THIS ISSUE OF THE *CCA NETWORK* IS DEDICATED IN MEMORY OF **SHANNON AYERS** AND **LILY ANN HALEY**

ccanetwork

newsletter of the children's craniofacial association   Cher—national spokesperson   2016: Issue 1

inside

reiss family

By Samantha Reiss

Jake Sidney Reiss and **Luke Rae Reiss** were born on May 27th, 2007. Within minutes of their birth in the delivery room, we realized something was different about Jake; something that we would soon find out would change his path and our lives forever.

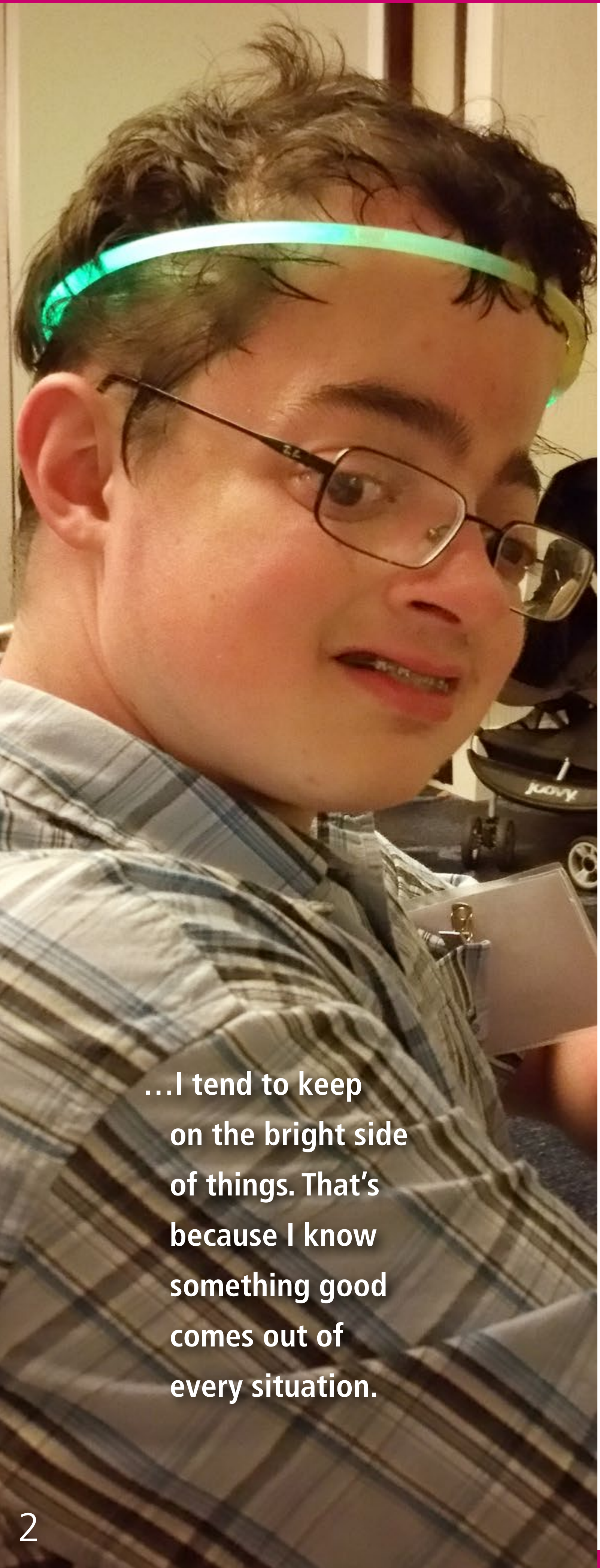
The overall process of having our children was always a little bit different. After trying for over a year and many different fertility treatments we chose to have IVF, in-vitro fertilization. Shortly thereafter, we were ecstatic that the treatment worked, and we found out we were getting a bonus baby to boot when they informed us we were having twin boys. The pregnancy was uneventful and we went through the standard routine of tests, genetic testing and, due to twins, more than our share of appointments and ultrasounds. All tests and results always came up normal and there were never signs of any medical issues. After 7 or 8 false alarms, we finally were ready to deliver the boys at 35.5 weeks, a decent gestation period for twins.

see **reiss family**, page 16

message from the executive director emeritus

And so we begin a new year. After 26 years I am retiring, and **Erica Mossholder** has assumed the role of executive director of Children's Craniofacial Association. Erica has served on the board of directors for six years and volunteered in media outreach. She then joined the CCA staff in 2015 as director of communications and outreach. Her knowledge of what it is like to live with a craniofacial condition will help enrich the lives of yet another generation of CCA. We are grateful to have found someone

see **char**, page 7



> …I tend to keep on the bright side of things. That's because I know something good comes out of every situation.

meet nick and sasha nugent

ccateen

Nick, in his own words

Hi. My name is **Nicholas Nugent**, but people call me Nick. We just moved to North Carolina from New York, and I am glad we won't see a lot of snow here. I have a little brother, **Sasha**, and we are est friends.

I like to listen to popular music and play video games—my brother and I can play PS3 all day. I like to read a lot, too, especially graphic novels and about history and mythology. I also like to read the Bible. And I have a good sense of humor — just ask my friends and family.

I like school and pretty much enjoy all of my classes. I will be a senior next year and hope to go to college and study computers.

Last year we went to Newport Beach, California for the CCA Retreat and we will be going to Ft. Lauderdale, Florida. I had a lot of fun and met some great people, some of whom I keep up with through Facebook.

I have Crouzon syndrome and scoliosis. It was my grandmother who bought the book *Wonder* for me, and I enjoyed every word of it. I've had so many surgeries during my life, but I tend to keep on the bright side of things. That's because I know something good comes out of every situation.

ccasupersib

Meet Sasha

Sasha Nugent is in the eighth grade and enjoys school, especially math. The 14-year-old from North Carolina is also an avid reader. He's read the *Lord of the Rings* trilogy, an incredible accomplishment. He's also into the *Percy Jackson* series of books, and *The Hunger Games* series is on his reading list (unless he's already finished them all by the time this newsletter is printed).

When he's not reading or exceling at school, he's most likely playing any number of PS3 games. He and his older brother, **Nick**, play them together all the time and both really love competing against one another.

Sasha and Nick went to Tennessee for spring break to relax and hang out with family. And both boys will head to this summer's CCA Retreat in Fort Lauderdale. It will be his second one. He, his brother and their mom went to last year's retreat in California. "It was warm, nice and fun," he said. His favorite part was the ice cream social. He made some friends last year and is looking forward to having a good time again this June in Florida.

Sasha was born with cleft lip and palate. He's had his share of treatments, surgeries and procedures over the years, but he has taken it all in stride. He said the thing is to not be scared, and to know that everything will be okay.

