially want to thank Jill Patterson for her continued help and support even during times of controversy. You rock!

Thank you to my rock, **Sue Dolby**, for her tireless work creating the stunning promotional memes and being my partner through many decision hurdles. **Tony Davis,** I owe you an enormous debt of gratitude. Thank you, **Rafael Ricione** (Cher Icon) for elevating our funder to the next level and being the sweetest, most understanding person on the planet! **Terry Hughes**, your memes and support mean the world to me. **Scott Clarke**, your artistry and contributions always rule the day. Cute as a button **Anna Moffit**, great edgy memes as always! **Lori Jerome** I can always count on you to be the voice of reason. Also, a huge thank you to the countless Cher fans who helped promote our funder.

Thank you to our generous donors who donated their own Cher treasures to give as prizes to make our funder fun and exciting as well as fulfilling: **Jill Patterson, Rob Gorecki, Sue Dolby, Lori Jerome, Terry Hughes, Jammie Patterson**, myself, and last, but certainly not least, **CHER** who generously donated an autographed pair of her own **Manolo Blahnik** heels! I hope I didn't leave anyone out as it was not my intent!

You all mean the absolute world to me. This funder would not happen without your love, help and support! It takes a village. It takes a CHER CREW!

TBT to 1970! I was just a tyke of 12 and totally in love with 'The Sonny & Cher Show'!!! ❤️📺❤️

donor in the spotlight

Thank you **Pest'R Us**! CCA supporter and Arizona business owner, **Eric Papadeas** hosted a **shred-a-thon** to benefit CCA Kids. He has owned the business for over 25 years. Over the years, he noticed all the papers piling up. He says, " In business, the IRS requires you to hold 7 years of receipts and invoices for tax auditing purposes. Records were everywhere. As I went through the cabinets to look for records that were 7 years or older, I realized other businesses may have a need to dispose of their records, too." The shred-a-thon was born.

The planning began with Eric asking the shredding service he used how to host a shred-a-thon at his office. Eric says, "I had my office send out an email to all my clients with a date and time to come by to shred their old documents." He asked a shredding service company to park their equipment in the Pest'R Us parking lot. They covered the cost of the equipment. "In the email," Eric says, "I said there would be a limit of 2 boxes for free, anything more would be shredded, too, and the cost of the shredding would be donated in full to CCA Kids."

Staff of Pest'R Us and the shredding company assisted Eric's clients with their boxes, while others served up hot dogs, water, and cookies on the day of the event. People were so moved by the mission of CCA Kids that some made donations through our website http://www.ccakids.org. Eric encourages others to run a fundraiser like this, as it was an easy one to bring to life. Together, the event raised **$1,300**! We are so very thankful for your ongoing commitment to CCA Kids!

Thank you, Eric of Pest'R Us Exterminating!
He and his community of clients raised over $1,300 for CCA Kids!

cronin's 5K

On Saturday, May 15th, the **Cronin Family** held a Half Marathon & 5K Run. Friends and family participated to raise money for CCA Kids. CCA Mom, **Angela,** says, "Back in January, I realized I needed a fitness goal to get me through the winter COVID months. So, I invited my friends, family and coworkers and many were eager to join me. We held a small event in Arlington, VT, on River Road. It's a beautiful road that runs along the Battenkill River."

The race started and ended on the Arlington Covered Bridge. There were a handful of half marathon runners, many who ran a 5K, and a few people that rode their bikes. They named the race **'Killin' the Battenkill'** and **NOVUS Clothing Co.** made our really cool race shirts. They also received a generous donation of post-race drinks from **Bailey's Café** in Saratoga, New York. Angela says, "We were blessed with beautiful weather for the occasion!"

Angela collected donations for CCA at the event and we are blown away by everyone's generosity! They raised an amazing **$1,546.00**! Many of her coworkers at **Prodigy Surgical** joined in the race and generously donated to the cause. The Cronin's are so grateful to their friends, family, and coworkers for their continued support of CCA. This loyalty means the world to our family, the CCA family at large!

