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## a golden heart

By Jessica McMahan

**h**e was made for this. We say this so often about our Griffin Riley. Through all the circumstances, the twists and turns, each new hardship to overcome, he takes it with such ease and grace. It leads you to believe he was literally made for this, this life so different and so very beautiful.

The day Griffin was born, March 5, 2009, at 41 weeks to be exact, we only knew about his precious broken heart. He was diagnosed with Tetralogy of Fallot during a routine ultrasound to find out his gender. We were thankfully in a women's hospital connected to the children's hospital for his birth, and there was a plan in place for a high-risk delivery. When the doctor lifted him up for me to see my sweet boy for the first time, all I noticed was how tiny he was! My O.B. had predicted he'd weigh well over 8



## message from the chair

**W**hat an incredible year this has been for the craniofacial community! With the buildup to the release of the movie **Wonder**, there is great focus on the "Choose Kind" message. Children's Craniofacial Association recognized the powerful message that *Wonder* delivers when the book was released. We now have programs promoting the use of the book in schools and getting the choose kind message out through WonderKid visits to schools. Since 2013, we have distributed more than 18,000 books to schools, supplied teachers with more than 5,000 *Wonder*



see **mcmahans**, page 18

see **chair**, page 22

# ccakid

## meet isabelle stanish



Seven-year-old Isabelle Stanish has a really cool birthday—New Year’s Day. She shares this special birthday/holiday with her younger (by 3 minutes)

fraternal twin brother, Jayden. This birthday, like all the others, she and her brother will stay up to ring in the new year and another birthday.



Isabelle is in the second grade, which she finds pretty easy. She always gets seven out of seven on her tests, “hard tests,” she calls them. She’s also an avid reader. *My Little Pony* books are her favorites as well as *Frozen* books. She has seen the movie *Frozen*, but she much prefers

*Descendants 2* and the TV show, *Descendants Wicked World*. She even dressed up as Evie from the first *Descendants* movie for Halloween. To her excitement, she got a lot of candy this year, including some yummy Milk Duds.

After school, Isabelle mostly likes to play. She has 4 brothers, including Jayden, and a sister, so there’s always someone to play with! She also goes horseback riding, something she’s been doing for the past year. Her horse is Sweet Annie, and Isabelle loves her.

Christmas came early for Isabelle this year—she got a puppy! She helps take care of and plays with Lola, an adorable English bulldog

who alternates sleeping with bursts of energy.

Isabelle and her family went to the CCA Retreat this year in Virginia. It was a new experience being in a room with so many going through the same thing, but all-in-all she liked it and met a good friend.

When it comes to other kids in similar situations who are facing a surgery or procedure, Isabelle had this great advice: “It’s ok to feel scared, but also know that no one is trying to hurt you, and that everyone is there to help you.”

*Thank you, Isabelle, for those warm and comforting words!*



# ccateen

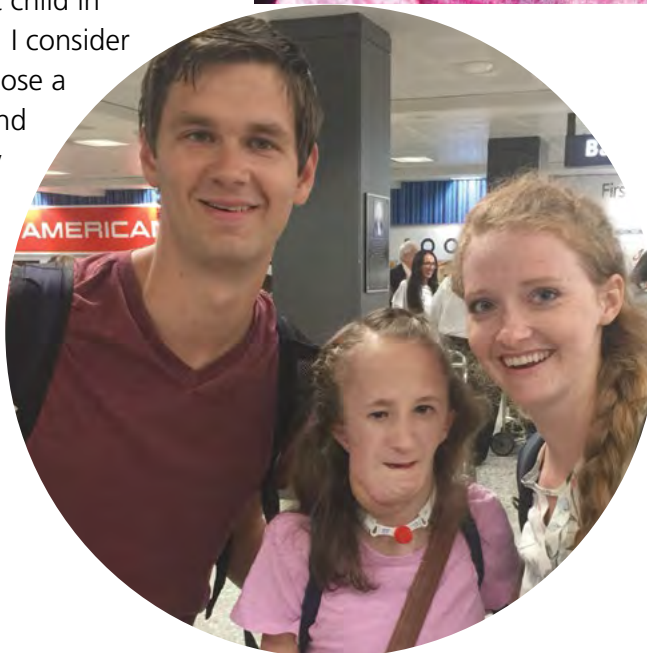
## meet haley rawlings

**m**y name is **Haley Rawlings**, and I am 17 years old. I live in Chambersburg, PA, with my mom and dad. I'm currently a senior at Greencastle-Antrim High School and look forward to graduation. I recently got my driver's license and enjoy driving myself and my friend to school every day. I plan to attend college for nursing with a goal of working with children in some way. I know that God has a plan for me, and I am anxious to see how He will use me. I attended my first CCA retreat this year and enjoyed meeting other families who are going through similar challenges.

I was born with Nager syndrome, and have undergone surgeries at several different hospitals: Hershey Medical Center, Children's Hospital of Pittsburgh, UCLA Medical Center and most recently at Children's Hospital of Philadelphia (CHOP). In July 2016, I started my last round of surgeries to

extract my upper and lower jaws. Last August I had both jaw joints replaced and I'm currently doing therapy to open and close my jaw. I just got my trach out a few weeks ago and will start orthodontic work soon.