> …the thing is to
> not be scared,
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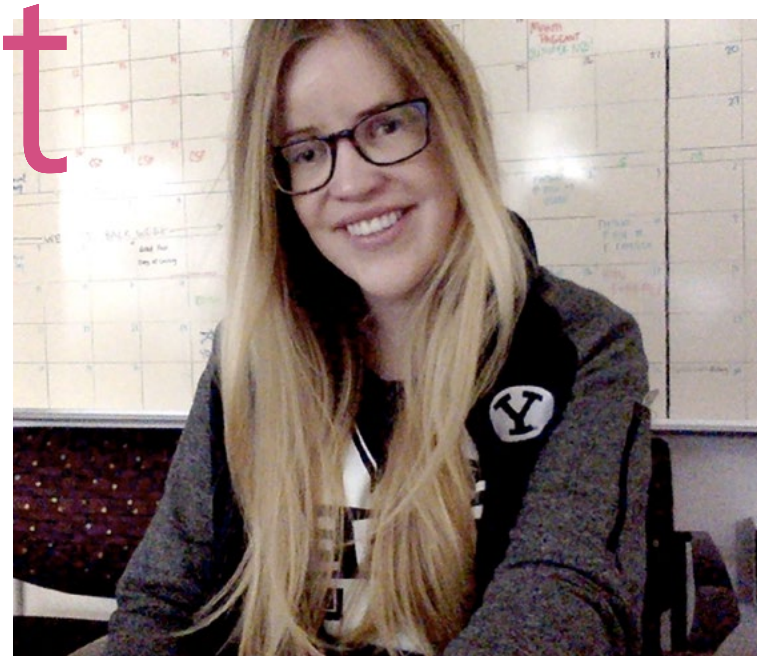
ccaadult



meet nichole hilton

I'm a latecomer to the CCA scene. Though I was born with Pfeiffer syndrome and share many of the life experiences others in this wonderful community have had, it wasn't until recently that I started connecting with craniofacial patients and families.

I attended my first CCA retreat last summer, and loved it. How inspiring it was to get to know some of you and to learn from your experiences, strength and optimism. I left Newport Beach feeling empowered and encouraged to share my own journey with others.

I was born in Tarzana, California. I have three older brothers and two parents whose examples of resilience and determination got me through my most discouraging medical episodes. There have been phases in my life when I've lost my perspective, when I've felt more bitter than blessed. But I've learned that what makes me "me" is not what I've been through (dozens of surgeries, bullying and ostracism, etc.) — it's how I act.

I've felt my worst when I've told myself I am my condition, and I must act (or not act) a certain way because I have Pfeiffer syndrome. I wish I had realized sooner in life that to be born into the channels of adversity is, sometimes, the greatest advantage.

I've tried to find a balance between being aware of and grateful for my condition and living a multifaceted life unaffected by medical limitations. I'm an avid plant-based recipe experimenter, a college student and a volunteer in my community. I lived in Norway for 18 months as a missionary for my church, and I plan to work in the nonprofit sector after I graduate. I love life, and I'm grateful for the hardships that have propelled me forward.

join the CCA Birthday Club

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

good news

by Cheryl Whitten

My son, **Matthew Whitten**, loves band music. As an infant, he loved listening to music, and I found that it was an effective way to calm him.

At an early age, he started playing simple tunes on the piano, and demonstrated good pitch and rhythm.

When he was seven, the drummer at church let him play the drums after the service and commented that he was actually playing them, not just banging on them.

For years, Matthew has begged to be in band. I tried to get the school to allow him to take band, but they refused because of his developmental delays. This year Matthew started high school and again begged to be in band. We were told that it was too late. Matthew was very disappointed.

Matthew has an iPad. It is his security object. He loves to watch YouTube videos on it. He specifically loves to watch videos of the **Arkansas Razorback Marching Band**. He became enthralled with them after seeing them play at a basketball game.

Matthew often watches their videos for two or more hours per day. They keep him calm during medical appointments. They became his refuge after his band disappointment.

In early October, I wrote a letter to the band and their director. I expressed my appreciation for the impact that they have had on Matthew. I let them know that they were more than just entertainment. In my letter, I let them know about Matthew's lifelong desire to be in his school band. I enclosed a photo of us at a Razorback football game.

That weekend at the football game, I noticed that all the band members were smiling and waving at me. A few minutes later, the band director came over and invited our family to be their guests at the Homecoming game on Halloween. He invited Matthew to be on the field with the band during half time. Matthew was excited!

The week before the game, Matthew joined the band for a practice. We weren't sure what his role would be. While we were waiting, they let him play on the drums. Matthew played the big bass drum and the snare drum and cymbals. He quickly learned the music and waited patiently, listening for his parts.

At the homecoming game, Matthew confidently took his place at the edge of the field. He played the bass drum then raced over to play the snare drum for "Ghost Busters." He danced with the band members to "Thriller," then finished the halftime performance by playing the bass drum again.

After the halftime show was finished, he returned carrying a gift of two sets of drum sticks.

He was thrilled to receive a digital drum set for Christmas, and plays them every day using his "Official Razorback Drumsticks."

testimonial

In April 2015, our lives were thrown a curve ball. Our son **Jordan** was three months shy of his fifth birthday and was showing signs of bilateral papilledema. We were referred to a pediatric ophthalmologist in Upland, CA, 75 miles away.

After a six-hour appointment, our son's ophthalmologist turned to us and said that he thought our son had Crouzon syndrome, a genetic syndrome that causes Craniosynostosis.

We asked what he would do if this was his child, and he said he would go straight to the emergency room at Children's Hospital Orange County (CHOC). So, we did just that. Little did we know that this ophthalmology appointment was going to end up being a five-day hospital stay 95 miles away from home.

Once we arrived at the emergency room, we were told that Jordan would need a CT scan the following day to confirm that Craniosynostosis was indeed the cause of his papilledema. The scan not only confirmed Craniosynostosis but also showed increased intracranial pressure requiring a VP shunt placement.

That day a geneticist took one look at Jordan and said she was 90 percent sure Jordan had Crouzon syndrome. She took a DNA cheek swab, and the results were confirmed in less than a week.

Talk about a shock! Our family lives in an area that is known for its resort lifestyle and large retirement community. That said, the medical specialists in our area are focused primarily on octogenarians. There are absolutely no specialists for pediatrics, whatsoever.

We had no idea how we were going to get the proper medical treatment for our son. We needed to take him to myriad physicians—neurosurgeon, ophthalmologist, ENT, orthodontist, and speech and hearing specialists — all who were close to 100 miles away from us.

I homeschool our son and am a stay-at-home mom. My husband is currently on workers' comp for a back injury, so we are on a tight budget. When Jordan was diagnosed with Crouzon syndrome, one of the websites our geneticist referred us to for information was CCA's. I was grateful to finally have some literature on Jordan's condition and was able to reach out to families in our similar situation for support. However, I had no clue that they also offered financial support.

We were already blessed with having connected with the Orange County Ronald McDonald House. With a small donation for the night, we are able to stay there while we attend appointments. Unfortunately, we have received a few phones calls from the Ronald McDonald House stating that they were at capacity and that the hotels that they use are currently booked. The Orange County Ronald McDonald House has to share these hotels with sporting events and concerts that come into the Anaheim area.

