

ccanetwork



newsletter of the children's craniofacial association

Cher—national spokesperson

2018: Issue 1

inside

- cca kid
- zain mustafa 2
- cca teen
- rasheera dopson 3
- cca supersib
- rj mustafa 4
- kendra gives back 5
- gingertown 6
- on the outside 8
- students in action 10
- looking back 11
- deal island elementary . 12
- choose kind, choose comacho 13
- healthy body image . . . 14
- testimonial 16
- calendar of events 16
- kiai! for kindness 17
- 3 cheers for volunteers . . 24



our incredible dominika

By Kevin Irvine

Karen and I had just finished our paperwork to become prospective adoptive parents, and were preparing ourselves for the months of waiting to be matched with a baby. However, our adoption counselor surprised us when she said that **The Cradle** (our adoption agency) had been taking care of an adorable little girl in its nursery for her first five months and that they felt we would be perfect parents for her. The baby's name was **Dominika**; she had a rare disability called Apert syndrome, and we were asked if we would like to meet her. Of course, we said yes! A couple weeks later, on May 18, 2006, we brought Dominika home to our Chicago apartment and our wait to start our family was over almost before it began.

see **dominika**, page 18



becoming an upstander

We talk about kindness a lot around here. We say one act of kindness can change the world. And I absolutely believe it. But how can we (and I mean *me*) create a critical mass of kind-behaving people? How do we put kindness into action?

Well, a few days ago I was in the car with the radio on, enjoying a much-needed warmish, sunny day in January. Since my free trial to Sirius XM expired, I have been getting back into the old-fashioned radio again, and let me just say they play a much better variety, and I've been getting back into touch with some true gems! One in particular, the song "Some Nights," by **Fun**. came on. I cranked it

see **exec director**, page 23

ccakid

meet zain mustafa

Six-and-a-half-year-old **Zain Mustafa** is first grader from Illinois, who likes school and loves anything having to do with cars and trucks. He looks forward to school every day, where his favorite subjects are gym and music. After school he enjoys watching his older brother, **RJ**, play basketball and take boxing lessons.

Recently, he spent winter break with his dad in Ohio, which was fun, and he has plans to go to this summer's family retreat in Salt Lake City, Utah. They had such a good time meeting new friends at last year's retreat in Virginia. The absolute best part for him was the dinner.

With his keen interest in cars and trucks, he's excited to see school buses and

firetrucks while out and about and enjoys playing and pretending with their smaller versions any chance he gets. While he's not playing, he likes watching his favorite shows—*Bubble Guppies*, *Wheel of Fortune* and *Mickey Mouse*—as well as his favorite movie, *Fat Albert*.

But his favorite thing to do is dance. Dance parties rate high with Zain, and he loves any music that gets him hyped up and showing his moves. We're sure his favorite part of this year's retreat in Utah will once again be the dinner dance. We hope to see Zain and his family then—and dance along with him!



meet rasheera dopson

hi there, my name is **Rasheera**. I'm 26 years old and I live in Atlanta Georgia. I was born June 5, 1991, and I was diagnosed with Goldenhar syndrome. Throughout my life I have had 102 surgeries.

So now that we have the details out the way, let's get to the interesting stuff. I tend to like to share more about myself outside of my medical history 1) Because my medical history is soooo long and 2) It's soooo boring (well at least for me it is). Sometimes I feel like a broken record having to repeat it all of the time. Anywho, I'm just a regular girl who enjoys doing things such hanging out with friends and family.

I grew up in Northern California, in the Bay area, outside of San Francisco, so I'm sort of a city girl at heart. In the summertime I love going to festivals and parks, eating ice cream and drinking lemonade. And in the wintertime I love sipping on hot cocoa and binge watching Christmas movies on Netflix. Outside of Christmas, however, I love watching action movies. I especially love the Marvel superhero movies such as The Avengers. My favorite Avengers are Thor and Iron Man.

I try to live my life to the fullest doing things that are fun and different. My mom raised me to be a risk taker despite my difference. So, despite having medical challenges, I like to have fun. Sometimes when I'm in my car driving down the freeway I like to turn on my Spotify playlist and blast my music. I like listening to old hits by Stevie Wonder or Michael Jackson.

Did I mention I love to dance? I absolutely love to dance! I hope this summer I can take some salsa dancing classes. Give me salsa music and tacos any day and I am a happy person.

I think it's important to not only do things you love but to try things that are new. You never know what you will like or dislike until you try something at least once.

So there you have it—a few things about me. If you are ever in Atlanta, you might catch me at a festival downtown or see me driving by on the freeway blasting my tunes.

ccaadult



ccasupersib

meet rj mustafa

hi my name is **RJ Mustafa**. I am 8 1/2 years old. My birthday is on August 19. I'm in third grade. I live in Bourbonnais, Illinois with my mom, my grandparents, aunt, uncle, and of course my special brother **Zain**. My dad lives in Ohio so that's my second home, too.

My favorite foods are pizza and chicken Alfredo. I enjoy playing basketball and I also take boxing lessons. I hope to be a surgeon one day so I can

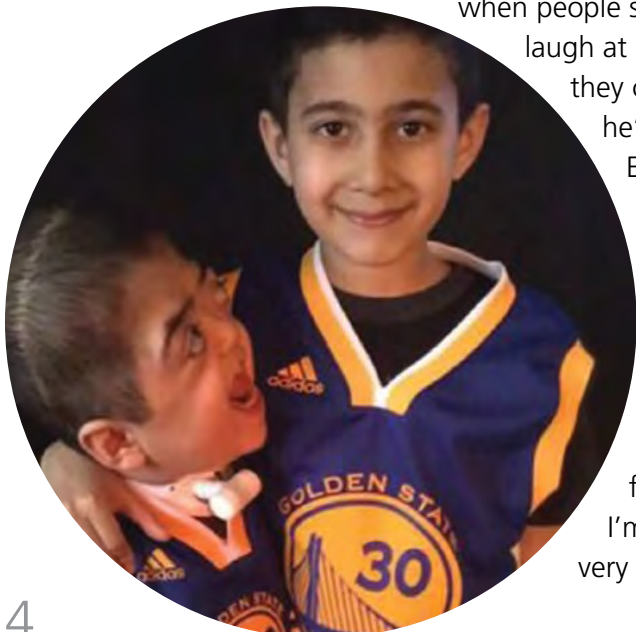
do surgeries on kids who are just like Zain.

My mom took us to the retreat in Virginia for the first time and I'm glad she did. I met so many kids just like Zain. It makes me feel good that Zain will grow up and feel he's not alone. I also got to meet other brothers and sisters who know how it is to have a special sibling. I know I am not alone too. And also my mom made new friends there. I hope she will take us to another retreat.