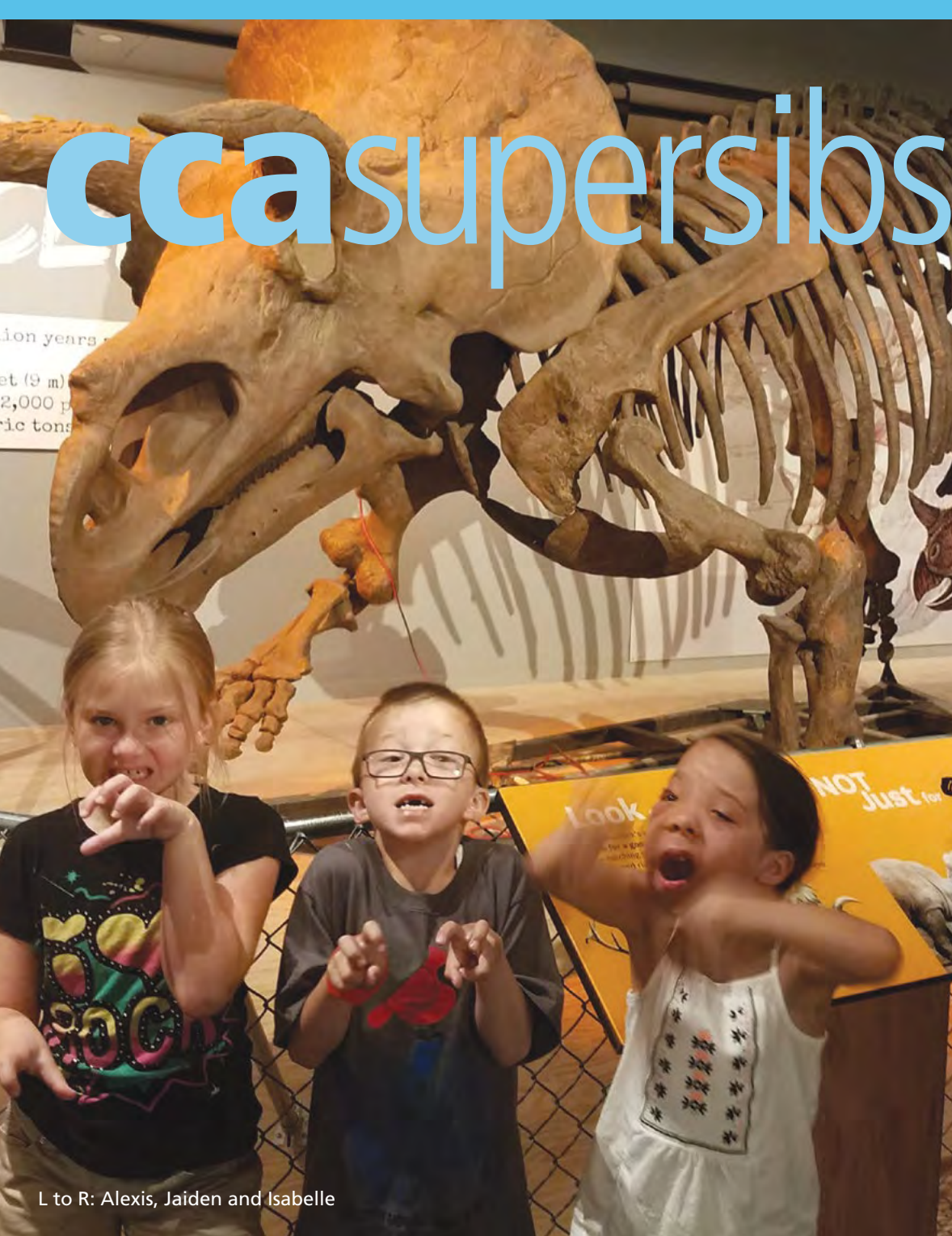
I have one brother, Hunter, who is six years older than me. He has always been kind and encouraging to me. He has also been a protector of me around kids who have not been kind. He married MaggieRose in May 2016, and they are expecting their first child in February. I consider MaggieRose a friend, and I'm really excited



to be an aunt. I love babies and enjoy working in our church nursery every week. I also enjoy reading, painting, cross stitch and watching movies with my dad.

*Haley and her family worked with Leitersburg Cinemas in Hagerstown, MD, and hosted a **Wonder** movie fundraiser that raised several hundred dollars for CCA! Thank you, Haley!*





L to R: Alexis, Jaïden and Isabelle

# ccasupersibs

## meet jaïden taylor

**m**y name is **Jaïden Taylor**. I am 7 years old and in the 2nd grade. I am three minutes younger than my twin sister, Isabelle. We both have NF1. I get nervous when we have to go to **Children's Hospital of Philadelphia (CHOP)** for MRI's. We both have tumors but you can't see mine. You can see Isabelle's and I like the way she looks and love her very much!

My favorite toys are dinosaurs and skeletons. I love the movie Jurassic World and my favorite T.V. show is Teen Titans Go! I also love to go camping with my family. We swim at the pool, play at the stream, fish, make arts and crafts and ride around on the golf cart. We always have a campfire and make s'mores.

My best vacation was when we went to Virginia this summer and attended our first CCA retreat. We played, met lots of kids, went to the waterpark, to Washington D.C. and stopped at a beach on the way home. It was so much fun spending time with my family. I love them.

## meet alexis fuller

**m**y name is **Alexis Fuller**. I am 8 years old and in the 3rd grade. My favorite movie is Aquamarine and my favorite T.V. show is *Liv and Maddie*. My favorite

place to go is Twin Grove Campground.

Isabelle, Jaïden and I play, go swimming and have fun. I also like football and I'm a cheerleader. Cheer is my favorite hobby! One

other favorite of mine is my Daddy's cheeseburgers!

We went to Virginia this summer and attended our first CCA Retreat. I had so much fun and can't wait to go back. We all loved sleeping in a hotel and dancing in the town square.





## spare a few for cca – the anderson family

Our family has been very busy since the Reston retreat this summer! After getting home from the retreat, we took a second trip to visit family in Minnesota, and returned mid-July, to have **Nathan's** second stage of his BAHA surgery. Both of his **Oticon** processors were activated in late August, so he was able to start second grade with newly-integrated processors. This was very exciting for him, as he no longer needs to wear the headband. He is so proud of his new processors, and loves to change out the stickers on the sides of them to match his mood or the occasion.

**Owen** attended Nathan's surgery for the first time this year, and got to experience what it is like to be at the hospital. He was an amazing support to Nathan both pre-op and afterwards, and like always,

proved himself to be a true super-sibling, willing to do whatever is needed to keep Nathan comfortable during the day.