This is where CCA stepped in. I spoke with **Annie Reeves**, and she explained to me that I had to submit our financials and state why we needed the assistance. I submitted the required paperwork and had a response within a week. I was in shock! We had qualified for fuel expenses to travel to his appointments, as well as a food allowance per diem. My stress level diminished.

The craniofacial road is difficult enough without a financial hardship, so I'm grateful for wonderful, unselfish organizations such as CCA. Thank you again for your continued support.

The Watkins Family

char, from page 1

so passionate about our mission, committed to our principles and values, and who has the education, resourcefulness and enthusiasm to lead CCA onward.

For me, the past 26-and-a-half years have been an incredible journey. I have met and become friends with the most amazing people. It was in September 1990 when a group of 10 families converged in Washington, DC, to testify before the House Budget Committee. I remember standing at the registration desk of the hotel when little, 4-year-old **Robbie Gorecki** came bounding up to us. At that moment, I knew I was where I needed to be. During that weekend I met families that CCA would continue to serve for the next 26 years, many with whom (including Robbie) I remain friends with today.

During these years, the organization would flourish and falter. But through it all we were fortunate that individuals who recognized CCA's value made their way to the organization and dedicated themselves to ensuring CCA would survive and continue to serve thousands of families affected by facial differences. These individuals came in the form of board members, volunteers, donors and staff, all of whom played an integral role. Because of these dedicated folks, CCA remains the premier craniofacial family support organization. There are too many of those folks to list here, but you know who you are and we thank you with all our hearts for your determination and dedication.

The "We Are Family" culture of CCA is what sets us apart from other nonprofits and support organizations. The belief that we're all united as one big extended family is the key to our robust, ever-growing community. The number of families who raise funds for the organization, the number of others who volunteer in areas such as outreach and awareness, and the number of families who support one another on a daily basis under the CCA umbrella validates our family culture. CCA has hundreds of families directly involved in one capacity or another and thousands benefit each year from our programs and services. In my opinion, finding a leader who believes in the importance of that family culture and who is willing and able to perpetuate it is key to CCA's ability to continue our mission and work. The fact that Erica has demonstrated her total commitment to the organization by having served on the board of directors and taking on a very active volunteer role in that capacity and then very successfully performing as communications and outreach director, proves her dedication to CCA and the families we serve, and it proves that she will do her best to uphold our "We Are Family" culture.

It has been an honor to serve as executive director of such a wonderful organization that has and will continue to enrich the lives of such a deserving community. CCA and the families we serve will always remain in my heart. And so, with total confidence in our new leadership and the happiness I feel knowing that I will continue to be involved, I pass the torch to Erica.

Char Smith, Executive Director Emeritus

"tastefully simple" by alexa's appeal for craniofacial awareness

Busy mom **Denise Rast** and her family have been involved with CCA since her daughter, **Alexa**, was very small. Today, she runs a great direct sales business with the popular "Tastefully Simple" brand.

Last June, she pledged that CCA would get 15 percent of purchases through the end of the year. We're happy to report Denise has decided to extend her offer indefinitely and will continue to donate 15 percent with any purchase! Just indicate "CCA" when you order at tastefullysimple.com/web/drast1.

Thanks so much Denise!

Cyberbullying: An Overview for Parents, Teachers and Students + Resource Guide

By **Earl Gage, MD –** Kids Plastic Surgery, Mercy Children's Hospital – St Louis, MO

What is cyberbullying?

Cyberbullying is a form of harassment and bullying that includes sending hurtful or threatening e-mails, text messages, or instant messages, spreading rumors or posting embarrassing photos of others. Cyberbullying can be an extension of bullying in physical spaces or only take place through technology.

How has the growth of social media, such as Facebook and Instagram and other apps affected bullying?

Technology has definitely impacted bullying. What used to be a face-to-face encounter that occurred in specific locations is now able to occur 24 hours a day, seven days a week. Technology—computers, cell phones, tablets, and social networking sites—create conditions that allow bullying to occur. One way to protect our children is to limit and/or monitor their use of this technology, or "screen time."

I ask parents, "Would you let your 12-year-old daughter walk alone down a dark alley?" Obviously, the answer is "No." Thus, the follow-up question is, "Then why would you let your 12-year-old daughter be on the world wide web or be texting unmonitored?" Parents and kids don't fully realize the negative side to technology and social networking sites.

What can teachers and educators do to address bullying?

Parents and teachers must work together and intervene when they see bullying take place. First, they must tell the student(s) who are doing the bullying to stop. They need to document what they saw and keep records of the bullying behaviors. Victims need to feel that they have a support network of kids and adults. Help the student who is being bullied feel connected to school and home. Students who are also being bullied might benefit from individual or group therapy in order to create a place where they can express their feelings openly and safely.

Be knowledgeable and observant

Teachers, educators, and administrators need to be aware that although bullying generally happens in areas such as the bathroom, playground, crowded hallways, and school buses it can also occur via cell phones and computers, where supervision is limited or absent. It must be taken seriously. Teachers and administrators should emphasize that telling is not tattling. If a teacher observes bullying in a classroom, he/she needs to immediately intervene to stop it, record the incident and inform the appropriate school administrators so the incident can be investigated. Having a joint meeting with the bullied student and the student who is bullying is not recommended — it is embarrassing and very intimidating for the student that is being bullied and may not address the needs of both parties adequately.

Involve students and parents

Students and parents need to be a part of the solution and involved in safety teams and anti-bullying task forces. Students can inform adults about what is really going on and also teach adults about new technologies that kids are using to bully. Parents, teachers, and school administrators can help students engage in positive behavior and teach them skills so that they know how to intervene when bullying occurs and be "Upstanders" instead of bystanders. Older students can serve as mentors for younger students and encourage a culture of kindness in their learning environments. Parents can help by modeling consistent and positive discipline at home and at school functions.

Set positive expectations about behavior for students and adults

Schools and classrooms must offer students a safe learning environment. Teachers and coaches need to explicitly remind students that bullying is not accepted in school and such behaviors will have consequences. Creating an anti-bullying document and having both the student and the parents/guardians sign and return it to the school office helps students understand the seriousness of bullying. Also, for students who have a hard time adjusting or finding friends, teachers and administrators can facilitate student interactions and meetings or provide "jobs" for the student to do during lunch and recess so that children do not feel isolated or in danger of becoming targets for bullying.

What can parents do if their child is being bullied?

Observe your child for signs of bullying

Children may not always be vocal about being bullied. Signs include: withdrawn attitudes, hesitation about going to school, frequent stomach and head aches, decreased appetite, nightmares, crying, ripped clothing, or general depression and anxiety. If you discover your child is being bullied, don't tell them to "let it go" or "suck it up." Instead, have open-ended conversations where you can learn what is really going on at school so that you can take the appropriate steps to rectify the situation. Most importantly, let your child know you will help him or her resolve the situation and that he or she should try not to fight back.

Teach your child how to handle being bullied

Until something can be done on an administrative level, work with your child to handle bullying without being crushed or defeated. Practice scenarios at home where your child learns how to ignore a bully and develop assertive strategies for coping with bullying. Help your child identify teachers and friends that can help them if they're worried about being bullied.

