

ccanetwork



newsletter of the children's craniofacial association

Cher—national spokesperson

2014: Issue 2

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life is full of miracles

By Jeannie Ewing

Sarah has always been somewhat of a medical marvel; even the events leading up to and surrounding her birth have left many people at the very least speechless and more often riveted and enraptured by her little life that is still unfolding each day. She was born with Apert syndrome, but, like most parents who have children with varying forms of craniosynostosis, we were oblivious to any sort of red flags concerning her development, at least prenatally.

I quickly dismissed the idea of prenatal testing when given the opportunity by my family doctor during one of my later obstetrics visits, and he never pushed the issue further; that fleeting moment in which I was given a decision that could have helped me determine whether or not something might be wrong with the baby passed without much of an afterthought. Beforehand, however, I did consider the possibility of genetic testing, but the reason I declined was twofold: one, I am an incessant worrier and knew if the results returned with less-than-stellar news, I would quite plausibly jeopardize the health of the baby by my fretting, and

see **sarah**, page 16



message from the program director

Can you believe the retreat is already over? Time sure does fly when you are having fun! The 24th Annual Cher's Family Retreat was held in St. Louis, Missouri June 26th through 29th, and was officially the **largest retreat to date!** One hundred thirteen families attended from 33 states with one family coming from Canada. Of the 113 families, 32 families were first-time attendees.

Our home for the weekend was the historic St. Louis Union Station Hotel. Union Station, the busiest train station of its time, was built in the 1890s and still

see **program director**, page 6





ccakid

meet ian bibler

Eight-year-old **Ian Bibler** is having one fantastic summer. The soon-to-be third-grader has gone to camp at a local high school, visited his aunt and uncle in Baltimore for a week and has made it to the neighborhood water park a few times to whoosh down his favorite water slides. He'd done all this by mid-July (the time of his interview), so he's been quite a busy guy. And, oh yes, he got to see not one, but two fireworks displays on the Fourth of July!

Another favorite thing Ian likes to do is collect seashells. Good thing he lives near Ponte Vedra Beach in northeast Florida, home to some of the most gorgeous—and seashell-rich—beaches around.

This fall, Ian will be going to a new elementary school, as his school district rezoned. Many of the same neighborhood friends will be going with him to the new school, too. Ian is looking forward to getting back to science class—his favorite subject.

After school, Ian takes karate classes, something

he has been doing for the last three years. Right now he's a blue belt. He has also played lacrosse for the past two years. During the summer, however, you can catch Ian and his older brother, **Eli**, duking it out with water balloons. (In fact, right before he was about to be interviewed, Ian and his brother were right in the middle of a particularly spirited water-balloon skirmish.)

Ian's all-time favorite movie is *The Hobbit*, with Frodo being his favorite character. He likes the TV show "American Ninja Warrior," and he's a big fan of rapper TobyMac. He has a dog named Casey, a four-year-old Shih Tzu mix, who weighs in at just 13 pounds.

Ian has Treacher Collins, syndrome and when strangers ask about his face, he politely tells them everybody is different and he was born this way. He doesn't worry going into a surgery or a procedure. "Stay calm," he says, "because God is always with you."

meet jessica barbalaci

hi, my name is **Jessica Barbalaci**, and I'm 20 years old. I live in Trenton, New Jersey, with my parents, **Bette** and **CJ**, and my older brother, **Michael**. I have a dog named Kasper and a cat named Little Rascal, who are both rescue animals.