At the same time as all of the surgery, we decided this year that we would like to hold a second fundraiser for CCA. We set a goal of raising \$5,000 on September 30th to end **Craniofacial Acceptance Month** with a bang. Owen and Nathan decided that bowling would be a fun way to raise some funds, while providing something family-friendly, where the kids could be involved. We spent the entire summer going to stores and local businesses, emailing companies, and reaching out to contacts to secure some amazing baskets to give out to raffle winners for the event. **Team Lentil** also came into town to speak to two different schools and encourage the

**Choose Kind** message to hundreds of children at these schools and at the event itself. We are so proud to announce that between the bowling fundraiser and the online fundraiser, we were able to raise **\$9,000** to help CCA promote their message of kindness and self-advocacy for our children and adults in this association.

As parents, **Dave** and I are so proud of both of our boys for so many different reasons. We hope that through these efforts, we are raising them to speak up for themselves and others, feel confident in who they are, and feel a need to help others who may need it. We are so thankful to CCA for the bonds and the connections we have formed with other families and kids, and we want to share that message



and feelings to those who have not yet experienced it. Nathan and Owen spend their year talking about how excited they are to see their friends next year at the next retreat. We hope that through our fundraising, someone else who hasn't been able to, can feel that as well. Here's to an awesome end to 2017, and we can't wait to see everyone in Salt Lake City!



# 2017 links of love golf tournament

The 10th Annual Links of Love Golf Tournament was a swinging success again this year! Thank you to all our loyal golfers and new friends. We held the event at **Firewheel Golf Park** in Garland, TX, and the event grossed \$12,000 for CCA Kids!

Despite a little drizzle early on, the players showed up and were greeted with Starbucks coffee and pumpkin bread from **Starbucks on Inwood and Willow** and they grabbed their box lunches while being fitted for golf gloves sponsored by **Credit Union of Texas**. The players then loaded into their carts, sponsored by **FairLease** and rode off for a fun round, with a surprise along the way. That surprise was a special Game of Chance over a water hazard, and **Andy** and **Melanie Yarbrough**, CCA Parents of

Executive Director, **Erica Mossholder**, tried to get players to test their luck to win CCA logo golf balls. On the course, players enjoyed **Real Ale** brews, thanks to **Ben E. Keith Beverages**.

Back at the clubhouse, volunteers **Khadija Moten** and **Margaret Lavender**, CCA Board Member, helped reset after the morning's registration for the post-tournament activities. **Jason VanSickel**, husband of **J. Jaye VanSickel**, CCA staffer, donated his time and talent to photograph the event, along with **Khadija Moten** and **Annie Reeves**.

Just in time, the players gathered back at the clubhouse for a dinner of delicious **Spring Creek Barbeque** and a ton of raffle prizes! The winners of the tournament were announced, with First Place going to **Team Lavender** again this year! A special thanks to the **Harrah Family** who helped us load up after the fun was all over. We are so grateful.

We hope even more players will join us next September!







## penny wars

When we watched the **Dankleson's** on Morning WGN, I contacted them about the possibility of speaking at our school. In the past, our school has had a theme for the school year and this year's was #EmbraceDiversity; the last school year was #ChooseKind. To start off our summer reading program, we purchased every student, 3rd through 8th a copy of *Wonder* to read. Since then we have adopted the #ChooseKind in our everyday lives. The Dankleson's were awesome enough to have a school-wide assembly for our children—it was wonderful! All they asked in return was a donation to Children's Craniofacial Association.

We decided to have "Penny Wars," involving all our students. "Penny Wars" is where we give each class a container, pennies count as positive points, all silver and paper count negatively. During a 2-week period, students jammed pennies in their classrooms, and then tried to sabotage the other classrooms with silver and dollar bills. In that time, we are proud to say that we were able to raise **\$1,158!** At that point, Dede suggested we do a Starfish Scholarship, which lead us to the decision to sponsor a Starfish to Retreat!

**Carol Romanenko**  
Burr Elementary PTO President





# craniofacial acceptance month

This year marked the 13th year CCA observed September as **Craniofacial Acceptance Month** across the nation. CCA families, friends, volunteers and related support groups widened the circle of acceptance for individuals with facial differences.

Several of our CCA families were able to get their local newspapers to feature them in the paper and some were even featured on their local news stations! We mailed out over 100 Craniofacial Acceptance Month press packets to 22 states! And, for the tenth year, CCA held National Picnic Day in September as part of Craniofacial Acceptance Month. CCA families across the nation held picnics in **California, Delaware, Indiana, Michigan, New Jersey, Pennsylvania, Tennessee, Texas** and **Utah**. This year The Craniofacial Center and International Craniofacial Institute joined us for our Dallas picnic, and invited their patients.

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

- Watkins Family
- Vysocky Family
- Emery Family
- Bruner Family

- Dowd Family
- Merrill Family
- Bowers Family
- Kearns Family
- Sarsi Family
- Shrum Family
- Sutton Family

We would also like to thank **Sandy Lake Amusement Park** in Carrollton, TX, and their generous donor for donating \$1,000 worth of amusement park tickets to our families who attended the CCA picnic!



PENNSYLVANIA



PENNSYLVANIA



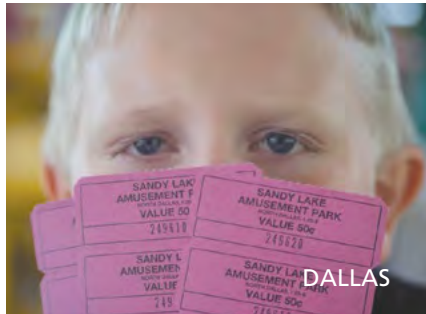
PENNSYLVANIA



TENNESSEE



INDIANA



DALLAS

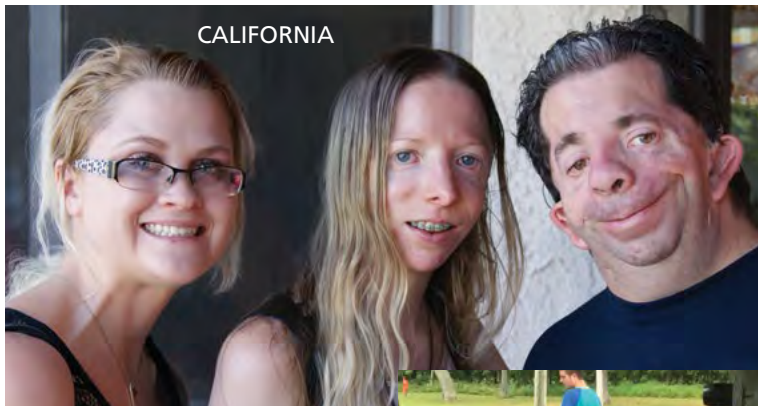




CALIFORNIA



CALIFORNIA



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# celebrating kindness with *wonder*