Ensure that as a parent you model calm, confident, compassionate behavior. Do not demonize the bully, rather take the stance that the behavior is not tolerated. Understand and relay to your child that bullies are often victims of abuse or trauma themselves and that while their behavior will not be tolerated, it is helpful to understand the motivation is not your child's fault.

Set boundaries with technology

Educate your children and yourself about cyberbullying and teach your children not to respond or forward threatening emails. "Friend" your child on Facebook, Twitter, Instagram, etc. and set up proper filters on your child's computer. Make the family computer the only computer for children, and have it in a public place in the home where it is visible and can be monitored. If you decide to give your child a cell phone think carefully before allowing them to have a camera option. Let them know you will be monitoring their text messages. As a parent, you can insist that phones are stored in a public area, such as the kitchen, by a certain time at night to eliminate nighttime bullying and inappropriate messaging. Parents should report cyberbullying to the school, even when it occurs after hours or on weekends, and follow up with a letter that is copied to the school superintendent if their initial inquiry receives no response.

Parents should report all threatening messages to the police and should document any text messages, emails, or posts on websites. Detailed record keeping is crucial.

What can parents do if their child is bullying others?

Make your home "bully free"

Children learn behavior through their parents. Being exposed to aggressive behavior, inconsistent discipline, family instability, or an overly strict environment at home makes kids more prone to bully at school. Parents and caregivers should model positive examples of healthy relationships with other people and with their children. It is important to proactively model and teach empathy and kindness.

Stop bullying before it starts

Educate your children about bullying. It is possible that your child is having trouble reading social signs and does not know what they are doing is hurtful. Remind your child that bullying others can have legal consequences.

Look for self esteem issues

Children with low self-esteem often bully to feel better about themselves. Even children who seem popular and well-liked can have mean tendencies. Mean and aggressive behavior should be explored and addressed by parents. Often new routines, individual, group, or family counseling, and creative outlets will boost a child's self-esteem and self-worth.

What can students do to stop bullying?

Report bullying and cyberbullying

It is important for students to report any bullying to a parent or an adult they trust. Often kids don't report cyberbullying because they fear their parents will take away their phone or computer. Parents should proactively communicate that they will support their child's reports of bullying and not take away their technology as a consequence. It is important for kids to remember that bullying is wrong and should be handled by an adult.

Don't bully back

It may be difficult to not bully back, but as the saying goes, two wrongs don't make a right. Try not to show anger or tears. Either calmly tell the bully to stop bullying or walk away. Train using further resources, like the ones listed below, to become more than a bystander… Instead, be an "Upstander" who models and promotes kind behavior.

Use the Buddy System

Whenever possible, avoid situations where there are no other students or teachers. Try to go to the bathroom with a friend or eat lunch in a group. When riding the bus, sit near the front. If you know a student who likes to bully others is in an area where you normally walk to lunch or class, try to use alternative hallway routes. Remember, report bullying of yourself or other students to your teacher, coach, principal and/or parent and align with students who are kind and compassionate.

see **cyberbullying**, page 10

cyberbullying, from page 9

Compiled by Earl Gage, MD and Children's Craniofacial Association

http://stlfacialcosmeticsurgery.com/about-us/meet-dr-gage/

Source: This information, including advice from bullying expert Susan Swearer, PhD, was published on-line by the American Psychological Association. More information may be found at http://www.apa.org/topics/bullying/online.aspx

Cyberbullying: Resource Guide

Free Online Resources

1. 10 Steps to Stop and Prevent Bullying from the National Education Association http://www.nea.org/home/51629.htm
2. Bullying Prevention and Intervention from the American Humane Association http://www.americanhumane.org/children/stop-child-abuse/fact-sheets/bullying-prevention-and-intervention.html
3. Cyberbullying Prevention and Intervention from the American Humane Association http://www.americanhumane.org/children/stop-child-abuse/fact-sheets/cyber-bullying-prevention-and-intervention.html
4. Developing a Positive School Climate: Top 10 Tips to Prevent Bullying and Cyberbullying http://cyberbullying.us/School-Climate-Top-Ten-Tips-To-Prevent-Cyberbullying.pdf
5. Responding to Cyberbullying: Top 10 Tips for Eductors http://www.cyberbullying.us/Top-Ten-Tips-Educators-Cyberbullying-Response.pdf
6. Help, My Child is a Bully! 5 Strategies to Handle a Child who Bullies Others http://www.urbandojo.com/2010/07/13/my-child-is-a-bully/
7. Why Do Bullies Bully? The Top 5 Reasons People Bully Others http://www.urbandojo.com/2010/06/16/bullying-reasons-why-do-people-bully-others-why-do-bullies-bully/¨

Three Top-Rated Programs Schools Can Implement

1. Second Step from the Committee for Children http://www.cfchildren.org/bullying-prevention
2. Positive Action https://www.positiveaction.net/applications/bullying-prevention
3. Olweus Bullying Prevention Program http://www.clemson.edu/olweus/

love more judge less shirts

Long Sleeve Flowy Tee (runs large)
$25

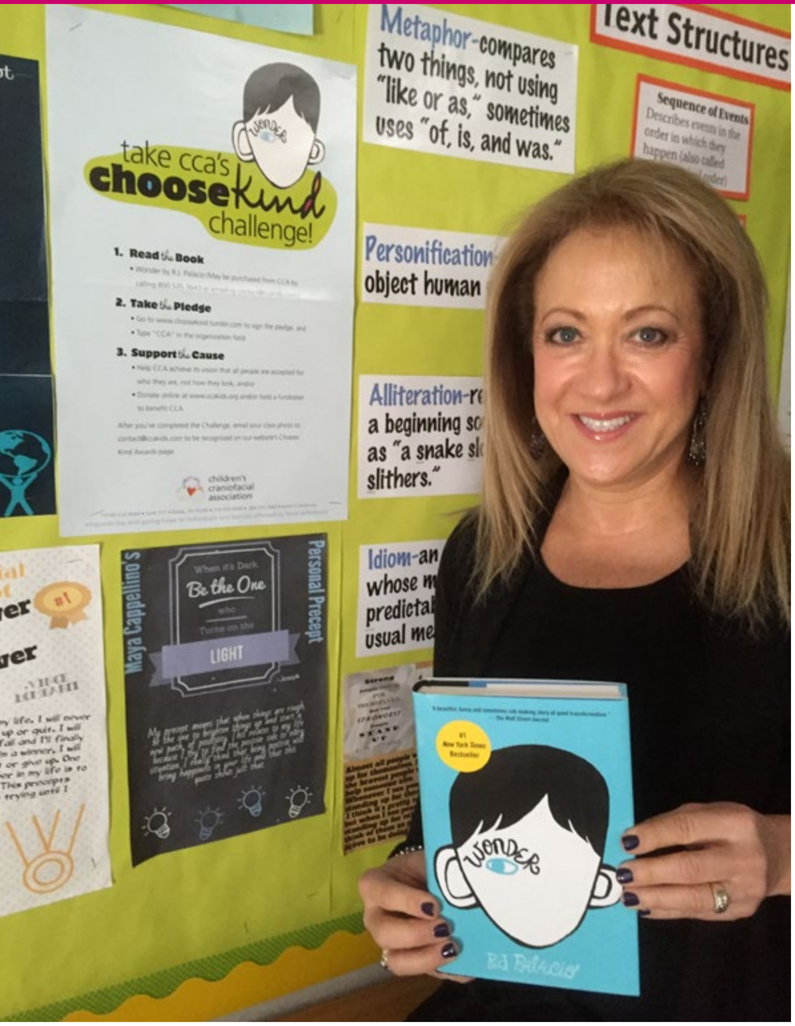
Slouchy Fleece Sweatshirt
$35

Unisex Baseball Tee
$25

Unisex Adult Jersey Tee
$25

Long Sleeve Youth Tee
$18

Thermal Onesie
$15



Chris Jones

3 cheers

for volunteers!