I feel bad that Zain has so many surgeries and I hate when people stare and laugh at him. I wish they can see he's perfect. Even though he likes to bother me and take my Legos from me, I'm still very lucky to



have him as my brother. He doesn't talk yet, but he finds ways to make us understand him. What I love most about him is that he's always happy and smiling. He has the best laughing sounds. If I had one wish, it would be to always keep him happy!



kendra gives back

We are so grateful for two amazing Kendra Gives Back Nights that we held at the end of last year at **Kendra Scott in Bridge Street in Huntsville, Alabama**, on November 17, 2017, and **Kendra Scott West Village in Dallas, Texas**, on December 5, 2017.

These fun events featured sips, sweets, and stunning jewelry, and are a time to get together and mix and mingle with friends. We also provide an opportunity to learn more about our cause and how CCA helps children and families.

For the Huntsville event, organized by **Paige Beitel** and **Melanie Yarbrough**, we were pleased to feature UK-based activist **Jono Lancaster (Love Me Love My Face Foundation)** who spoke about growing up without a support network and why he has dedicated his life to helping children with facial differences learn to love themselves. Jono spoke during the evening. Later that night, he was featured on **ABC's 20/20** talking about the release of the film *Wonder* and his visit with the **Newman Family**. He moved the crowd gathered there, and everyone was thrilled to get a photo op with their

new favorite international friend.

Thank you again to our wonderful sponsors, who brought out all of their staff and helped us promote the event: **Dunagan Yates & Alison Plastic Surgery, Alison Wellness Clinic, Beitel Pediatric Dentistry** and **Limbaugh Orthodontics**.

We also want to thank **Ashley Lawson**, Kendra Scott manager, and her entire team for providing the most hospitable and beautiful ambiance for our guests. They kept the wine flowing, and didn't stop ringing up guests and building custom Color Bar jewelry for three straight hours! The Huntsville team proved they are dedicated



to philanthropy and were an absolute delight!

The event was so successful, and resulted in a CCA record-breaking Kendra night raising more than **\$1,200** for CCA from shoppers and donations at the event.

Shortly after the Huntsville event, CCA headed back to our Dallas store in West Village and did it all again. While it was a smaller event,

it was still incredibly impactful to CCA, and we raised another **\$400!** The manager, **Ashley Zorn**, was wonderful as she gave out CCA tote bags to everyone who made a purchase, and shared with them how CCA impacts kids across the country. Thank you so much to everyone for being a part of these fashionable philanthropic nights! See you at the next one.



gingertown – a sweet holiday tradition



seeing all the kids checking out the tasty town and finding their favorite buildings.

This delightful event raised a record-breaking **\$23,306** for CCA and we are so grateful to everyone who participated and donated! We were happy to have **Michael** and **Brittany Brown**, CCA Family, join us as we accepted the “big check!” Clearly, Michael was impressed! We extend our deepest thanks to **HKS, Inc., Southwestern Blueprint, The Theodore, Seasons 52 Restaurant**, as well as, **RJ Reissig**, Project Manager at NorthPark Management, **Pamela Mitchell** (who made it her personal mission to top last year’s record), **Liz Meyer, Shelby Foster, Brenda Buhr-Hancock, Kristin Casner**, and **Loryn Weddle** of NorthPark Center, **The David M. Schwartz Architects Charitable Foundation**, and all of the Gingertown construction crew!

How sweet it is to have supporters like you! Mark your calendars for next year’s live build on **December 4, 2018 from 5 – 9pm.**

CCA is honored to once again be the beneficiary of the annual **Gingertown Dallas** event held at **NorthPark Center** each holiday season. The 2017 event marks our 8th year as the recipient charity. The intricate creations were displayed on the first floor of the luxury shopping center, so visitors could enjoy it as part of the art experience that NorthPark offers. Each year, teams of local architects, engineers, and design professionals build a stunning miniature town out of candies, sweets, treats, and of course—gingerbread!

The Gingertown event was established in 2006 by **David M. Schwartz Architects** in Washington, DC, and started in Dallas in 2010. We are so grateful for this unique and fun event that encourages visitors to donate to CCA when they view the display. We witnessed the exhibit’s live build. It’s wonderful



**THANK YOU
DALLAS
GINGERTOWN**



NorthPark Center
in association with
DMS Architects Charitable Foundation

January 26th, 2018 DATE:

PAY TO THE
ORDER OF: Children's Craniofacial Association \$ 23,306.00

Twenty Three Thousand Three Hundred and Six DOLLARS

FOR: Gingertown Dallas 2017

000000000559 00000000012



on the outside

By Jenna Ottow

having a craniofacial difference is hard. I was born with Apert syndrome which means I was born with most of the bones in my skull, hands, and feet fused together. These bones are still fused today. A craniofacial difference is on the outside, and it's obvious. All the time. Sure it can literally be masked with sunglasses, scarves, surgeries, or hats. These masks are useful to dodge the second looks, gawks, or whispers, but after those layers come off, the wounds, scars, wide set face (for me) are still there, staring back. Apert syndrome has followed me my entire life. I am

almost always the only person in the room with a physical difference. I stick out like a sore thumb. I try not to think about it. It is confusing, lonely, and unsettling.

I've learned from a young age that the stares, whispers, and gawks won't go away. Ever. I realized that in order to survive, to make this life of mine habitable, I needed to change my perspective. For one of my college scholarships, I wrote an essay on a Nathaniel Hawthorne quotation, "Life is full of marbles and mud." It was hanging on the wall in the classroom where I was supposed to master the art of cooking. In the essay, I explained that in order to get through the mud, the focus had to be on the marbles. Always. Celebrate the marbles in first class style, own the marbles, that way, when mud rears its ugly head, marbles will always have a place. A place to look forward to. That's all. A lifetime of experience has taught me to barter the marbles to avoid the mud.

A few years ago after a very filling holiday visiting family, I was boarding an airplane with my parents. My Dad prefers to sit in the



exit row. At 6'3" his legs get squished in almost all modes of transportation. The exit row on a 747 has more legroom as it serves as the emergency exit, making a 3-hour flight a little more bearable. That is where we sat on this flight. My Dad and I on the ends, my Mom in the middle. Passengers were getting settled, compartments were opening and closing and the telepathic pleas from the parents to overtired children begging for a "tear-and-drama-free" flight hung in the air. Turns out the children would not be providing the tears that evening. The three of us had just

listened to and agreed with the rehearsed statement from the flight attendant explaining the responsibility that comes with sitting in the exit row. I believe you have to at least be 15 years old to sit in this row. At the time, I was in my mid-twenties. Phones were getting turned off, and smaller carry-ons were being shoved under seats. There was a silence, yet we weren't moving. A different flight attendant approached our seats with haste.