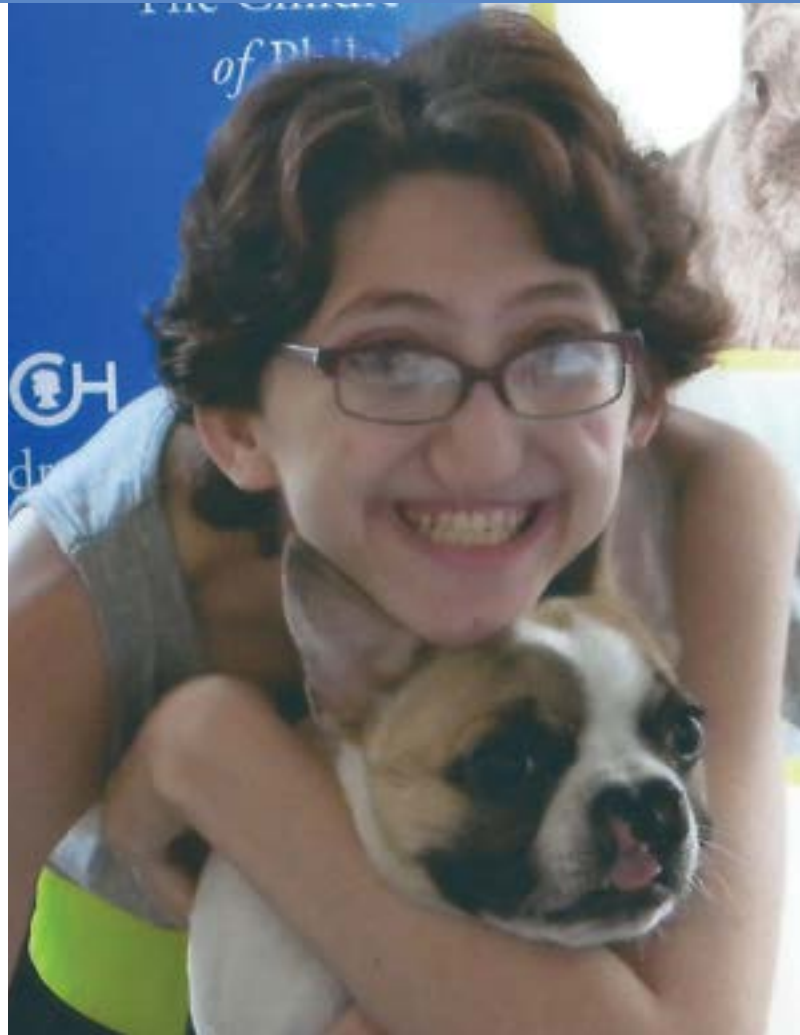
I was born with a cleft lip and palate. I've had seven surgeries, the first one when I was three months old. I just had another one in July, hopefully my last one. I don't like surgeries very much, but with my amazing doctors at Children's Hospital of Philadelphia I always come out looking great. They have done so much for me, and I am so grateful to them.

One thing I have always struggled with is school; I have always tried my

best and gotten through it. One big achievement I have accomplished was graduating high school. I attended Conwell-Egan Catholic High School in Fairless Hills, Pennsylvania. I've done a lot of things while I was in high school. I was in the school choir and drama club, and I was on homecoming court my senior year. Although it may have been tough at times, I did have a lot of fun.

Now I am off to college at Mercer County Community College in New Jersey, where I'll study to become a Special Education teacher. I know it will be challenging, but I am ready for it. I am very excited to start a new chapter in my life.

Some things I like to do when I am not in school are singing, dancing, acting, going to Philadelphia Phillies games, watching hockey with my family and going to see one of my favorite singers, John Eddie. I also really love going to CCA retreats every summer. I have made many



friends from many different places, and it is always so much fun.

Another thing that has been cool is I got to meet **Lentil** the French bulldog puppy who was also born with a cleft lip and palate. He is so sweet and one of the coolest dogs ever. Plus his mom **Lindsay Condefer** is pretty cool, too. Lindsay and Lentil even came to retreat with us last year. That was a lot of fun.

I have also been involved with being a "Wonder Kid" (along with my friends **Danny** and **Connor**) and going to different middle schools in New Jersey, talking about the book *Wonder* and helping kids

see that we are all just normal kids who like to do normal-kid things, even though we might look a little different. It has been a great experience for me.

I hope you liked getting to know me a little better. I've had a pretty tough life so far, but I'm a pretty tough girl. And I'm excited to see what the future holds for me.



cca grad

meet eli bibler

Living with Treacher Collins syndrome

Would you be scared if you were born with a birth defect? Would you be sad if people stared at you when you go places? What if it was your face that made you look different from everyone else? Well, this is what it's like for my little brother, **Ian**.

Ian was born with Treacher Collins syndrome eight years ago. Treacher Collins syndrome is a facial birth defect so rare that it is found in only one out of 50,000 babies. In Maryland, where we were born, there were only three other children with Treacher Collins in the entire state. The hospital pediatrician actually had to Google Ian's symptoms after he was delivered. Pretty unimaginable, don't you think?