CCA is fortunate to have volunteers serving in many capacities—awareness, fundraising, networking and more. We treasure each of them. They help push us closer to achieving our mission and vision. One such volunteer is **Chris Jones**.

Chris comes to CCA as a friend of our board chairman, **Bill Mecklenburg**. She lives in Coto de Caza, California, with her husband and 19-year-old son. Chris has been with the **Capistrano Unified School District** since 1988, where she teaches 6th grade English and social studies at **Ladera Ranch Middle School**. She is also on the district team to develop Curriculum Alignment Guides for the English Department. Since they have adopted *Wonder* as one of their 6th grade books, Chris has been working on that particular guide along with the others.

Chris has taken it upon herself to see that the book *Wonder* is read in as many schools in her area as possible. She manned a table at the Ladera Ranch Middle School fall registration and has been instrumental in getting the books into other schools as well. We consider Chris our "West Coast *Wonder* Distributor!" We know this takes a lot of time and effort on her part, and for that we say thank you and Three Cheers for super volunteer Chris Jones!

NOW SELLING YEAR 'ROUND

"I read Wonder!" T-Shirt

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

FREE SHIPPING ON T-SHIRTS!

Special Quantities / Sizes / Prices available upon request

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Dallas Holiday Party

CCA, together with **Drs. Jeffrey Fearon, David Genecov** and **Carlos Barcelo**, hosted the 26th annual holiday party at Southfork Ranch, in Parker, TX. The much-anticipated event was held Saturday, December 12, and around 400 attendees joined us for a morning full of fun!

Hank FM Party Patrol was the entertainment, and everyone really enjoyed participating in the fun, music and games. Parents had just as much fun as the kids, especially during the dad-dance competition and wrap-your-mom contest. Kids literally wrapped their moms with wrapping paper!

Everyone enjoyed cake, punch and other goodies as well as arts and crafts. The kiddos wrote letters to Santa as well as decorated their own cookies, picture frames, Christmas ornaments and more. Some even had their faces painted. They were also able to go on board a real fire truck, thanks to the **Parker County Fire Department**!

Families went home with lots of door prizes which were donated by several local businesses. Prizes included tickets to **Six Flag's Holiday in the Park**, a Mickey Mouse Christmas plush, a gift card to the **Magic Time Machine**, passes to **Amazing Jake's** and more! Each year, the highlight of the party is the big guy from the North Pole, **Santa Claus**, and this year was no different. Children took their picture with Santa, and everyone went home with a toy and keepsake photo.

CCA would like to thank **Southfork Ranch** for hosting as well as their amazing staff! A huge thanks goes out to our wonderful volunteers from the **Italian Club of Dallas**, **Grace Abell** and her friends, **Tyler Hanson**, **KLS Martin** and **Medical City Children's Hospital of Dallas**!

Midwest Holiday Party

The Annual CCA Midwest Holiday Party was held on December 5 at the **Parkway Chateau / Brat Stop** in Kenosha, Wisconsin. Families from both Illinois and Wisconsin gathered to visit, enjoy a pizza lunch, Christmas cookies, crafts and a visit from St. Nick. Kids sat on Santa's lap for photos and to tell him their wish list. A special thanks to **Lynn & Jessica Jaskowiak** for contributing toys and gifts. We're so glad everyone could join us, and we'll see you all next year!!

Nichelle Noble poses with Santa

Dominika gives Santa a heads-up by showing him her wish list during craft time and lunch!

Kinze Johnson, Jessica Jaskowiak and Dominika Tamley with Santa peeking out from behind!

cca's retreat room reward

Fundraising Proposal to CCA Families

Children's Craniofacial Association has a special way to reward families who raise funds for CCA, those whose efforts support CCA's programs and services for everyone.

Any family contributing at least **$5,000** in net funds for CCA within a calendar year, will have one hotel room stay awarded at the following year's retreat at no charge to them for the 4-day period (includes the Educational Symposium night).

We're pleased to provide a free customized donation site for anyone who wants to help raise funds for CCA. Contact CCA and we'll help you set up a personalized page. Of course, you can always use Firstgiving.com, and now GoFundMe.com has an option to donate directly to a certified charity. Tell your personal story or post an event you're having. You may even set a goal and track your success! When you tell your own story about your CCA kid, folks want to help because they know YOU! This is an especially easy way to fundraise. While it may seem intimidating to ask for donations face-to-face, online fundraising is simple and easy to share through your social media channels.

September marks Craniofacial Acceptance Month and is the perfect reason to appeal to family and friends for this effort.

This invitation to fundraise for a Retreat Room Reward is open to everyone, even those who already hold events throughout the year This program includes any type of fundraising. Contact CCA for ideas, more information and to ask questions.

All those who wish to participate will be asked to sign the following Fundraising Agreement as a "confirmation of understanding" of the provisions of this program.

Friends and/or relatives may help and/or may donate and ask the amount be credited toward your goal. You or they may also donate by December 31st any balance to make up the difference you might be short after fundraising!

We are so grateful to our families who understand the importance of paying forward the hope that CCA provides. We believe the Retreat Room Reward is a win-win for everyone, and together we are making the world a kinder place.

Fundraising Agreement

Children's Craniofacial Association has a special way to reward families who raise funds for CCA, those whose efforts support CCA's programs and services for everyone.

The ____family
Family Name
would like to participate in the program to raise funds for CCA. This is a confirmation of understanding about the provisions of the reward program. **December 31st is the deadline for each upcoming year's retreat award.**

The undersigned person and their family understand this program provides for **three nights (plus one symposium night if applicable) (four total) one room** hotel stay at the next retreat. **Registration Fee Applies and must be paid by each family.**

It is further understood the family effort must garner NET funds of at least **$5,000** for CCA in order to receive this award.

It is also understood there are no monies given to families for their effort and if the goal is not met there will be no "reward" / compensation nor carryover to the following year.

All funds raised must go directly to Children's Craniofacial Association and the reward is only for the Retreat hotel stay. (This provision may not go toward any other purpose or be used under any other circumstances.)

This invitation is extended to all CCA families and includes any type of effort to raise funds for CCA. Friends and/or relatives may help and/or may donate and ask the amount be credited toward your goal.