We want to say a huge thank you and 'way to go' to: Angela, Ben, Emma, Megan and Michael Cronin!

red overview

by Kara Jackman

with advice and input from: Stacey Atkins; Lisa Bock; Liz Cox; Emerald Demor; Laurel Sanborn; Heather Sutton; and Courtney Vysocky

The RED device procedure and recovery may be a daunting process, but our panel of caregivers has helped to demystify and prepare your family for the "big one." In this overview, we will walk you through the steps to take before the surgery, the best post-operative tips, and how to conquer the recovery process at home. We will give you tips and tricks for optimal hygiene, nutrition, and comfort. Are you ready? Yes, you will be!

The Rigid External Device (RED) may be a necessary surgical intervention that your child requires. It is a staged process, involving one surgery to attach the device, wearing it for a defined period while turning the device, followed by a waiting period while wearing the device, and then a removal surgery.

The goal of the RED is to improve air flow through the airway, realign the jaws on a vertical and horizontal plane, and reset the position of teeth for better dentition and mouth closure. The surgery improves your child's ability to breathe, chew, and continue to grow into their bodies.

BEFORE

Our expert parent panel suggests preparing for the surgery early given its invasive nature and lengthy recovery time.

We suggest the first thing to start with is developing daily practice with meditation, prayer, or a soothing ritual. Proactively calming the mind will prevent surgical trauma and assist in healing. Plus, taking care of your mental health is important for the entirety of your life, but is especially important for this milestone surgery.

A good place to start -- for both you and your child -- may be **downloading a meditation app**. Easy and accessible, the Calm App, Headspace, and Balance are all good ones that are great for beginners. Keeping your mind right during the easy and the tough times is so critical for a smooth recovery. If meditation is not your thing, make sure you are taking time each day to check in with your child. One therapist recommends a daily question, "What was the rose of your day and what was the thorn?" This sets up a clear time each day for children to feel safe and talk, and over time they will come to recognize this ritual as a safe place to share feelings.

Other techniques to practice include grounding techniques like counting things in the exam room, singing, or smelling a favorite essential oil (lavender and peppermint are calming) as ways to stay in the moment. Prefer to talk it out? Help your child shift their mindset by encouraging them to consider what benefits this surgery will provide for them.

Image credit: KLS Martin

Focus on the benefits rather than the costs of the surgery, to make a positive difference in the process. It is important to remember that the RED and midface advancement surgery are not all about looks. The removal of the trach, the ability to sleep without a CPAP machine, and the ability for the facial bones to grow are huge motivators to celebrate with your kid, too.

EMPOWERING YOUR CHILD TO MAKE THE BEST DECISION AROUND THE TIMING OF THE PROCEDURE IS KEY, TOO.

Allow them to feel and describe what is best for their bodies. Whenever possible, trust them and their judgement, and allow them to make decisions on the course of treatment. "Either/Or" questions are great options here. For example, "We need to do the surgery either the week of July 1 or July 21. Which do you prefer?" or "We can start the IV when you arrive or we can first use some numbing cream, but you will need to be there 30 minutes earlier. Which way would you like to do it?" These simple choices give your child a sense of control in the moment, and also build their proficiency in being their own care manager.

REVIEW THE PROCEDURE AND THE ACTIVITIES AROUND YOUR RECOVERY WITH YOUR MEDICAL TEAM IN ADVANCE

Viewing before, during, and after X-Ray imaging and photographs of other patients can help your child and family understand how the road ahead will look. A tip that nearly all panel members agreed upon was: do some rehearsals! Practice with the WaterPik, start using mouthwash (make sure you check with your team what brand/flavor they will want you to use), take a nap with a neck pillows, try out recipes for a soft food diet, and simulate suture cleaning on dolls or siblings, to familiarize your child with the recovery process. The transition from post-operation to recovery will go smoother when there is less resistance to the newness and the variety of products involved.

HARNESS THE SUPPORT OF FAMILY AND FRIENDS

Involve your entire family, especially brothers and sisters, in the preparation for the surgery, too. Bring them to appointments when possible to see the device on dolls or skull models. Youtube videos are another useful tool that you can watch with family and friends. In general, the more siblings and friends know, the less fearful they are. The more practiced they are with the products you'll use, the more help they will be in the recovery period, giving them a way to contribute and feel appreciated. Educate them on the benefits of the surgery as well, so they can remind your child that they are undergoing this procedure for a good reason. Hearing this encouragement from a friend or sibling will go even further than words from parents and providers! One of our SuperSibs shared with their sibling that she would look like a celebrity after it was all done. Kids know how to relate to other kids, so enlist their help and make sure to recognize their efforts.