She leaned over my seat and said to my parents, "She will have to move. We're sorry for any



inconvenience, but she can't be here."

Apparently, a judgement was being made based on my physical appearance that I could not handle the duty of sitting in the exit row, despite my previous confirmations. My parents, not really sure what their role was in this, looked at me, with my mouth agape as I looked at the attendant.

"You're talking about me?" I asked her. The attendant nodded, still looking at my parents. "First of all, I'm right here. You can look at me, not them. Secondly, talking around me as if I can't hear you is unnecessary, and frankly insulting." I felt disrespected because this flight attendant didn't think to approach me first. I was angry, and embarrassed because of the small scene that I had the starring role in. Furthermore, I was literally paying for this insulting behavior. I wasn't even given a chance to defend myself. I was stunned. Not wanting to delay the flight and too tired to protest any more, I moved.

The flight attendant mumbled out a canned apology and showed me my new seat. Thankfully I had the row to myself, I cried silently to myself almost the entire flight. I wrote a letter of complaint

to the airline, narrating the incident. A few weeks later the response that came back indicated that the flight attendants had done nothing wrong. I'm not going to say the flight attendants were wrong in their judgment, it didn't actually occur to me until right now what would have happened if the airplane had run into trouble. Again, it was more about how the situation was handled much more than why it happened. I was not surprised, however to learn that shortly after this incident, the airline went out of business. Karma.

After this incident, I did a lot of research on the rights of a traveler with a disability. Thanks to the government, air travel is amazingly accommodating. Now, when I travel, I utilize the services available, especially when I'm alone. It's less nerve wracking to travel with the government on your side. One of the biggest, and really the only accommodations that I'm qualified for is being able to board early. I have limited range of motion because of some residual bone fusion that surgeries never resolved, I can't raise my arms above my head, coupled with being 5'1" means lifting a carry-on into the overhead compartment is not happening any time soon.

Passengers boarding an aircraft can be chaotic, and my needs for assistance can be inconvenient in the midst of all the bustle. By boarding early, I'm able to get assistance without being an inconvenience to my fellow flyers, and more importantly, avoid the sea of stares as I find my chosen seat - away from the exit row.

Life is full of marbles and mud, or accommodations and emergency exit rows. Sometimes, using the marbles to avoid the mud makes all the difference.

Jenna Ottow was born with Apert syndrome. She lives in Milwaukee, Wisconsin. She works in the health insurance field coordinating care and advocating for patients' needs. She enjoys hiking with her dog, watching the Green Bay Packers, and reading. Jenna also enjoys socializing, a good glass of white wine, and any reason to find the silver lining.



students in action

Recently, **Armstrong School** in Hoffman Estates, IL, third- and fourth-grade classes visited **Feed My Starving Children – Schaumburg**, where they worked together to pack 23,112 meals while wearing CCA “Choose Kind” shirts. That’s 107 boxes of food, which will feed 63 children for a year.

“Wow—that is so great!” one student exclaimed when the total was revealed.

Armstrong students have also been fundraising to support the organization and share the importance of “choosing kindness” through their actions. The school donated **\$300** which will feed four children for almost a year! Thanks to **Derrick Sun**, teacher, for sharing this story with us.



students in action



Everyone in our middle school, Brasher Falls Central School in New York, and some of our local community members read the book *Wonder*. This dinner was our grand finale! Students made signs in shop class and art class. We had a raffle for the signs at the dinner. Each sign had an inspirational quote like the precepts from *Wonder*.

Thank you to librarian, **Rebecca Dullea**, for organizing this fundraiser for CCA!



looking back from a distance

By Christian John Hadjipateras

As I gaze out of the plane window, the pitch black slowly begins to give way to the dawning of a new day. The stunning sight of red and orange appearing on the horizon is a familiar sight to travellers of transatlantic flights heading back towards Europe. For me, it's an image permanently seared into my mind because I witnessed it countless times during my teenage years. So, being that young, I wasn't some average businessman on his way home from a meeting across the pond. It was, in fact, due to having to make many trips from London, where my family and I lived back then, to Chicago for a series of operations I had to have to reconstruct my nose, owing to the various conditions I was born with.

Those days, as I mentioned, were years ago—back in the early 2000s. Right now though, I'm flying back from a charity event in Chicago for a foundation I've been involved with for the last couple of years, which has been a wake-up call. This particular foundation is dedicated to raising money for the Craniofacial Centre to provide care for kids born with genetic

abnormalities, which range from cleft palate to other disorders that affect the cranium and facial bones. I have always held the belief that everyone, from all walks of life, should try to make a difference, no matter how big or small. Given that I was born with several of the issues mentioned, being involved is a small way of helping those kids who face similar obstacles to the ones I did. Admittedly, it took some time for me set in motion my part of giving something back after all the care I'd received from countless surgeons and nurses throughout my path of multiple surgeries. But, as the saying goes, better late than never.

This was my third consecutive year attending the foundation's annual event. Now that I'm writing this on the flight home, I hope that my small contribution helped to bring in much-needed funds to the Craniofacial Centre. However, there was a different and unexpected highlight to my visit. Every time I visit Chicago, I make a point of going



to see the surgeon who reconstructed my nose all those years ago. I'll refrain from naming him because,

despite his undoubted position as one of the best nasal reconstructive surgeons in the world, his modest character is evident to me and all his other current and former patients, in that he never seeks publicity like so many surgeons do today. So,

see **looking back**, page 22

APRIL SHOWERS ARE COMING...
GET PUDDLE READY!



kids' sizes 10-3

wonder galoshes
by roma boots
available in the
cca webstore
for only \$29
bit.ly/ccashop

Julia Roberts
Owen Wilson
Jacob Tremblay
wonder
BASED ON THE NEW YORK TIMES BESTSELLER

november 17 .



brought in donations to create a gift basket to raffle with *Wonder*, *Auggie and Me*, *365 Days of Wonder*, a \$50 movie gift card and a t-shirt we made for our trip to see *Wonder* on the big screen. What makes this so impressive in my eyes is that all of the money raised was raised by only 16 students in a period of about 7 weeks! We like to use the phrase “small, but mighty,” to describe ourselves because even though we are a small school, in a small community, my students are capable of doing mighty things.