Please fill out a new form each year! *The undersigned confirms understanding the above information and agrees to conform to deadlines, goals and limits to benefit all CCA Kids:*

Dated ______________________________20______

____
Family Representative

____
CCA Representative

how to raise funds for cca

CCA depends on funds donated by individuals, proceeds from family and friends' fundraising efforts, corporate giving and foundation grants. As the number of families CCA serves grows, so does the need for additional funds. So, any help our readers contribute is most appreciated. Here are some ways to help.

- **www.goodsearch.com** (Powered by Yahoo) Enter Children's Craniofacial Association as your beneficiary charity. (You only have to do this the first time. You may add others if you wish.) CCA will receive up to a penny each time someone uses the GoodSearch search engine.
- **GoodShop.com, iGive.com and AmazonSmile** Go to GoodShop.com, iGive.com, or Smile.Amazon.com online shopping sites, all featuring hundreds of great stores including Best Buy, Macy's, Apple, Amazon, and more. It's easy! Just shop as you normally would! You get the same prices, but a percentage comes to CCA! Don't forget to install the iGive button on your Internet browser, and you'll automatically be redirected to the donation portal when you navigate to a participating site.
- **Cash for Trash!** Save your discarded cell phones and empty laser / ink cartridges. Print a free shipping label online at http://www.fundingfactory.com/goal/ccaink to mail in your cartridges and see the progress we've made on our $1000 goal for 2016.
- **Matching Gifts** Many companies offer a matching gift program that could double—or even triple—your gift to CCA! Contact your human resources office to find out if your company has such a program.

  One family donated $2,500 and had it matched in order to get their free retreat hotel stay!
- **Planned Giving** Tax preparation time is also a good time to consider long-term tax savings . When you consult an attorney or investment professional regarding your wishes for distribution of your assets in your will, consider a provision for CCA and secure the gift of hope and empowerment for generations to come.. Join CCA's Legacy Society. Call CCA for more information.
- **CCA Webstore** You can shop at CCA's webstore for t-shirts, Wonder Gear, and new items are coming soon. Check it out on our website. Every purchase supports CCA in a tangible way!
- **Clubs / Hobbies** Have your club organize a benefit for CCA. Use your hobby or something you love to do to raise funds.
- **Denim Days** Raise funds at work for CCA. Establish a special day or days for employees to make a designated donation (cash or check) to CCA in return for wearing blue jeans. The donation is usually $1 to $5, depending on how often the event takes place (for example $1 for a weekly donation, $5 for a monthly donation). Any higher amount would be at the discretion of the donor.
- **Civic Organizations** Public awareness leads to contributions. Contact and solicit opportunities to speak to your local civic organizations such as Rotary Clubs, Kiwanis Clubs, even HOG organizations. CCA loves our "biker" supporters. Distribute brochures and/or newsletters or other CCA-sanctioned materials for awareness and information. Ask for contributions.
- **Friends / Family Letter Appeal** Draft a letter to family, friends and acquaintances—anyone who has met or encountered your child. Contact CCA for a sample letter.
- **Kitchen Shut Down** Raise funds by raffling off chances to win meals for every day of the week, so the winner can "shut down" their kitchen. Local restaurants can donate meals or gift cards. This idea could also be used for a week of entertainment, such as movie rentals or theater tickets. Call CCA for more information.
- **Collection Cans** Ask local businesses to place a can or box (provided by CCA) to collect donations.
- **Get On Board!** Read our newsletter and learn about and participate in the events, raffles and funding efforts of CCA and our supporters. And, when you are finished with your copy of our newsletter, spread the news! Pass it along or leave it in a waiting room. (Remember to remove your address label.)
- **FirstGiving** There is a free customized CCA "firstgiving" site for anyone who wants help raising funds for CCA.

  Log onto firstgiving.com/ccakids and tell your personal story or post an event you're having. You can even set a goal and track success! When you tell your own story about your CCA Kid or why you are involved with CCA, folks will respond because they know YOU!
- **Birthday Club** Celebrate your special day by celebrating others! Donate your birthday to CCA and join our Birthday Club. You'll get a commemorative gift and if you come to Retreat, a special recognition!

reiss family, from page 1

Suffering from the normal feelings of anxiety and nervousness, we were excited to finally meet our twin boys. After the nurses were working on the screaming boys to the side, we noticed that Jake's hands appeared stuck together and there was an immediate difference from his twin brother. We could tell there were subtle glances and whispers amongst the nurses as we kept asking, "What is wrong with our baby?"

Panic stricken, we kept asking for an answer that no one in the delivery room wanted to deliver. Finally, someone said we have an idea but a different doctor will have to come speak with you. Making matters worse, it was Memorial Day weekend and the doctor delivering the babies wasn't even our normal doctor, and quickly left the delivery room as if she didn't want any part of this situation.

On the Monday after, a geneticist visited us in the hospital room and matter of factly informed us Jake had Apert syndrome, and his life would be very different from his twin brother and our expectations. Apert syndrome is primarily characterized by specific malformations of the skull, midface, hands, and feet. The skull is prematurely fused and unable to grow normally; the midface (that area of the face from the middle of the eye socket to the upper jaw) appears retruded or sunken; and the fingers and toes are fused together to varying degrees

He painted a very grim picture of surgeries, endless doctor appointments and medical care. He told us Jake would never be like his brother and would have severe cognitive delays. As new parents, our hearts sank and we couldn't comprehend how our lives had instantly changed forever.

Both boys were placed in the NICU and sadly we had to leave the hospital after a couple of days without either of our boys. Jake remained in the NICU for a month and only then was our new family home together for the first time.

A couple of fateful moments shaped our next year. First, our visit with the hand surgeon in the NICU where he shockingly informed us Jake would have four fingers but that's okay—so does Mickey Mouse. We were floored at the insensitivity he displayed and immediately knew he would never operate on our child.

This led to some interesting circumstances, in which we discovered a friend of a friend who lived next door to someone who had a daughter with Apert syndrome. We immediately got in touch with a doctor on the East Coast who performed the hand surgeries in two steps versus 10 separate surgeries. **Dr. Joseph Upton** was a very difficult man to get ahold of and 3000 miles separated us, but finally after writing him a heartfelt email, he informed us he would be in San Francisco for a conference and he would meet with us in the lobby.

We jumped in the car and drove the six hours to meet with him. He took a look at Jake's hands and instantly informed us he could operate on him and give him five fingers on each hand. Instant relief turned to immediate planning to

figure out how we could fit in two hand surgeries and a cranial advancement in his first year of life. The cranial surgery was the most difficult and scary given the sensitivity of the area of operation and Jake had far less material to work with making the 10-hour surgery increasingly difficult. Our goal and light at the end of the tunnel was that Jake could eat birthday cake at his first birthday with his 10 fingers. What a year it was, fitting in three surgeries, learning how to be parents of twins, and, quite frankly, trying to keep it all together while exhausted as many new parents are.