Since the book *Wonder* came out in 2012, CCA has been using it as a tool and a resource for our families to use to introduce the general public to a story about life with a craniofacial condition. Our **#ChooseKind** initiative has reached over 25,000 students since its inception. Our "I Am Auggie Pullman" video has over 1,000,000 views on Youtube. We've ordered 22,500 special edition *Wonder* books to date and have been distributing them across the country to classrooms

We've provided teachers with over 1,500 educator folders since July... and spent over \$10,000 in postage. We had dozens of local and national media stories ran on CCA families, including a primetime special on the **Newman Family** on **ABC 20/20**. You can see a roundup of the "real *Wonder* stories" on our website: [ccakids.org/real-wonder-stories](http://ccakids.org/real-wonder-stories). We partnered with **GapKids** as the beneficiary of their Kindness t-shirts designed by students and we received a \$100,000 donation from **Snapchat!**

But the most important number is ONE. We are one community, one family, with one goal: to create a world where people are valued for who they are, not how they look.

And more than ever that vision of ours seems possible, and the ones creating this future is the students who have participated in the #ChooseKind initiative – we hear weekly reports of teachers calling this "the *Wonder* generation."

Students are choosing to practice empathy towards one another. They seek to understand differences. They offer kindness, understanding, and empathy towards each other, not because it is an obligation or for a reward, but truly because kindness is a value they share; a virtue they believe will change the world.

This story that created a movement is a beautiful portrait of family and kindness, and when we heard it was being made into a movie, we devoted ourselves to working with the filmmakers to bring this story to life with authenticity, dignity, and warmth. On all accounts, we think the producers, cast, crew, and everyone involved succeeded! In fact, **Wonder** the movie has already been nominated for three Critics' Choice awards, including Best Young Actor, **Jacob Tremblay!** Thank you, **RJ Palacio** for writing this instant classic, this movement-inspiring, this incredible work of art that touched us all so deeply and profoundly.

Thank you to **Elle McKinnon** and **Nadji Jeter** for traveling to Dallas to visit children at **Medical City Children's Hospital** and then

attending our Dallas VIP **Wonder** Screening taking endless photos with our guests! The cast of this film is the most genuine and kind group of actors in the world, we are convinced. Thank you **Todd Lieberman** and **David Hoberman** and **Stephen Chbosky** for bringing this story to life. Thank you to **Julia Roberts** and **Owen Wilson** for eloquently playing the parent heroes we all look up to and aspire to be as champions for our kids. Thank you **Izabela Vidovic** for representing our SuperSibs, who are truly our first friends and fiercest advocates throughout life. Thank you **Millie Davis** and **Noah Jupe** for showing us that it's more than being friendly, it's being a friend.

Thank you author and advocates, **Missy** and **Mia Robertson** of **Duck Dynasty** on **A&E** for coming to Dallas to meet fans and take photos, lend your support, and contribute to the national conversation of acceptance. Thank you **LeeAnne Locken**, of the **Real Housewives of Dallas** on **Bravo!**, for also coming to our Dallas event to meet our guests, pose for photos, and lend your spokesperson in our local community. These



and students. We have processed over 4,000 t-shirt orders, to all 50 states, Canada, Germany, and Spain, lovingly packed and fulfilled by a team of 3 people. (Thank you for understanding and patience in this endeavor!)





celebrities are using their time and talent to bring awareness to our families, and we are so grateful for the opportunity to bring our stories to the national conversation!

Without a doubt, the buzz of this movie has had the single biggest impact on CCA that we've ever experienced. In conjunction with **Lionsgate**, we were honored to host 15 special screenings with CCA families and our medical professionals. Some of the screenings were sponsored and others were held as fundraisers, but all of them had a huge impact on the local community. We want to thank all of our generous

sponsors and incredible hosts! Your hard work is an investment in CCA Kids and we are determined to move forward with renewed passion and purpose to advance the status of craniofacial families nationally and internationally.

Throughout the holiday season, please keep taking your friends and family to see the movie and keep the conversation going! Remember, *Wonder* provides us the opportunity to share our stories, and most importantly, share kindness with everyone we meet.

#### **New Brunswick, NJ**

Thank you, **Suzanne Ashby** and **Olivia Rae**

**Vargas, KidzDent**, and all of your sponsors!

#### **Eatontown, NJ**

Thank you, **Emily, Gary**, and **Nancy Merrill**!

#### **Tridelpia, WV**

Thank you **Abby, Tom**, and **Melissa McGowan** and **Bordas and Bordas Law**!

#### **Pittsburgh, PA**

Thank you **Sumer Panza** and **Nick, Mike**, and **Rose Wiese**, and **Marshall Middle School**!

#### **Vernon Hills, IL**

Thank you **Peter, Jacob, Darin**, and **Dede Dankelson, Graber Orthodontics, St. Joseph's School**, and **District 128 Students**!

#### **St. Louis, MO**

Thank you **Dana Kiley, Dr. Brown**, and **Mercy Children's Hospital**!

#### **Little Rock, AR**

Thank you **Don Roberts Elementary**!

#### **San Diego, CA**

Thank you **Shane, Shawn**, and **Courtney Vycocky, Peggy Dugas**, and **Rady Children's Hospital**!

#### **San Jose, CA**

Thank you **Teresa Joy, Darryl**, and **Deena Dyson**!