I wish I captured their faces when I told them how much money they raised! One student said, “I have never felt this happy and I didn’t win!” That is what it is all about: feeling good because you did something for someone else. Needless to say, I am one very proud teacher on so many levels!

deal island elementary school

deal Island Elementary School teacher, **Michelle Messick** contacted us to share her *Wonder* story. Her class will be sending two families to CCA’s Annual Family Retreat and Educational Symposium on Starfish Scholarships. She tells us how her students raised the money for CCA and the activities she planned around the book.

Messick inspired these students to give back in a big way. Two families will benefit from this community’s hard work and outpouring of love. Thank you so very much for all the

kindness emanating from Maryland. You will have a profound effect on our craniofacial community in June. Thank you!

Ms. Messick writes...

Our class decided to raise the money after reading *Wonder*. CCA graciously donated the books last year to our school because I had to borrow a class set every year. This year my students felt led after reading materials from CCA to send a student to the annual retreat.

Never in our wildest dreams did we imagine raising enough money

to send TWO families! Our school, Deal Island Elementary, is located in a small community, Deal Island in Somerset County, Maryland (Eastern Shore of Maryland). The students



choose kind, choose camacho



buying or selling a home?

Contact Brittany to be referred nationwide to a Realtor who will take “wonder”ful care of you, and donate to CCA in the process!

CCA Mom and Keller Williams Realtor, **Brittany Brown** (center) with the Trent family of Dallas, Texas.

Through a unique partnership that started with the movie *Wonder*, **The Camacho Home Group of Keller Williams Realty** pledged a contribution to CCA of **5% of 2018 net commissions!** We cannot thank them enough! The **Trent Family** is the first closing of the year where CCA is the direct beneficiary of this pledge. Thank you Trent Family and Brittany!

Brittany is a CCA Mom to **Michael**, who has Treacher Collins syndrome, and to **Allison**, an amazing SuperSib who already advocates for her brother in the most special way!

CCA Families, contact **Brittany Brown** first for any real estate needs at 214.838.3669 or Brittany@CamachoHomeGroup.com. Through her national referral network of top real estate agents, Brittany can help CCA families with any real estate transaction across the country (and certain locations globally), and support CCA with a financial contribution at the same time ... this is truly a win-win towards a **\$50,000 goal!** Brittany will ensure you work with a great agent in your area and together we can further support the CCA mission!



Brittany Brown with Michael and Allison

#50kforcca

helping your child develop a healthy body image

Canice E. Crerand, PhD • Clinical Psychologist,
Assistant Professor of Pediatrics and Plastic Surgery • Nationwide Children's Hospital

What is Body Image?

Body image is defined as how a person thinks and feels about his or her own physical appearance. We all have our own likes and dislikes about our looks. It is important to remember that body image is subjective and personal—how we see ourselves can be very different from how others see us. Thoughts, feelings, and behaviors about appearance are often linked together (e.g., negative thoughts about appearance can give rise to negative feelings such as sadness or anxiety, which, in turn, may lead to behaviors like avoiding activities).

Where Does Body Image Come From?

Many different factors can affect how we think and feel about our looks. For example, comments and compliments about our appearance (e.g., “You have your father’s eyes,” or “You have a beautiful smile!”) can influence our self-perceptions about appearance. Teasing or bullying about appearance can also affect how we think and feel about ourselves. Societal ideals about how we are “supposed” to look can impact our body image particularly since these ideals are often featured repeatedly on television, social media, and in magazines. Even children’s toys often reflect societal ideals for appearance. Unfortunately, there can be a lack of diversity in the images and ideals presented (related to race, ethnicity, body shapes and sizes, facial appearance, disability status). It is easy to feel “different” when there are few examples in the media of people that represent the beautiful variations in appearance that exist in the world. Not surprisingly, some dissatisfaction with appearance is common among children and adults alike, particularly given society’s emphasis on appearance and the tendency to compare ourselves to these ideals.

Why is it important?

How we think and feel about appearance can affect our self-esteem and quality of life on a daily basis. Body

image dissatisfaction can cause problems with daily activities such as going to school, participating in social activities, or even things like having pictures taken for family events, school, or for social media. It can also be a risk factor for other problems like depression, social anxiety, and eating disorders.

Can Body Image Change?

It is common for body image to change as our bodies grow and change over the course of our lives. For example, adolescence is a time when most, if not all, people become more aware of their appearance and attractiveness, particularly as interest in dating increases. It is not uncommon for teenagers to feel especially self-conscious about their appearance, owing in part to changes related to puberty and physical growth. As teens grow into adulthood, they may feel less self-conscious and more accepting of their appearance.

Because body image is subjective and really about thoughts and feelings, it is possible to change your body image without actually changing how you look through surgery, weight loss, or other appearance-changing strategies (e.g., wearing make-up). Changing thoughts or self-talk about appearance can help improve body image concerns.

Children and adolescents with craniofacial conditions often undergo reconstructive surgery to address aesthetic and functional problems related to their conditions. Surgery can change their physical appearance and be influential in changing their body images. However, some children or teens may express disinterest in surgery because they are satisfied with their appearance. Others may have surgery that significantly changes how they look, yet still report feeling dissatisfied with their appearance. It is important to keep in mind that surgery may not be the only answer to improving body image and to keep the individual child’s perspective in mind when making decisions about surgery, particularly during adolescence and beyond.

© 2017 children’s craniofacial association

What Can Parents or Caregivers Do to Support a Healthy Body Image in Their Child?

When children are born with facial differences, parents often worry about how their child will think and feel about themselves as they grow up and how other people may treat them. These are valid concerns. The good news is that parents can help children develop a healthy body image from an early age.

- Prepare and rehearse an age-appropriate response to appearance-related questions. This can help children with craniofacial conditions feel more comfortable responding to questions and also increase their self-confidence and understanding of their facial difference.
- Help your child develop a positive body image by modelling one yourself (e.g., don't put yourself or others down because of appearance in front of your child).
- Validate your child's feelings and remind them that everybody has something about their appearance that they don't like.
- Encourage children to focus on what their body can *do* as opposed to how it *looks*, and to think about what they like about their appearance.
- Compliment your child's abilities, talents, and other characteristics, as well as their appearance.
- Teach your child to think critically about media images of appearance ideals. Are the images real? Have they been air-brushed or photo-shopped to look more perfect? What are advertisements really selling?
- Discuss qualities that make people attractive *beyond* physical appearance (e.g., humor, confidence, kindness).
- Be mindful of the language you use to talk about differences. Avoid using terms like "deformity" or "anomaly" when talking about your child's craniofacial condition or appearance differences. "Facial differences" or the name of the craniofacial condition are more appropriate terms to use.
- When talking about differences, encourage and model using neutral descriptors ("small ear" or "wide set eyes," "pink cleft scar") rather than making criticisms or judgments about features ("ugly").
- Encourage and model confident body language—making eye contact when talking with people, good posture (e.g., standing up straight), and smiling. Body

language can go a long way towards increasing confidence and encouraging positive responses from other people. The more your child practices confidence, the more confident he or she will begin to feel.