For the next few years, we had some minor surgeries, but the worst was behind us, and Jake tackled development milestones only slightly behind his twin brother. Since we now had a new abundance of time—of course we jest—it was time to have another child. Well maybe that surprised us a bit, but true, a little girl, **Olivia Eden Reiss**, joined us when the boys were only 17 months old. Three kids under the age of two has a slightly scary ring to it, but once you tackle the harder stuff life throws your way, the normal items don't seem daunting anymore.

Jake continued to flourish and the more items that we put in our rear view mirror, the more back to normal life seemed.

One of our favorite moments of the next year was walking into the same geneticist's office that had delivered us the initial diagnosis. He genuinely was shocked when Jake walked into the appointment and reversed his original stance and did inform us he thought Jake would be able to take care of himself upon growing older. It was something we already felt watching Jake tackle the many obstacles in his path, but a true moment of joy to hear the doctor change his earlier tune that had worried us so much on day one.

Over the next several years, Jake started school, and with only a small amount of extra help, he was just another kid in the class. Jake is blessed with a special personality, an infectious smile, and he seems to attract adults and kids alike. We think this has helped him recover from his many surgeries and tackle the challenges he faces in every day life.

We made the decision to mainstream Jake in school, keeping him with his twin brother. We felt this would push him to strive to learn and it has been a great experience.

Thus far, Jake has enjoyed school, and all of the kids have been supportive of him, especially the little girls who all surround him to play.

At the end of the first grade year, we decided to remove the comfort zone and separate the boys into different classes for both of their respective benefits. Jake was making good progress, although experiencing some challenges. We decided to have him repeat first grade so that he could continue his progress and catch up to his classmates. Although we were worried how he would receive this info and watch his twin brother move on to a new grade, it wound up being a great decision for Jake. This year he has made great strides in catching up and learning alongside his classmates, while even interacting more on his own with his classmates.

Jake surprises us all the time, overcoming his physical limitations as he now climbs all the playground equipment even though he can't bend his fingers. He also learned how to ski this past year and has mastered swimming and, unfortunately, he even mastered the XBOX remote ;-).

In the next year Jake will have his 12th and largest surgery to date—his midface advancement. We will continue to tackle the obstacles that come our way and remember our surgery mantra which is "get to the smile." This is always a huge benchmark after surgeries when our Jake smiles again to let us know he is feeling better and recovering.

Our initial feelings of despair upon discovery of his diagnosis have turned

see **reiss family**, page 19

the difference between nice and kind

I spent way too many years being nice.

Now I'm learning that it is better to be kind.

What's the difference, you ask?

Well, being nice is something you do to please others and it is actually quite self-serving. (Please hear me out.) Being nice is agreeing to mop the floors after a serving shift, when really it's someone else's turn. Being nice is agreeing to come in early with the donuts for the meeting, even though you have an intern for that. Being nice is saying, "Oh, yeah, we should hang out," with an old friend but then never following up. Being nice is avoiding confrontation, but saving face.

Being kind is quite the opposite; kindness often goes hand-in-hand with bravery. Kind acts are done from a place of self-confidence and self-worth. Being kind to everyone and everything you meet is something you practice for the greater good, sometimes without even seeing the direct result. It is something you do because you want to make the world a better, more understanding and more accepting place. You know you've been kind when you experience joy, compassion and love.

Being nice may make you feel needed, but being kind makes you feel connected.

If you often find yourself overwhelmed, underappreciated, or just wanting to flake out a lot … ask yourself, are you trying to be nice or are you practicing kindness?

A nice person compliments your sweater, but a kind person asks how you're doing and really listens. A nice person laughs uncomfortably at an off-color joke, but a kind person says, "Guys, that's really not funny." A nice person is afraid to confront a bully, but a kind person is confident in taking action (whether it's confronting the bully or getting help from an adult). A nice person is focused on gaining people's approval, but a kind person is compelled to act.

For me, I spent a lot of years mistaking niceness for kindness. Now, I know the value of kindness and I believe it can change the world. And what really empowers me is that I realize kindness is a practice. Every day you get to try again and not every day will you succeed, much like yoga or golf or painting … there is no winning goal to reach. You get better with every stretch and every stroke. So with a little practice, you might just find that unnerving need for approval has turned into a peaceful, grateful existence.

***

I am so fortunate to have found CCA as an adult. Growing up I was happy, as I've always been optimistic, enthusiastic and driven, but on the inside I was facing a fierce, quiet struggle. Throughout school, I felt like an outsider, lonely and nervous if I would ever get to experience life fully because of my facial differences. The adolescent years were excruciating, plain and simple. And while I can't say they're much easier for anyone out there, I know that having strong relationships in your life is what makes the difference between surviving and thriving. And that's what motivated me to choose a career concentrated on making a difference in people's lives.

I was introduced to CCA Kids as an adult by my friend, **Tony Davis**, when I lived in Tuscaloosa, Alabama (Roll Tide!). Tony was a director on CCA's board at the time, and I remember standing in his kitchen, with him telling me, "You need to know about CCA." He then told me about the work, the kids and, of course, **Cher**. Immediately, I started volunteering with Tony through serving on the board of directors. I was welcomed like family, treated like an equal and introduced to some of the most amazing people I have ever had the pleasure to know.

When **Char** began talking about retirement a few years ago, I honestly didn't think I would wind up trying to fill her shoes. But I knew I wanted to work hard and build a career that makes me proud. I also knew that I prefer to work for a cause that supports the values I believe in. And finally, when the opportunity came my way, I knew I wanted to carry on the amazing 26-year legacy that is CCA to the best of my abilities.

Now, I'm excited to say that together we are making the world a kinder place. Sometimes it is providing much-needed financial assistance for a family on medical travel and sometimes it is connecting a new family to a network of parents united to care for each other. Sometimes it is working with a whole school district to rally for kindness and sometimes it is simply finding another young person with a facial difference who's never met anyone else "like them" and watching the years of isolation melt into instant connection.

This is what CCA does and this is what I do. I hope you are as excited as I am for the future of CCA and what we can accomplish together. Char will remain one of my closest and dearest mentors through this process, and for that I am truly grateful.

Yes, there are more changes on the horizon, too—monthly e-newsletter, a new webstore and more ways to get involved with CCA. Plus, we're increasing the amount of financial assistance we're providing to families this year, and in 2017 we're already planning for the biggest Retreat ever.

Stay with us friends. It's a great time to #ChooseKind together.

Erica Mossholder,
Executive Director

Wonder Gift Sets

now available all the time!

Go to ccakids.org/wonder-gear to order yours!

reiss family, from page 17

into an incredible life lesson as Jake has taught our family and friends so many things about himself, and more importantly, given us a new perspective on life.