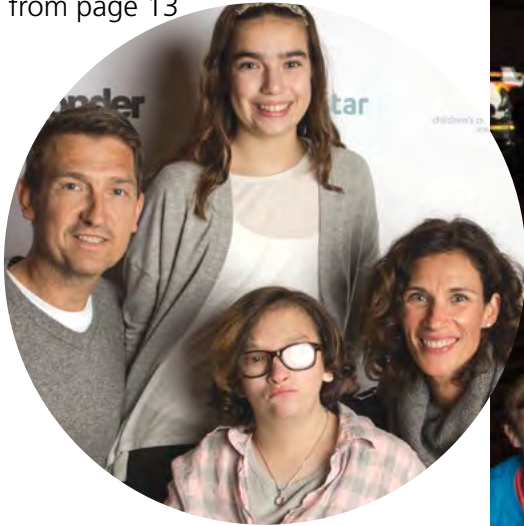
#### **Rancho Santa Margarita, CA**

Thank you **Morgan, Bill**, and **Christine Mecklenburg**!

see **wonder premiere**, page 14



**wonder premiere,**  
from page 13



### Hagerstown, MD

Thank you **Haley, Travis,**  
and **Julie Rawlings** and  
**Leitersburg Cinemas!**

### Geneva, WI

Thank you **Mallory**  
and **Cathy Broz** and the  
**Geneva Theatre!**

### Dearborn, MI

Thank you **Nathan,**  
**Owen, Dave** and **Liz**  
**Anderson** and **PKSA**  
**Karate, Tonya Germain!**

### Houston, TX

Thank you **Haley Streff,**  
**Athena Krasnosky,**  
and **Texas Children's**  
**Hospital!**







## Seattle, WA

Thank you **Nathaniel, Jacob, Russel, and Magda Newman, and Coinstar!**

## Dallas, TX

Thank you **Michael and Brittany Brown, Camacho Home Group, World Craniofacial Foundation, and Medical City Children's Hospital!**

Thank you also to the **American Cleft Palate-Craniofacial Association (ACPA)**, to **Jessica Jezowski** and the **Moebius Syndrome Foundation**, **Breanna Lamprey** and **Beth Reilly** of **Project Au-Some**, and **Holly Bernardi** and **Loma Linda Children's Hospital** for working with CCA on their amazing **Wonder** events, too!





# testimonial



**O**n May 17, 2013, my daughter **Kanynn** was born. As every new mom does, you count fingers toes and look at everything on your child to ensure they are perfect. I noticed a few things weren't normal. She had a bump on her forehead, her nose and right eye were not symmetrical, and she had a space between her upper gum line.

I was told she would need braces when she got

older, the bump was a birth mark, and the asymmetry was because she came through the birth canal, and that it would go away in week or so.

When we took her to her 8-month checkup, she wasn't rolling over, sitting up, or reaching any other age-appropriate milestone. We were sent from Montana to

**Seattle Children's** that December. By then the bump stuck out 1 inch from her head and was 2.25 inches in diameter. The bump was actually a hemangioma tumor attach to her brain. The asymmetric facial issues were a form of Craniosynostosis.

We started seeing the Craniofacial team at Seattle Children's, where Kanynn had the outer portion of the hemangioma removed. Unfortunately, it didn't solve her issues.

Almost every organ in her body is affected in one way or another: heart, kidney, bladder, large intestine, esophagus and bowels. This February we found she has a mass on her liver, and last December, we found a space in her upper gum which they thought was a missing tooth, is actually a bone gap that goes from the roof of her mouth through her skull.

Last August, she had lacrimal stents placed in both nostrils to open airways and tear ducts that were completely restricted. Four days after returning home to Montana, her body rejected them because of the bone gap, and they began to come out through the corner of her eye. We now are facing an additional surgery to keep the airways and tear ducts open.

Currently, she sees more than 20 specialists at Seattle Children's. We have made 65 trips from Montana in four years, because no one in Montana has the expertise to care for her. I am a single mom of three (16- and 18-year-old boys as well) who works seasonal road construction.

Our insurance needs pre-approval for everything. Most of the time they want me to find a physician who is closer. But because of her complex medical issues (her Seattle team calls it "Kanynn syndrome") she must be cared for at a specialized children's hospital because of being high risk. Most of the time she is treated in an outpatient setting, so we pay out of pocket for hotel, flights, etc. for multiple days.

There are limited resources available when your child doesn't have a "textbook medical diagnosis" as to why things are happening the way

they are. I've never been one to ask for help or wanted to feel pitied. We had a GoFundMe to help with expenses, but it didn't generate enough to help us.

As a parent, you want your child to have the best medical care, so I reached out to a fellow cranio mom, who gave me CCA's info to see if they would be able to assist in any way.

Being 600 miles away from the only facility that can take care of your child is tough. I contacted them and they helped us the very next trip, which happened to fall the week of Christmas. (We arrived home Christmas Eve.)

They booked and paid our hotel cost and helped reimburse most of the trip. They also gave me additional information on other organizations who could help.

I was laid off for the winter. Without the help of CCA, I wouldn't have been able to take my daughter from Montana to Seattle and give my kids Christmas.

We are so grateful for everything they have done to help our family, and they have the most caring and understanding staff. We are blessed that we have become a part of the CCA family and they have become a part of Kanynn's journey. I hope to meet them all in person one day to say thank you.