- Help your child become aware of his/her own inner critic about appearance, and develop ways to talk back to it—"Okay, so I'm not a super model, but I have a lot of features that I like about my appearance." If you catch your child saying something negative about his/her appearance, ask "Would you say this to a friend? To your mother or sister? Then why is it OK to say it to yourself?"

When to Seek Additional Support

Psychologists or other mental health professionals with training in cognitive-behavioral therapy can help children or adolescents struggling with body image concerns. Cognitive-behavioral therapy is a type of treatment supported by research that can help your child learn skills to change thoughts and behaviors that may be contributing to appearance-related distress and related social difficulties. Consider consulting a psychologist or other mental health professional if your child experiences any of the following:

- Your child makes frequent, negative statements about his/her appearance or is spending a lot of time thinking or worrying about his/her appearance.
- Your child becomes upset or seems depressed (sad, withdrawn) because of worries about his/her appearance.
- Your child avoids social activities, family events, or school because of his/her appearance concerns.
- You and your child disagree about the need for additional reconstructive surgery.

Resources

- Changing Faces: changingfaces.org.uk/
- Dove Self-Esteem Project: selfesteem.dove.us
- Book: *Your Body is Awesome: Body Respect for Children* by Sigrun Danielsdottir

Inspirational Figures

- Lizzie Velasquez: lizzievelasquezofficial.com/
- Carly Findlay: carlyfindlay.com.au/

testimonial



Words could never explain the blessing that CCA has been to our family. Our 26-week ultrasound revealed that our son, **John Reece Thomas**, would be born with a bilateral cleft lip and palate. Although we were full of joy awaiting the arrival of our third child, we were anxious about the treatment he would need, where we would have the procedures performed, and how we would be able to afford the best care possible.

After hours of research and prayer, we knew that **Children's Hospital of Boston** was where we would be going, and it's just over 1,000 miles from our home in Northeast Georgia. The cleft team in Boston referred us to CCA, and the assistance

they have provided has been nothing short of a miracle. The financial assistance provided for airfare, lodging, and meals, and has made our journey much less stressful than it could have been. We have been able to focus more on the medical procedures and care for our child as a result of the help from this great organization.

Our hope and prayer is that one day we will be able to give back to CCA to help give other families the option of receiving the best treatment possible, regardless of location.

Thank you from the bottom of our hearts to such a fine organization and group of people to deal with.

– **Lyndsey Thomas**

calendar of events

date event contact

2018

April 10 7 PM	Special Needs Trusts Informational Meeting John and Judy Gay Library 6861 W. Eldorado Pkwy McKinney, TX 75070	juliannawnicholl@gmail.com
April 18-19	7th Annual Morgan Meck Invitational <i>benefitting Children's Craniofacial Association</i> Coto de Caza Golf and Racquet Club Coto de Caza, CA	
May 3-4	12th Annual Elizabeth Toon Charities Concert & Shootout <i>CCA is a grant recipient this year of this event.</i> Gilley's & Dallas Gun Club Dallas, TX	carolyn@elizabethtoon.org
Jun 28-Jul 1	28th Annual Family Retreat Little America Hotel Salt Lake City, UT	ARees@ccakids.com 214.570.9099 800.535.3643
September	14th Annual Craniofacial Acceptance Month Nationwide	ARees@ccakids.com 214.570.9099 800.535.3643
Sep 22	Alexa's Craniofacial Awareness Dinner & Comedy Show <i>benefitting CCA</i> Antigua Event Center Riverbank, CA	alexasaceforcca@gmail.com
Dec 4 5-9 PM	Gingertown Build NorthPark Center 8687 N. Central Expressway Dallas, TX 75225	

registration
is open for
the 2018
cca's annual
family retreat

June 28-July 1
in Salt Lake City, Utah

Please join us for an educational symposium, talent show, dinner/dance and much more! For more information, please contact Annie Reeves,

ARees@ccakids.com

We hope to see you there! Register by May 1, 2018 to get the early bird price of \$100. Registration will increase to \$125 starting May 2nd.



kiai! for kindness



Josie Marcum, Brooklyn Wojtyniak, Master Alex Covert—who kicked 183 kicks in one minute!

Shane Merem of Storm Taekwondo in Commerce Township, Michigan held a Kick-a-Thon at his studio with students of all ages and talents. They raised over **\$5,000** for Children’s Craniofacial Association through their efforts, which will help send families to retreat and shipments of *Wonder* books to schools.

The event was streamed live on Facebook. Merem asked the Facebook audience for contributions. Then he introduced the kids and adults that would be showcasing their karate kicking skills. Finally, each student had their moment in the limelight as they raised funds with each kick. **Kiai!** Some students even completed some of their

kicking at home to be sure they made all the action happen that someone so generously donated towards!

Merem is a passionate individual. He is very motivated to give the students not only the physical tools for success, but the mental motivation as well. Merem heard about CCA from one of his students, **Brooklyn Wojtyniak**. The goal was to send her and her family to retreat on the Retreat Room Reward, but Storm Taekwondo did so much more than that in raising awareness and promoting kindness!

Generous donors offered up prizes for those donors that gave the most money. One group of people earned the ability to attend a Red Wings hockey game thanks to another Storm karate dad, **Ben Marcum’s**, boss at **INTRA Corporation** in Westland, Michigan. Looks like these big earners had a great



Top fundraisers at the Storm Taekwondo Kick-A-Thon won tickets to the Detroit Red Wings hockey game.



All the Kick-a-Thon Participants

time at the game! (below)

Marcum praises Merem’s efforts by saying, “Shane is an amazing Martial Arts Instructor and his school is growing and doing an amazing job developing young kids into champions of life.”

This kick-a-thon is a great model for future fundraisers. If you have a studio, Storm Taekwondo is willing to walk you through how to run such a fundraiser.

A sports or activity-related fundraiser like this allows many people to get involved, give reasonable amounts of money that make sense for them, and can be completed



Brent and Brooklyn Wojtyniak with Hank, Ben, and Josie Marcum (L-R)

in a number of different venues. Fundraisers can choose any repetitive activity. You could do a dance-a-thon, basketball shot-a-thon, or even a yoga-thon! Each person sponsors a specific number of shots, or length of time that the participant spends completing the activity. People can donate one unit, or more, depending on the metrics you develop.