GO TO THE SALON

Go to the salon. Another huge tip that many parents shared with us in preparation for the surgery was to cut their child's hair before heading into the hospital. One parent expert shared that she joined in the fun and shaved her head for the procedure, too. Certainly that is not required, but finding humor and camaraderie in difficult situations can definitely help bolster your child's resilience. Talking about how much and when to cut their hair is another one of those times your child can make a decision all on their own that you can support.

SURGERY DAY AND PICU RECOVERY PERIOD

Contact the Child Life department in your hospital before you go in for the surgery. Child Life can assist in the pre-op area with distracting games, a reassuring presence, and the mindfulness techniques you practiced in the months leading up to the surgery. They can also provide iPads, emotional support animals, musical instruments and more throughout your stay.

Assure your child that they are safe and their pain will be managed by the medical professionals. Share with your child that they may spend some time in the PICU after the surgery. Shine a positive light on the hospital and medical team. Kids take cues from you. If you show confidence, they will too! Let them know you researched this hospital and the team and you chose them for their skills and because they are the best team to do this surgery.

In the days following the surgery, parents should look out for unusual swelling and bruising and complaints of intense pain from your child. Keep a notebook of questions and notes for the doctors when they visit the room. Record the responses with a voice message app on your phone so you can review them later, and share them with others, if needed. You may be tired and stressed, so don't rely on your memory alone.

Additionally, our parents strongly suggest that your child take their first shower post-op at the hospital with the help of nursing staff. They highly encourage practicing wound care and oral cleansing with medical professionals, too, before leaving.

CAREGIVERS, TAKE CARE OF YOURSELF!

Caregiver self-care will result in better care for your child. Bring top-quality instant coffee, or your favorite tea bags, healthy snacks, and phone numbers of experienced CCA friends to call and chat with. Bring fun books to read, or line up movies and shows to watch on your favorite streaming service that will keep your mind light and bright. All of these things will help you weather the storm with ease and grace.

AT HOME RECOVERY

Let's be honest, the panel agreed: the recovery after the RED device is a long one. It takes a village to get through to the other side. Recruit siblings, extended family, and friends to help you and your family out. Your village can help with meals for your family, TV show suggestions, or keep your kiddo engaged by playing quiet games together, or exchanging small gifts.

Caregivers will have to turn the distractors each day for a period of time, and then the RED is worn without turning for an additional four to six weeks. The panel reassured everyone that the turning was manageable. Often one caregiver is designated as the turn-manager, as they are emotionally and physically able to complete the task with as little "drama" as possible. If you are the caregiver, do not act squeamishly or be overly apologetic during turns. Be patient and take a few deep breaths together, but stay strong, knowing this is the right treatment at the right time.

Keep your child comfortable with contouring neck pillow, and ice packs for their eyes and face. Choose shapes that will cradle the face well. CranioRehab has some good ones that comfortably wrap around the head.

A unanimous tip from the panel was to prepare yourself for the secretions that will ooze from the sutures, mouth, and nose. It surprised all of our panel members, so they wanted you to mentally get ready for a lot of bodily fluids. Cleaning the sutures and skin can be painful, but is necessary. Find a positive way to entertain your child perhaps with an iPad or music to help improve their mood while this activity takes place. Triple-antibiotic ointment, cotton swabs, mouth rinses, and lots and lots of button up shirts are your tools through this process. Don't be surprised or shocked at the amount of oral and nasal secretions you see daily. Of course, contact your medical team if color and consistency changes to rule out infections and complications, but know in advance you will deal with secretions. If your child is sensitive or self conscious about these secretions, prepare them in advance as well. Have some strategies in mind for coping with them in public. Maybe you wear bandanas, maybe you keep wipes and a small mirror at their desk, but make sure they understand they are not "gross," and they are normal. Their hygiene is another area where they can be empowered to practice self-care.

Finally, we've put together a list of products to consider having on hand for preparation and recovery.