— **Jamie Vanisko**







## donor in the spotlight—hannah klein

*We want to extend our warmest gratitude to Bari Klein, who pledged to donate to CCA when she read her speech during her Bat Mitzvah service at Temple Beth David in Commack on November 4th, 2017, with her sister, Hannah. We were so moved by her words, we wanted to share them here! Bari donated \$1000 to CCA! Thank you, Klein family for your amazing example of kindness.*

The name of the Torah portion Hannah and I read this morning is Vayera from the book of Genesis. This Torah portion starts off when Abraham sees three strangers walking toward his tent. Although he doesn't know these people, he immediately prepares water for them to wash their feet, and cakes and a calf to eat. The visitors told him that within the next year, Sarah will have a child. They were skeptical, but Sarah did have a child, who they named Isaac. This portion teaches us about hospitality. While in 2017 we don't welcome strangers by giving them water to clean their feet, we should still try to follow in Abraham and Sarah's footsteps by being kind and welcoming. For example, if there was a new student at school or camp, my friends and I were very welcoming and would let them join our group. I can understand this lesson because I have experienced hospitality. Over the summer, my family and I went to a retreat for families with kids who have craniofacial differences. While we were there, it was clear to me that everyone was welcomed. We could talk about anything that was on our mind, and everybody understood more or less what we were going through. Everywhere

that you sat down, the people were kind, unlike a middle school cafeteria. Hospitality is much more than just one person being kind to one other person. Communities are also very welcoming. Temple Beth David is an extremely welcoming place; people have come back once they have their own families. My grandparents joined many years ago and my family and I still belong to this temple. When I get older, I hope to remember this lesson, and make sure to be accepting to everyone that I meet, no matter who they are. I plan to donate a portion of my gifts to Children's Craniofacial Association, also known as CCA. They hold events for families with facial differences to meet other families like them. This helps many kids learn and accept who they are. CCA also helps families with their travel-related expenses.

I would like to thank all the people who have helped me get here. Mrs. Chaiken, Cantor Blum, Cantor Halpern, and Rabbi Klafter for helping me learn and chant my Torah portion and to write this D'var Torah speech. I would also like to thank my parents, who have helped me from the very beginning. They drove me to all my lessons, and I would not have gotten here without their help. Thank you, and Mazel Tov, Hannah.



Emma and Jacob Tremblay with Hannah and Bari Klein at the CCA Retreat





pounds, but there he was—this little guy, a full two pounds lighter!

As they whisked him to the warming table to clean him up, the room full of doctors, nurses, specialists, and students went into a simultaneous whisper. An awkward hushed whisper that was deafening to this momma already highly aware of his fragile heart. “What’s going on? Is he ok? Is everything alright? Will someone just tell me?” Hesitation is a cruel joke to a mother on a delivery table, let me tell you.

“There is something wrong with his little face” someone finally said. A normal response maybe would be panic, worry, or sadness upon hearing that; especially since we had been preparing for months to possibly head right into open heart surgery after birth. Now that seemed to be yesterday’s old news next to this shocking revelation. The instant

avoidance of eye contact from the swarm of people invading my room, a sacred space only a mother can understand, could have sent me spiraling downward as well. But I wasn’t sad. I wasn’t panicked. In an almost holy sense, I was so peaceful. “Can I please just hold my baby now? Before you take him away?”

Let me back up in this story for a minute.

Three weeks shy of one year before Griffin was born, we lost our second pregnancy through a miscarriage. When I was pregnant with my first son, it was textbook perfect. There had never been any history of complication of pregnancy in our families. The idea of such things was not even on our minds. So, when we lost our baby, it was a shock. I lived life in a state of numbness for weeks.

When we became pregnant just a few months later with Griffin, I vowed I wouldn’t be so naïve this time. All of a sudden the reality of loss, sickness and congenital disorders—they were no longer just about someone else you hear about. It hit us that this possibility could be our story just as much as anyone else.

So, when we got the heart diagnoses, I went to the dark place, the place of looking up any other

issues that could come with this defect. We had an amniocentesis to be more prepared in case of surgery right after birth. When those tests came back clear, everyone sighed in relief. But, in this momma’s heart, I had a feeling that something else was going on. I kept it to myself, only sharing with my husband how I felt. I prepared my heart, because I wasn’t going to let anything catch me off guard on my sweet boy’s birth day.

So as everyone in the room worried that day Griffin entered this world, I did not. As they all scratched their heads and crinkled their eyes and foreheads into faces of sadness, I did not. “Can I please just hold my baby now?” And I did. And he was perfection. I cried, because it was like he and I had this little secret the whole time.

He went off to the NICU and when the geneticist



came in to talk to us, he handed us a single medical print out with the diagnosis of Goldenhar syndrome labeled at the top. In all my research, facial differences had never come across my screen, so I had no idea what this was. When I asked him if this diagnosis was compatible with life, because several of the things that had come across my screen were not, his eyes got wide and his mouth fell open.

“Of course, it is!” he said, shocked at my





question and the way I so matter-of-factly asked him. This is the thing, we had just lost a baby. I had gone to the dark place and lined up potential scenarios to prepare myself for whatever might come next. In that moment, I just needed to know if my baby was going to live, because if not, then we needed to stop talking so we could go, sit, and hold our son.

To know he was relatively healthy and had a long life ahead of him to live, and the daunting list of potential health issues, surgeries, therapies, educational hardships had NOTHING on the fact that our boy was HERE and our boy was ALIVE! As the doctors tried their best to describe Griffin's conditions, one part being asymmetry of the left side of his face, they shared about potential future surgeries that could help correct this.

One of those options was taking a bone graft from one of his ribs and using it to grow Griffin's jaw. "The crazy thing is," the doctor shared, "is that the x-rays we took of Griffin's abdomen shows that he was actually born with an extra rib on his left side!" Instantly the holy peace returned, and in that moment we felt our life shift. The shift may have pointed in the direction of different, difficult, and

unknown. But the shift also pointed us towards hope, miracles and purpose. I saw this moving picture in my mind of part of Griffin's jaw bone being placed in his rib cage and God's gentle voice saying to him "This is your story."

We all have one, right?! A story. But what makes the difference is how we choose to accept ours and live it out. I very humbly share this because in all honesty, this IS how Griffin entered the world. The stage was set for this moment by heartache and loss, but God used that circumstance to give life to our son, who without a doubt, was made specifically for this story he's been handed. The climate of our attitudes, our outlook, our faith was so strong and resilient. He's HERE, he's ALIVE, and in every moment of his story so far he has spread encouragement, hope and happiness. And being he's only 8 years old, this is only just the beginning.