Excellent job and many, many thanks to Shane Merem, Storm Taekwondo, all the talented and disciplined kick-a-thon participants, the **Wojtyniak family**, and the **Marcum family** for their thoughtfulness and generosity.

dominika, from page 1

Disability was not new to us—Karen was born with a disability called sacral agenesis that affected the growth of her spine and has used a manual wheelchair for most of her life. I was born with hemophilia (a bleeding disorder) and acquired HIV through blood products while still in elementary school. We had both logged many hours in hospitals and with doctors growing up in the San



Francisco Bay Area. We met through the work that had become our careers in the disability rights movement.

Adopting a child with a disability wasn't our goal, but we knew enough from our own experiences to say that we wouldn't rule out a child based on medical conditions. Nonetheless, we'd never heard anything about Apert syndrome, and knew we had a lot to learn in a short amount of time. Dominika's first cranial release surgery was scheduled for just two

weeks after we brought her home! The Apert.org website and email group was extremely helpful, in those pre-Facebook years. The first person from the community that we spoke to was **Cat Sears**, and she helped us so much!

We fell in love with Dominika when we first met her at The Cradle and she showed us the aspects of her personality that have remained a constant throughout the first 12 years of her life: bubbly, enthusiastic, loving, curious, attentive-to-detail, and resilient. On her first night home, we dutifully placed Dominika on her back in her crib. Dominika's shoulder joints were fused, so she couldn't raise her arms very high and would have difficulty rolling herself over, we had learned. In the middle of that first night, we freaked out when Dominika achieved an unexpected milestone and turned onto her stomach! Two panicked parents called the nursery at The Cradle, Dominika's first home, and they reassured us that we should just turn her back over and she would be fine, since she had demonstrated her newly developed arm strength.

Dominika's first three years were a whirlwind of surgeries, recovery, medical appointments, early-intervention therapies

(PT, OT, speech, developmental), discovery, fun, exploration and, of course, trial and error. The surgeries were pretty standard stuff for kids with Apert syndrome: second cranial vault surgery, multiple finger syndactyly release surgeries, ear tube insertion, open palate closure, shunt placement for hydrocephalus, etc.

Even though we had grown up with disabilities—and experienced surgeries of our own—it was different, and more difficult, experiencing it as parents. One hallmark that we both noticed, however, is that Dominika regularly achieved a new developmental milestone as she recovered from each surgery or procedure. We came to expect it, and looked forward to it.

Another theme that developed was that we realized Dominika was going to figure out how to do some things in her own way and in her own time, and that we weren't always going to be able to predict how that would happen.

There were times when we had to creatively intervene, however. One



example is that Dominika had a hard time sitting up from lying down, since she couldn't raise her arms very far. Typically, she rolled over to something that she could kind of climb on to get her torso higher, then her abdominal muscles would take over. I had some adjustable exercise steps in our home that I had used when recovering from knee replacement surgery and Dominika began using them to lift herself up. We started lowering them so that she was raising herself from a lower and lower level.

Eventually, we had a hunch that she didn't really need the steps at all anymore. I placed a hand towel on the floor and told Dominika to "use" that to sit herself up. She rolled over to the hand towel and just sat up, using all stomach muscles. It didn't take her long to realize that she didn't "need" the towel on the floor anymore!

During Dominika's first year, we started using sign language when we talked to her, to give her an easier tool to communicate than verbal speech. Even though Karen and I both knew conversational American Sign Language, it wasn't very complicated, just adding a sign when we used common words like "milk," "drink," "eat," "more," etc.

It turned out to be just about the best decision we made as parents. Dominika seemed to understand everything we said, but she was unable to say most words clearly. It didn't stop her from talking—she regularly told stories, commented on events and shared whatever was on her mind, we just couldn't understand some of what she said. However, with sign language, Dominika could add enough to her expressive communication that it made it easier for her to be understood.

Once she realized that she could sign and we would know what she meant, Dominika began inventing her own signs for things that were important to her, such as a custom sign for her favorite store, Target! By the time Dominika began preschool, after she turned 3, she could say only a dozen or so words clearly but had established a sign language vocabulary of 70 to 80 signs.

For preschool, Dominika enrolled in a blended class, which had six kids with disabilities, 14 without, which was a great place for her to learn, grow, and have fun. Besides the benefit of having both regular and special education teachers in the classroom, we were very glad that she had disabled peers with her in an inclusive setting, and not just typically developing kids.

We began the process to get Dominika an augmentative communication device. However, during the months after she started school, the rest of Dominika's teeth came in and her speech improved rapidly. By the time the communication device arrived, when she was three-and-a-half, it was



clear that Dominika no longer needed it, so we sent it back!

As Dominika grew up, we did our best to help her develop a strong identity and sense of herself as a disabled person that we knew she would need once she began to understand a world that she would be a part of, but in which she would always stand out.

A benefit of being part of the disability community, both in Chicago and elsewhere, is that Dominika had many opportunities to be around people who also stood out because they looked or acted differently. One of the things we love about Chicago is that it has had an annual **Disability Pride Parade** every July since 2004, which draws people with all types of disabilities (plus families, friends, and allies) from all around Chicago. Dominika has been fortunate to have an annual public reminder that having disabilities and being different is OK.

It was harder when Dominika was around five years old and began

to notice that some people—and especially young kids—treated her differently, stared, or made unwelcome or rude comments. If one of us were nearby, we would sometimes step in to introduce Dominika or help her simply answer the most common question: "Why does her face look like that?"

The extra attention didn't cause Dominika to shy away from the opportunity to perform on stage, however. From an early age, she loved dance classes and the recitals that came with them. When Dominika began elementary school, she was excited to learn that every class had at least two performances/assemblies that she would get to perform in every year. Fourth through eighth graders can also audition for the school musical once a year, and Dominika now looks forward to this every spring.

We knew it was very important for all of us

see **dominika**, page 20

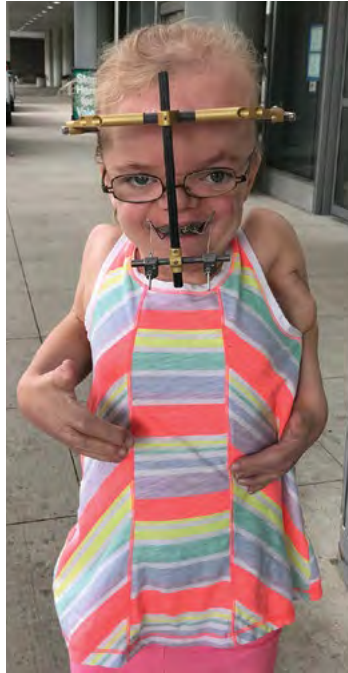


dominika, from page 19 to meet or connect with other people with Apert syndrome and other craniofacial conditions, and have felt so lucky that it has gotten easier to do over the last decade. We've tried to meet as many people as we can in the Chicago region, and connected with many more by email, and later, Facebook. In 2008, when Dominika was two-and-a-half, we took her on a Disney cruise with a large group of folks from the craniofacial community and then did it again in 2013, when she was old enough to fully appreciate both the chance to meet other kids and adults with similar disabilities but also some of the Disney characters, especially the princesses!