We are grateful for the many lessons and experiences that have come our way since having Jake. We have made so many friends through the community, and last summer we had the truly remarkable experience of attending the CCA retreat in Newport Beach. We want to offer a special thanks to CCA organization and staff who provide a wonderful connection for all of us who now share in a larger communal extended family.

calendar of events

date	event	contact
2016		
Apr 15	**4th Annual Texas Moms' All the Way for CCA Golf Tournament** Wildcat Golf Club Houston, TX	Becky White ledestiny@gmail.com
Apr 16	**HISD Wonder 5K Fun Run to benefit CCA** Registration begins March 1st Hutto, TX	angela.hartman@huttoisd.net
April 27-28	**5th Annual Morgan Meck's Match Play Invitational** Coto de Caza Country Club Coto de Caza, CA	BMecklenburg@ses-ins.com
May 12 5-8P	**Liberty Burger Fundraiser** Liberty Burger-Forest Lane 5211 Forest Lane Dallas, TX	AReeves@ccakids.com 214.570.9099 800.535.3643
Jun 23-26	**26th Annual Cher's Family Retreat** Hyatt Regency Pier 66 Ft. Lauderdale, FL	AReeves@ccakids.com 214.570.9099 800.535.3643
Jul 16	**2016 "Miles for CCA Kids" Benefit Ride**	lewisboykin55@gmail.com
Aug 28	**Seth's Stride** Canton, OH	Stacy Horne stacykhorne@gmail.com
September	**12th Annual Craniofacial Acceptance Month** Nationwide	AReeves@ccakids.com 214.570.9099 800.535.3643
Sep 9	**9th Annual Links of Love Golf Tournament** Firewheel Golf Park Garland, TX (Dallas area)	JPatterson@ccakids.com 214.570.9099 800.535.3643
Sep 10 11A-1P	**9th Annual National Picnic Day** Sandy Lake Amusement Park Carrollton, TX	AReeves@ccakids.com 214.570.9099 800.535.3643
September 10	**Raegan's Rally/Walk for CCA** Deerasic Park Cambridge, OH	Ashley Daugherty ashleyddaugherty@gmail.com

Last November, a special sales evening was held at a Dallas location of **Kendra Scott**, where 20 percent of all sales that night benefitted CCA. The store accepted phone orders and also shipped any item in stock for free. In just those three hours, **Kendra Scott Dallas West Village** "gave back" around **$500**! Thanks so much to **Ashley Zorn** and her team at the store and to all who participated!

a living legacy

We are so grateful for those who have thought ahead—many arranging planned giving according to their wishes—many times without even telling us. Those who have made the decision to champion CCA by leaving our charity in their will are providing a lasting legacy for years to come with their gifts.

For this reason, we initiated the CCA Legacy Society, for those who name Children's Craniofacial Association as a beneficiary. Through this effort, we will chronicle information about our Legacy donors who care for our future and the wellbeing of our CCA kids.

If you wish to fill out a declaration form and become a Legacy member, please contact us. If you have already set up a bequest in CCA's name, please allow us to include your intentions in our records, describing your gift of security for the future of Children's Craniofacial Association.

sponsors needed for cher's family retreat!

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

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

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

June 23-June 26
in Fort Lauderdale, Florida

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

For more information,

please contact Annie Reeves,

AReeves@ccakids.com

We hope to see you there!

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

Bookmark This!

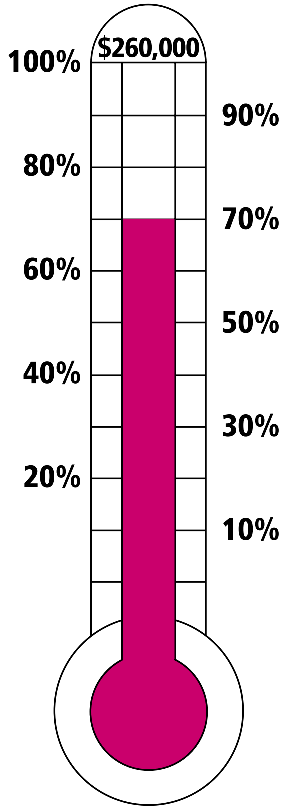
When you shop through these links, CCA gets a donation! You can also install the iGive button that will automatically redirect you when you are shopping at a participating site!

Smile.Amazon.com

iGive.com

GO PAPERLESS and view the newsletter online in FULL COLOR! Please sign up on the home page of our website! **Save the environment and save money for CCA.**

2015 FAMILY FUNDRAISER GOAL THERMOMETER



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

www.ccakids.org/donor-list.html

state assistance:

did you know that many states offer funding/small grants to individuals with disabilities and their family members to attend advocacy trainings, learning events and conferences? The **CCA Annual Family Retreat qualifies** because of our educational symposium. If you would like more information regarding your state assistance program, please visit ccakids.org/state-funding.html

gingertown dallas 2015

CCA is honored to be the chosen beneficiary of the annual Gingertown Dallas event held at NorthPark Center each winter holiday. The 2015 theme, "Gingertown Beach," held last December, brought together teams of local architects, engineers and design professionals who "built" stunning sweet creations. They remained on display from December 1-13, so shoppers could enjoy them and donate toward the effort if they wished.

The original Gingertown event was established in 2006 by **David M Schwarz Architects** in Washington, DC, and Gingertown Dallas began in 2010 when DMS decided to add new locations for participation.

We were recently presented with a check for **$17,125** representing funds from support of generous event sponsors, participants and attendees. We are extremely grateful to all involved, especially to **NorthPark Center** and to **David M. Schwarz Architects Charitable Foundation** for this amazing opportunity. There are few things sweeter in life than icing, but the generosity of all the Gingertown participants takes the cake!

donors in the spotlight

From the first time **Gary and Nancy Merrill** of Tinton Falls, New Jersey, became acquainted with Children's Craniofacial Association, it was kismet. Their 12-year-old daughter, **Emily**, was born with Goldenhar's syndrome. Although they have yet to attend an annual Family Retreat, they know countless other CCA families, have helped with CCA fundraising, have helped send others to "Retreat," are regular donors, and even hosted a Craniofacial Acceptance Month picnic last September! These many reasons are why we shine our spotlight on them this issue. A special thanks to you, the Merrills, our Donors in the Spotlight, for the many ways you give!

matching gifts

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

Donate Your Vehicle

Easy Process.

Free Pickup.

Tax Deductible.

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

SUPPORT US TODAY!

Just Call 877-570-4222

ccakids-cardonations.org

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

american legion post news

by Jaci Sammhammer

On December 19, 2015, **American Legion Post 317**, in Yardley, Pennsylvania had a Christmas Party. During the gathering they held a 50/50 raffle to benefit Children's Craniofacial association. **$530** was raised at the event and then was split with the winner, **Chuck Conn** who out of the kindness of his heart and his love for children donated his half back! My legion family is always willing to help a great worthy cause whenever they can. Thank you all!

A Message from Post Commander, ***Gene Tecce****:*

"**Jaci** is an unbelievable young lady with courage and strength that makes us proud that she is part of our organization. Her dedication to our veterans and the American Legion mission is beyond reproach and many times she has gone that extra mile to help our organization achieve its goals. I have watched Jaci on many occasions step up and offer her time to assist us even with her own difficulties set aside. If Jaci is an example of your organization's efforts to have these children live a fruitful and productive life, then I can think of no better organization to help financially as the evidence of your work is seen daily here at our Post. Please continue your efforts and we thank you and your organization for all that you do for these children."

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If you no longer wish to receive this newsletter, please send an email to AReeves@ccakids.com or mail the label to the CCA office and ask that it be removed from the mailing list.

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