"Mom, today a kid at school asked why my face looks like this. I just told him I have a Golden Heart." I paused, "You mean you have Goldenhar, right?" He matter-of-factly looks at me and says, "Yeah, I had surgery on my special heart and I have a Golden Heart!" For a good part of his life, this is how Griffin described himself—



and we never corrected him! The sweet innocence in his interpretation (or lack of hearing us correctly) actually sums our boy up pretty well!

Griffin is the one you want as your friend; he loves everyone and is kind, respectful and thoughtful. He notices who needs help in class and he comes to the aid of a hurt friend on the playground. He brings light into everyone's world! Griffin is the comic relief, witty, hysterical, a jokester who will laugh at even the corniest jokes! We're pretty sure he has no sense of fear, he doesn't worry, is full of confidence and not fazed by what anyone thinks of him. Griffin loves animals (especially sharks, his dog Bear and 11 chickens), Minecraft, gymnastics, golf and swimming. His favorite things to do at

home are ride 4-wheelers, play in the fort with his super siblings, Hunter (his big brother and biggest support) and Hudson (his little shadow), enjoy bonfires (with s'mores!) and exploring in the woods. You can always find him tucked away drawing or writing stories. He has stacks of self-made books he's always "working on." Griffin is in the third grade this year and he loves math, art and, of course, lunch!

As we have navigated the medical world—the many doctors, therapists and clinics we visit on a regular basis—Griffin's attitude is the same as it is with everything else in his life: No worries, it's just what he's got to do! He has been blessed so far to not have had any of the major surgeries yet that see **mcmahans**, page 20



**mcmahans**, from page 19

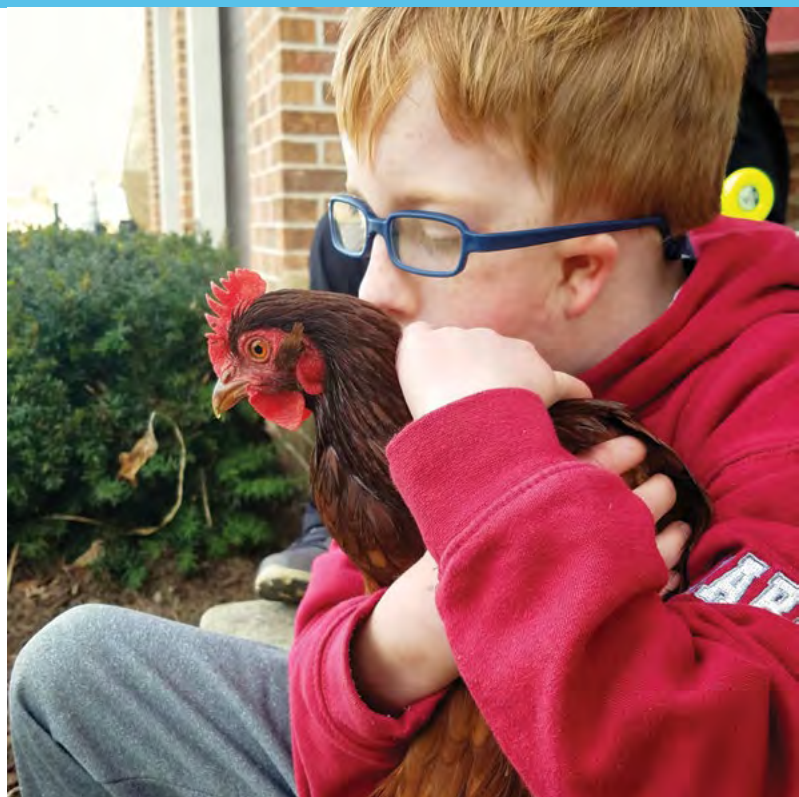
linger above our heads, each year walking away from our craniofacial team meeting with a, "You're good 'til next year!" We are thankful for that and he doesn't mind the sleep studies, CPAP machine wearing, and tonsils being removed that help him maintain that status.

With his diagnosis does come more than face-related issues. He is deaf on his left side and is missing his cochlea that rules out most hearing devices, but he can use a personal amplification hearing aid at school. Griffin has scoliosis, which over the years has actually IMPROVED! He had open-heart-surgery at 4 months old, and will have one of his valves replaced as a young adult. Griffin has a hypo-plastic thumb on his left hand that he actually just had surgery on this past summer! The joints in his thumb do not

bend, but they were able to transfer muscles to the base of his thumb to help make it stronger. His goal is to wear a ball mitt and be able to catch! He also is seen for his vision and orthodontics.

Through the years, as we have shared all of Griffin's journey—the uncertain scary moments, the triumphs and the miracles, like healed spine curvature, an extra rib waiting to be used for a jaw, a heart so strong his cardiologist only wants to see him every two years, and an all-clear from his geneticists after a two-month wait for test results when they suspected a life-threatening disease. As we've shared it all, people are encouraged!

We hear from strangers how his story is giving them hope with whatever they are going through. People are learning kindness and acceptance,



bravery to reach out to someone with differences. Children are shown grace through their curious questions and how to see something special in themselves. Griffin's peaceful stance in this life he's been given has helped us use it for good, not letting one moment go by without attaching purpose to it. He was made for this.

Can I tell you something incredible, though? Griffin's not alone. Our journey broadened this past summer when we were finally able to meet the CCA family face to face. We knew that it would be so very good for Griffin to have this community, and he was instantly addicted to all our new friends! What we didn't know is how much we had been missing out. Our life is blessed with a huge

support system of family and friends.

We have never felt alone in this life with Griffin. But as we were embraced at the CCA retreat by everyone, it hit us how much we needed them and we had no idea! We had an overwhelming realization of all the "golden hearts" within the CCA family. It was life changing for Griffin and our family to take our place that was waiting for us among all the hearts shining so bright with their families, each made exactly for the life they've been given. What an extraordinary moment to be among such Golden Hearts—and we say, "Shine on, Friends!"