For many years now, we have also looked forward to meeting (or reuniting with) friends from around the Great Lakes region at the CCA's Midwest Holiday Party, organized by **Jill Patterson** and her family. In 2017, we finally attended the annual CCA family retreat! We loved seeing old friends and meeting many new ones, and can't wait to do it again in Salt Lake City.

As Dominika developed, we had a number of expected medical interventions, like her head and hand surgeries, many sleep studies for sleep apnea, and her diagnosis

of mild conductive hearing loss in 2010, but also some unexpected ones. In 2012, we discovered that Dominika had a tethered spinal cord and would need surgery to release it. The



surgery was smooth but the recovery required her to remain lying down at home for ten days (with only 5 short breaks allowed per day!)

In 2014, Dominika had surgery to realign her left arm, which had been shifting back further and further every year. In 2015, we began trying to slow down and correct Dominika's worsening scoliosis by using a back brace. By the end of 2016, it was clear that she couldn't avoid surgery and Dominika had spinal fusion surgery in January 2017. It was a pretty intense surgery, but it went well

and had the amazing effect of helping Dominika to grow three inches in one day! Dominika has always been strong and resilient but she surprised even the hospital physical therapist after that one, insisting on standing up the day after surgery and "graduating" from PT faster than any patient before her!

In August 2017, Dominika had the big one: mid-face surgery! We found a great team at the **Rush Craniofacial Center in Chicago**, **Dr. Christina Tragos**, plastic surgeon, and **Dr. Alvaro Figueroa**, orthodontist. For the most part, it all went smoothly, and Dominika figured out how to do most things while wearing the RED device. With a little incentive from a temporary

boost in her allowance, she even went back to school wearing her halo for the last few weeks!

Since the surgery, the biggest change has been how much more easily Dominika can breathe. She is now able to move air through her nose for the first time in her life!

As a child of the smartphone generation, Dominika never got into television but has been a fan of all kinds of videos on YouTube instead, especially daily family video bloggers, cooking and baking demonstrations, and DIY craft videos. Dominika also loves pop music and has been to concerts by Meghan Trainor, Katy Perry and Kelly Clarkson.

In school, Dominika has an IEP and gets a little extra





support with math and reading which helps her to succeed in her general education classroom. Through school, she's been able to make some good friends and the school has been very proactive in efforts to prevent bullying.

Ever since Karen got her handcycle, a few years



back, going on family bike rides has been one of our favorite things to do during the warmer months. Karen and Dominika have also participated in one of the many adaptive sports programs in the Chicago region, through **Dare2Tri Paratriathlon Club**.

In 2017, one of Dominika's dreams came true when she received a gift of her first adaptive cycle, thanks to **Creative Mobility**, in St. Charles, Illinois. During her first weekend with it, she rode over 20 miles! Another of Dominika's wishes became reality in 2017 when we adopted our dog, **Chaka**, who (we think) is

a "chuggle": Chihuahua, pug, and beagle mix.

One thing that Dominika has had to get used to is occasional interactions with news reporters, thanks to having two disability rights advocates as parents. She has become a very poised and thoughtful interview subject, sharing her feelings about a range of topics, including dolls with disabilities, the app "Music.ly," the movie *Wonder* and serving as co-Grand Marshal of Chicago's **Disability Pride Parade!**

Growing up in Chicago means that Dominika has developed expertise on riding public buses and trains, which has also helped her to become more comfortable figuring out how to manage the extra attention that she attracts. This has also given us an opportunity to help Dominika be more independent, which she loves. When we ride the train home from school, she often asks me to ride in a different car, so she can do her own thing. Now that Dominika is 12 years old and in sixth grade, we're exploring more ways that she can be independent, which is important to all of us.



As Dominika moves closer to adulthood, we're confident that the vision of CCA will become the reality for more and more people, and that Dominika and other young people with disabilities will gain attention for who they are, not how they look.



looking back, from pg 11

as always, I passed by his office. While I was waiting, a lady walked in with a plaster over her nose, which brought back many memories of what I looked like when I was in between surgeries, as I too had to make do with one of those.

The lady didn't appear to be in the best of moods as the surgeon was running late (a habit my family and I can remember all too well). When he did finally appear, we exchanged pleasantries and he introduced me to this lady saying, "Christian had his nose reconstructed just like you're doing now." It was a brief introduction and, after having a good chat with my surgeon and reminiscing about old times, I headed for the exit and said a brief good-bye to the lady, who was still in the waiting room.

On the day I checked out of the hotel, I had a half hour to spare, so headed to the bar for a quick bite before heading to the airport. I walked in and there was the lady again. We both commented on what the chances were that we'd both been staying in the same hotel. So I joined her at the bar and we got talking. Alison was her name and she explained how she ended up having to have her nose reconstructed. Her circumstances were different to mine in many ways, but

the biggest contrast was that this was happening to her later in life.

Alison was very open in describing how her procedures had been tough so far—she's around halfway through the reconstruction process. Some days were harder than others, she said. It was a familiar statement to me in that I endured those frustrating times too, especially going through it during the adolescent years.

That said, I emphasised to her the importance of remaining positive and leaning on your friends and family when you need them. I told her how, when looking back on those times, it was worth all the pain, and she is aided by the fact that, like me, she is in the hands of the best, so the end result will be worth it.

Before we said our goodbyes, Alison said something that touched me. She said I had inspired her, which was very humbling to hear.

I hope our brief encounter made Alison feel better. While we only spoke for a while, I had no doubt that she possesses the strength and determination needed. But we all need a helping hand sometimes, and I like to think our brief conversation was what she needed that day.

I'm looking back out of the plane window again

at the seamless sunrise. That image is ingrained in my memory from all those years ago. I used to say to myself that I was chasing the sun and that I'd get to it when I had my last surgery. That day came some years ago. And it'll come to Alison too. Just a little more patience, and that strength and determination I saw, will see her through.