PRODUCTS THAT OUR CAREGIVER EXPERTS FOUND USEFUL

HYGIENE & COMFORT

- Water Pik
- Oral Swabs
- Biotene Mouthwash
- Cepacol Mouthwash
- Diluted Hydrogen Peroxide Rinse
  - (¼ tsp to 6 oz of water to rinse in mouth and spit)
- Neck Pillow
- Cetaphil Face Wipes
- Ice Packs
- Eye Mask Ice Pack
- Squeeze Bottle for Liquids (and Liquid Diet)
- Long Handled Kids Spoon
- Small Bowls for Purees
- Large Oral Syringes for Cleaning & Eating
- Cloth for Oral and Nasal Secretions
- Bottle Brushes (to clean squeeze bottles)
- Bottle Caddy (Rubbermaid)
- Food Grade Squeeze Bottle
- Pillow Cases
- Q-Tips
- Antibiotic Ointment
- Washable Mattress Pads
- Hair Detangling Spray
  - to reduce tugging and pulling on hair

NUTRITION

- Yogurt/smoothie pouches
- NUUN Electrolyte Tablets
- Gatorade Energy Gels
- Ensure
- Boost water supplement
- Travel blender to use in the hospital
- Squeeze bottles with angled squirt-straws for eating and drinking
- More Bottles for Eating and Drinking

CLOTHING

- Button-Up Shirts
- Tank tops
- Wide V-neck T-shirts
- Zip Up Hoodies
- Button up Pajama Set

CONCLUSION

We hope this overview provides you with suggestions to help you and your family weather the RED device and midface advancement surgery. Please reach out to us at contactcca@ccakids.com if you have questions, or would like to be paired with a caregiver mentor who has experienced this surgery first-hand.

CHECK OUT THE PANEL DISCUSSION VIDEO ON OUR YOUTUBE PAGE:

financial assistance testimonial

by Stacy Noble

This is our son Henry! Henry and his best friend **Podkin** (his dog) were born with a rare birth defect called Microtia with aural atresia and hemifacial microsomia. In simple words, Henry was born with a severely underdeveloped outer ear without an ear canal and the right side of his face is smaller than the left. Henry has severe hearing loss in his right ear. Microtia Atresia is a very rare congenital birth defect (I loathe using that word, but it is textbook!) that affects 1 in every 20,000 births.

I was so excited when I stumbled on **Children's Craniofacial Association**! This organization embodies everything that my family and I stand for! They are an incredible support group that normalizes facial differences! Annie has been amazing in helping make Henry's dream of having TWO BIG EARS a reality.

Microtia has affected our family in positive and negative ways. The best things that our family, specifically our children, have learned through Henry are humility, standing up for those who can't find their voice, and being kind to everyone! Our family motto is **"always be kind and never give up!"** What I want most for our children is to be the kind kid in class. Henry's siblings have seen the negative side and how hurtful others can be when one is born different. It's heartbreaking. They can't understand why kids stare at Henry or say mean things just because he was born different. They have also been teased because their brother is different. Any time they join a new team or a new club, they have to start all over by answering everyone's questions and confronting all of the stares; they do it with such grace and kindness. Henry and I had several talks about how God made him special by giving him a little ear, so that's what he and his siblings tell everyone! I am so proud of them! It is harder for Henry to handle the comments and stares. It has made him very shy and less confident around others outside of his circle. He used to come home and say that a couple of kids were making fun of him because of his little ear, and he would say, “but Mommy, it's okay, I just tell them what you tell me...I just do my best and that's okay because God made me special!” Typing this and thinking about it still makes me cry! How cool is this kid and why does he have to be this strong at five years old? When my children see other kids and people who were born different, they go out of their way to make sure they speak to them, smile, and say 'Hi!' Microtia has been a reminder that we are all made differently, and we all have something great to share!