# my choose kind classroom

I have read *Wonder* with my 5th graders for three years in a row. Every year that we read it, my students are transformed. Past students come by my classroom and ask if my current students are enjoying the novel. Of course it is very personal for me, being the mom to my own “*Wonder*”, **Henry**, who was born with Apert syndrome. When I saw that the movie was about to be released I started following any and all *Wonder* social media pages. I joined the “**Wonder Certified Kind Classroom**” Facebook page and entered my students into the challenges. We created and submitted t-shirt designs, created our own precepts, and started a Kindness Jar. The Kindness Jar gets a river rock with a student’s name written on it when they are caught being kind. An example was in our robotics club a few students stopped what they were working on, to support students who were struggling with their own project, although they were in competition! I thought that was really cool. We were super excited to learn that my entire class had won a private pre-screening of the movie through the *Wonder*



Certified Kind Classroom challenge. On October 26, we took a field trip to our local movie theater and saw the film. My students were beyond thrilled. They loved the movie and many went back to see it again. Then a couple of weeks later, the *Wonder* Certified Kind Classroom awarded us with 50 additional movie tickets!! I gave them to the 6th graders who read the book with me last year. It’s been so rewarding and my students felt so incredible to be one of the 380 classrooms to be selected nationwide to see the movie. They built amazing compare/contrast powerpoint presentations which compared the book to the film. They overwhelmingly responded to both and created such in depth presentations. I am so proud of them.

**Rachel Johnson**  
Turlock, California





**chair**, from page 1

Packets, and connected more than 25,000 students with WonderKids through school visits or Skype sessions.

The book itself has been a great platform for our organization and for our community. How we have used it to support our mission is in part the result of an incredibly dedicated staff and volunteer Board of Directors that continuously look to the future and challenge ourselves to be the best organization we can be for individuals affected by facial differences. The board and staff defined a plan for the use of *Wonder* and we have spent the last several years delivering on that plan. This was the result of an annual activity where we take a step back from the day to day activities and spend some time thinking about CCA's future at the Board of Directors annual strategy retreat.

In October, the CCA Board of Directors and staff spent a weekend doing just that. This 2-day meeting is always exciting and energizing for everyone involved. We spend a short time looking at what CCA has accomplished but more importantly, we focus most of our time thinking about and planning for CCA's future. Our overall goal is to set the strategic plan to ensure continued success

for the organization. Coming out of this year's meeting, we have 4 strategic focus areas that will be the groundwork for our objectives for the next several years:

- **Increase number of customers served**—we have grown the organization substantially in the last few years but we know there are more people who can benefit from all that CCA has to offer.
- **Sustainable Financing**—in order to work towards our vision of a world where everyone is accepted for who they are not how they look, we need to ensure the organization is able to financially support the programs and services that will enable growth.
- **Increase organizational capacity**—to accomplish all our goals, we need to make sure the organization has the capacity to achieve them. We will evaluate staffing, processes, metrics and tools to make sure we continue to serve our customers at a high level. We will also look to define skill sets needed from future board members as well as ensuring the processes used by the board are best in class.
- **Excellence in Psycho-social support**—core to

our mission of enabling and giving hope to individuals and families affected by craniofacial differences is delivering programs and services that provide psycho-social support. We strive to continue to raise the bar in this area.

The board and staff have a passion to provide excellent programs

and services for CCA's customers. We will use these focus areas to guide all of our efforts over the next several years, continuing to drive CCA to be the best organization it can be.

**George Dale**

Chair, Board of Directors



Dear CCA,  
We placed in the mail today a donation of **\$866.70** from the fifth grade class at **Veale Elementary** in Washington, Indiana. We were so touched by the book *Wonder* that we had to do something to help CCA Kids. My students sold root beer floats at our local school chili supper. All supplies were donated by the students' families and teachers. So 100% profit made goes to CCA. With the extra root beer and ice cream, the students sold root beer floats at lunch to the whole school.

We were one of the blessed classrooms that received a special screening of **Wonder** in October.

Thank you for all you do.

**Nikki Sparks,**  
Fifth Grade Classroom Teacher



# calendar of events

date      event                      contact

**2018**

Feb 28      **Rare Disease Day**                      [ContactCCA@ccakids.com](mailto:ContactCCA@ccakids.com)  
Nationwide

Jun 28-Jul 1      **28th Annual Family Retreat**                      [AReeves@ccakids.com](mailto:AReeves@ccakids.com)  
Little America Hotel                      214.570.9099  
Salt Lake City, UT                      800.535.3643

September      **14th Annual Craniofacial**                      [AReeves@ccakids.com](mailto:AReeves@ccakids.com)  
**Acceptance Month**                      214.570.9099  
Nationwide                      800.535.3643

## 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, [AReeves@ccakids.com](mailto:AReeves@ccakids.com)

We hope to see you there! We are accepting applications for scholarships for this Retreat until December 31, 2017. Register by May 1, 2018 to get the early bird price of \$100. Registration will increase to \$125 starting May 2nd.



## car raffle winner

**W**e want to thank everyone again who participated in our First Annual Car Raffle! The winner of the car was **Adam Freiss** of Pittsburgh, PA! Congrats, Adam!

Adam chose a great bright blue Dodge Dakota. Here he is taking the keys from **Nick Wiese**, whose family hosted this exciting fundraiser.

The Wiese Family, along with several other CCA Families, including the **Seitz, Vivo, Abel, and Yarbrough** families really turned up the heat this summer on the competition by selling tickets. We offered an incentive this year that any family selling over 10 tickets would be entered into a drawing for a Retreat Room Scholarship at the 2018 Retreat in Salt Lake City, and the **Abel Family** of Houston won! We are so excited they'll be joining all of us.

We especially want to thank **Jana Vivo, Melanie Diaz**, and their families, for outfitting their town in CCA's Love More, Judge Less shirts. Through their efforts, we sold an entire order of baseball tees and tanks to their friends and attendees at the Steel Valley Super Nationals.

Thank you to each and every participant and each and every seller!

Together, we raised over **\$85,000** for CCA Kids!



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Cher

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23. Miranda Williamson