Born and raised in London, UK, of Greek origin Christian John Hadjipateras has his Higher National Diploma in Business from Southampton

Solent University, UK. He previously worked in maritime shipping industry, has lived in Los Angeles, CA, and worked in TV/Film production industry and attended the New York Film Academy in Burbank, CA. He is now based in Athens, Greece.

Editor's Note: This piece was published in the Huffington Post originally and we are reposting it with his permission.

SPECIAL NEEDS PLANNING SEMINAR

Parents or guardians of special needs individuals, please come join us for a free informative evening on planning for our children's future.

TUESDAY, APRIL 10, 2018 | 7 PM

**JOHN AND JUDY GAY LIBRARY
6861 W. ELDERADO PARKWAY
MCKINNEY, TX 75070**

Attorney Richard (Rick) D. O'Connor will be sharing information on special needs planning. He will be covering topics such as how to preserve eligibility for means-tested benefits (such as SSI, Medicaid, Medicaid Waivers), Wills for parents of special needs children, special needs trusts and alternative special needs trusts, choosing a trustee for a special needs trust, as well as general estate planning principles. Following the presentation, Mr. O'Connor will be answering any additional questions.

For any questions regarding the presentation, location, or time, please email Julianna Nicholl at javnicholl3@gmail.com

"The City of McKinney and the McKinney Public Library System are not in any manner connected with this meeting, and neither the City of McKinney nor the Library endorses any position expressed by the groups sponsoring this event."

exec director, from pg 1
up to enjoy this forgotten favorite.

The lyrics rang out,
*“But I still wake up, I still see your ghost
Oh Lord, I’m still not sure what I stand for.
What do I stand for?
What do I stand for?
Most nights, I don’t know...”*

It struck me and I got to thinking: I claim that I know what I stand for—kindness—but do I actually *stand* for it? What does it mean to STAND for something? I started thinking about what kindness looks like in action and then one of those ghosts (moments) came to mind.

I was at the airport, seemingly where all horror stories begin. A particularly angry customer was yelling at two men behind an airline counter for “not doing their jobs,” as his luggage had been delayed. Clearly his situation was beyond the control of the two agents at the desk, who had nothing to do with tagging the luggage, putting it on a conveyor, transporting it to the plane, loading it on the plane, and then getting it off said plane and back onto the carousel at his destination. Yet these two men were receiving the brunt of his frustration. I was the only witness around.

In that moment, I too was tired. I was frustrated. I was having my own luggage problem and I was coming down with a cold to boot. The angry man ratcheted up his voice, and I looked at the guys and said, “I’ll come back.” He proceeded to empty his vitriol on them and then storm out the door, cussing. I watched in dismay, several waiting areas over.

When the storm had passed, I walked back up to the counter and offered some pithy response like, “Some people are just really awful, huh?” The guys barely responded, looking positively miserable.

Cut back to my day in the car... That experience came to mind as Fun. pummeled me with the question, “What do you stand for?”

After another moment of regret, I thought of our work at CCA. That night, I was a bystander. Not an upstander, like I spend so much of my time trying to advocate for others to be.

I reflected: I was not in any danger that night and I easily could have looked at the angry customer and said, “Sir, please stop insulting these guys. They had nothing to do with it.” But I didn’t.

Yes, I tried to offer consolation to the clerks when the damage was done, but it was weak and inadequate.

And then, I thought of our CCA Kids. When a bully, or just a popular kid, starts teasing or pestering, what do we want the other students to do? Wait until the bully’s damage is done and only then offer a kind word? Or intervene and stop hate and bullying in its tracks.

Obviously, it’s the latter.

To safely and proactively intervene, though, we must empower and teach students. We must give them tools not only on what to say, but how to access their confidence from within to do better. We have to instill and compel a willingness to do more than just stand by. Certainly, it is what we aim for with our #ChooseKind initiative. We offer lessons and give students the confidence and actual words to say to a bully, “Hey, that’s not right. You need to stop.” Then, the instructions to involve a teacher or another adult. However, these skills need to be rehearsed and role-played, so when the tense moment occurs, kids jump into their script and feel ready to act. This can be done in schools and at home, and should be certainly modeled by adults, like me.

It’s truly simple, but it is so profound. We must stand up, not just in schools, but in our everyday lives. At work. At

the airport. And, on the Internet.

Yes, there may be some risk involved, but most often, the only risk is overcoming our own fear, fatigue and indifference. That’s when I hope you’ll recall that powerful message, “What do I stand for?” And your answer will be a strong, confident, “I know, and I must act.”

Kindness, advocacy, and action are a practice. You’ll miss opportunities, just like I did, but let them be a reminder that you can change the world, but you’ve got to put some skin in the game. Had I intervened, perhaps the bullying man would have considered how egregious his actions were and felt remorse. Perhaps the two guys at the counter would have felt inspired to pay it forward, or perhaps they just would have gone home to their families that night with a little less baggage (pun intended) and lighter hearts, with more energy to love on their own kids. I can’t be sure, but I am sure that when given the opportunity again, I will choose kindness in action and be the upstander that is needed in the given situation.

So, go listen to the song and resolve to put kindness into action. I know I have.

Erica Mossholder
Executive Director

Honorary Chairperson:

Cher

Board of Directors:

George Dale, *Chair*, Corning, NY
Kelly E. Cunha, Tampa, FL
Dede Dankelson, Libertyville, IL
Margaret Lavender, Norman, OK
Bill Mecklenburg, Mission Viejo, CA
Russel Newman, JD, Seattle, WA
Haley Streff, MS, CGC, Houston, TX
Steven Weiss, Dallas, TX
Rose Wiese, Mars, PA

CCA Network Editor:

Kelly Liszt, copybykelly.com

**CCA Network Design
and Production:**

Robin Williamson,
Williamson Creative Services, Inc.

Executive Director:

Erica Mossholder, MBA

Program Director:

Annie Reeves

Development Director:

Jill Patterson

**Marketing & Communication
Coordinator:**

Kara Jackman

voice 214.570.9099

fax 214.570.8811

toll-free 800.535.3643

url CCAkids.org

The views and opinions expressed in this newsletter are not necessarily those of CCA.

If you no longer wish to receive this newsletter, please send an email to AReeses@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.

3 cheers

for volunteers!



Country Superstar **Kacey Musgraves** with CCA Volunteer

Christian Scalise, thank you for raising awareness with your awesome spokesperson! As Kacey likes to sing, in her song, "Biscuits" ...

"Taking down your neighbor won't take you any higher

I burned my own darn finger poking someone else's fire

I've never gotten taller making someone else feel small

If you ain't got nothing nice to say, don't say nothing at all!"