Microtia has greatly affected Henry's confidence outside of his own circle. In crowds of any size, Henry retreats and hides behind me. Even playing his favorite games of soccer and baseball, he would rather sit out and not compete if it means that he will have to answer questions or see kids stare at him. He is the sweetest little boy ever and would do anything for you if he trusts you to treat him as if you don't even notice that he is different.

financial assistance, continued

For the last two years off and on, Henry has asked for a “big ear” and each time I thought, well, this will pass, he’s too young to understand this choice. I have always said that if Henry wants a “big ear,” then I will move mountains to get him one, but he needed to be old enough to understand his decision. I was thinking that he would be at least ten or eleven before we needed to make this decision and explore this route. However, over the summer, it became incredibly clear that six was old enough! He continued to ask for a “big ear” and I continued to say, “What? Big ears are lame,” and “I want a little ear like yours!” He would always roll his eyes and that would be the end of our conversation. Well during our quarantine, we cooked all of our meals at home, never ate out, and Henry always helped me cook. I noticed that he had been eating a ton of food, way more than normal. At first, I thought, wow, he’s going through a growth spurt! Then one night, he ate two hotdogs, two helpings of macaroni, and three helpings of beans. I thought, my goodness! He scooted back from the table and said, “Oh my belly hurts, I'm so full!” I said, “Yeah, well, why did you keep eating?” His response broke my heart. He said, “Well, I gotta eat a lot because I gotta get bigger and bigger! If I eat enough food, then I can grow bigger, and when I grow bigger, MY EAR WILL POP OUT LIKE A FLOWER!” Oh my goodness, I just about lost it! I then had to explain that that is not how it works, and he didn’t understand. Then, with tears in his eyes he said, “Mommy, why did God make me special with a little ear? I just want to be born like **Kalem, Ellie, and Sully** and you, with TWO BIG EARS!” And with that, I knew he was old enough to understand what it meant to get a “big ear!” The very next day, I went on a search to find out how I could make his wish come true! There are several doctors that can create an ear like shape, but most of them do not specialize in making ears and the other method is to cut three of his ribs in order to create an ear. This is my baby boy, and I didn’t want a makeshift ear, or a trial ear. I wanted a professional ear, an ear that would bring out his confidence and one that he would not regret and one that he would be proud to show the world! I finally found the doctor that was perfect for Henry! Her name is **Dr. Sheryl Lewin**, and she is currently the only one in the world to create a 3D scanned **Porous Polyethylene Implant Ear Reconstruction** or P.I.E.R. Her work is truly amazing and life changing for her patients! Children and adults literally come from all over the world for her innovation, advanced skills, experience, and track record! This will be an eight hour surgery and will require us to stay in California for a minimum of two and a half weeks to ensure a successful recovery! Since the ear is the most challenging and intricate body part to recreate, there are very few doctors even qualified to perform an ear reconstruction let alone create a high quality realistic ear. Dr. Lewin is the only doctor in the world that is qualified to reconstruct a perfectly symmetric ear to match your own! Henry is 1 of only 54,000 people in the United States born with Microtia and Atresia. Due to her medical title as a Plastic Surgeon, she is out-of-network for every insurance. She and her team work very hard to fight insurance for patients with microtia because it is not a plastic surgery; it is a surgery for medical necessity! During Henry’s ear reconstruction, Dr. Lewin will also implant a bone anchored hearing aid so that he will be able to hear just like you and me!

Children's Craniofacial Association is helping to make Henry's wish come true. Henry was so excited that he signed his own application for CCA! Their support means the world to Henry and to us! Without people like Annie, Henry would not be able to get his wish of TWO BIG EARS! I remember the exact moment that I read Annie’s email! I was shouting with so much excitement that my neighbors could hear me! I could not believe it! We are so incredibly grateful and crazy thankful for her and the people at CCA!

With so much love,
Henry, Stacy, Josh, Kalem,
Ellie and Sully

thank you to our 2021 facebook fundraisers:

names are listed in alphabetical order by the fundraiser campaign owner

1. Alisa Faber
2. Amanda Sandoval
3. Angela Yurkanin Allen
4. Angie Batton
5. Ashley Bock
6. Casey Deakins
7. Charles Kinder
8. Chelsea Buyalos
9. Cheyanne Sharpe
10. Chris Sisney
11. Cory Lloyd
12. Dianna Hill Hodges
13. Donna Marie Roberts
14. Dorina Watkins
15. Francis Menard
16. Graham Ormerod
17. Greg Daniels
18. Haley Holubec
19. Haley Turner
20. Ian Parkinson
21. Isabel Moreno
22. Jaci Marie Samhammer
23. Janelle Crystal
24. Jeanie Ross
25. Jennifer Boyer Hedlund
26. Jennifer Dockter
27. Jennifer Mau
28. Jeremy Stowe
29. Jill Laufbaum
30. JJ Henson
31. Joel Brusk
32. Josefina Glykofrydis
33. Judith Kemler
34. Kara Jackman
35. Karen Arnold Silfies
36. Kary GB
37. Katie Hartke
38. Kelli Kelly
39. Kellie Lloyd
40. Kristi Cuddy
41. Krystle Rizzo
42. Kyle Hoelting
43. LeeAnne Thompson
44. Lisa Bowers-Alters
45. Lisa Singh
46. Lisa Stanford
47. Maddie Cameron
48. Markus Piaskowski
49. Mary Ann Heston
50. Megan Mejia
51. Melissa McQueen Benfer
52. Melissa Reneigh
53. Mena Stephany
54. Nathaniel Newman
55. Nicole Cheri Clifford
56. Paige Michelle Edwards
57. Patricia Simon
58. Payton Parish
59. Rachael Blitvich
60. Robb
61. Rose M. Seitz
62. Russel Newman
63. Sarah N Mike
64. Sasha Strasdat
65. Shannon Duzan-Fowler
66. Shastina Hightshoe Kemper
67. Stacey McAllister
68. Steven Tyler
69. Sydney Rathbun
70. Tamara Nord
71. Tami Litfin
72. Tammi Trude-Gonzalez
73. Tanya Tiger
74. Tenny James Philip
75. Terri Mlotek
76. Thomas M Lee
77. Tisha Shellenberger
78. Torey Harrah
79. Victoria Green

thank you

create your own facebook funder

Facebook is a great way to raise funds for CCA Kids. Facebook takes 0% in fees and you can set up your fundraiser with a few quick clicks.

- visit: www.facebook.com/fund/ccakids/
- click - **Raise Money**
- click - **"Non Profit"** and then **search** for "Children's Craniofacial Association"
- click: **Children's Craniofacial Association**
- select - **a goal amount** and **end date**
- click - **Next**
- enter - **a title** for your fundraiser - Birthday Fundraiser or CCA Fundraiser, etc
- enter - **tell your audience why you are raising for CCA** (We already have some words in there but it is all totally customizable)
- click - **Next**
- select - **a cover photo** - we have a bank of photos to choose from or you can upload your own
- click - **Create**

IT'S THAT EASY!

upcoming events

SEPTEMBER

Craniofacial Acceptance Month

North Texas Giving Day | Sept. 23rd

SEPTEMBER 8th-9th
CALIFORNIA

MORGAN MECK 10TH ANNUAL GOLF CLASSIC INVITATIONAL

CONTACT:
Christine Andler, candler@ccakids.com

SEPTEMBER 11th
TEXAS
Mary Heads Carter Park Pavillion (2320 Heads Ln., Carrolton, TX 75006)
11:00am - 1:00pm

DFW CAM PICNIC

CONTACT:
Annie Reeves, areeves@ccakids.com | RSVP by Sept. 4th

SEPTEMBER 11th
MICHIGAN
Bicentennial Park, Ben Celani Pavilion (35400 W 7 Mile Rd., Livonia, MI 48152)
1:00pm - 4:00pm

CAM PICNIC
Lunch will be provided, bring your own drinks

CONTACT:
Kellie Dowd, kdowd22@gmail.com | RSVP by Sept. 4th

SEPTEMBER 12th
NORTH CAROLINA
James L. Dorton Park (5790 Poplar Tent Rd., Concord, NC 28027)
11:00am - 2:00pm

CAM PICNIC
Bring your own lunch and drinks

CONTACT:
Jesanne, wjrodenreynolds@gmail.com | RSVP by Sept. 3rd

SEPTEMBER 19th
OHIO
Santa's Hide-A-Way Hollow (15400 Bundsyburg Rd., Middlefield, OH 44062)
10:30am - 3:30pm

CAM PICNIC
Lunch served in the pavilion

CONTACT:
Elf Valerie, valhurstoh@gmail.com | RSVP by Sept. 3rd

OCTOBER 4th
Timarron Country Club Golf Course | Southlake, TX

6TH ANNUAL PAR PREMIER GOLF TOURNAMENT BENEFITING CHILDREN'S CRANIOFACIAL ASSOCIATION

CONTACT:
Christine Andler, candler@ccakids.com