The main problem of Treacher Collins is a lack of bones in one's face. When his face was being formed his treacle cells stopped reproducing, so the bone in his ears, eyes, cheekbones and jaw didn't fully develop.

The physical features of Treacher Collins include downward-slanting eyes, a smaller lower jaw, lack of eyelids, high palate, malformed ears and conductive hearing loss. The eyes are often referred to as "sad eyes." The small jaw meant he could not breathe well enough on his own, nor could he eat on his own. And since Ian's ears are really only little lobes he is considered profoundly hearing impaired or deaf without a hearing device.

If all of this medical stuff sounds complicated, you are right, it is! Ian has had 17 surgeries at three nationally recognized hospitals but most of them in Cincinnati, Ohio, where my parents found an



amazing surgeon. This smart and talented doctor has helped regrow and form my brother's jaw two times already in his short life. With these surgeries, Ian is in extreme pain, needs a feeding tube to eat, and has lots of swelling which takes weeks to go down. Remember, Ian is only 8 and has about 10 to 12 more years of these necessary surgeries.

Being Ian's big brother is, well, I'm not sure. For me, all I see is my little brother Ian with long surfer hair and kick me all the time. So at home, being his brother is easy. Yet, when we are in public I see other people, mainly kids, staring

and pointing at Ian's face. Sometimes they even say rude and mean things to him. When I read the book, *Wonder*, I knew just how Auggie's big sister, Via, felt. Yet, I realized how sad and frustrating it was for Auggie too.

When you have a family member with a birth defect it can be hard, but most days it's okay. I know God has given Ian so much courage and a great personality to be able to live with Treacher Collins. But Ian isn't the only one living with Treacher Collins, my mom is, my dad is, my grandparents are **and so am I**.



ccasupersib

2014 morgan meck's match play



to contribute more than **\$80,000** to benefit Children's Craniofacial Association.

As **Morgan** stated in her opening speech, the tournament is now officially a "tradition" that brings together great friends from across the country as a fundraising and awareness-building "destination event." **Coto de Caza Golf and Racquet Club** was the host venue and all out-of-town participants stayed at the **Laguna Cliffs Marriott Resort & Spa** in Dana Point, California. Private dinners were held at **Hanna's Restaurant and Bar** in Rancho Santa Margarita and at the **Vue Restaurant** overlooking the Pacific Ocean in Dana Point.

CCA dads, Darin Dankelson and Tate Gorman, truly moved the group with their tributes to their sons, **Peter** and **John**, and the miracle work CCA does for CCA kids and their families. Darin also spoke about the critical role the retreat plays in creating

peer groups and lifetime friends for CCA siblings.

The event's Platinum-level sponsors were **EverGuard Insurance** and **SES Insurance Brokerage Services, Inc.** Gold-level sponsors were **Kevin and Jennifer Trapani, Maria Amelio, Greg and Donna Bonnell, Blair and Shelley Schrum** and **Zurich North America**. Silver-level sponsors included **Lexington Insurance, John Carr / CSI Insurance, Andrew and Eileen Bustillo, Jenelle Harmon** and **Ryan Vallone, Shelly Soenen** and **Michael Sprague, Mike Del Giorgio** and **Tracy Kish** and **Partner Reinsurance Company**.

CCA and the Mecklenburg family would like to thank all of the volunteers, participants, contributors and auction-item donors who have made this a memorable and meaningful event.



On May 7 and 8, **Bill Mecklenburg** and **Christine Condino-Mecklenburg** hosted the third-annual Morgan Meck's Match Play Invitational benefitting CCA. After two days and 36 holes of golf, the championship was ultimately decided with a sudden-death match play contest, with **Eric Miller, Robert Reader** and **Gabe Munoz** claiming victory over the first runners-up **Jeff Patty** and **Robert Kacer**. **Maria Amelio** won the Women's Championship for the third consecutive year, and **Ian Leisegang** won the individual Low Gross Championship.

The true champions were our CCA kids, who inspired this small group of friends and corporate sponsors



See list of donors, sponsors and participants on page 14.

program director, from page 1

has many of the original architectural features today, including the Grand Hall with its sweeping archways, fresco and gold-leaf detailing, mosaics and Tiffany glass windows. Nightly, our families enjoyed remarkable, 3D light shows projected on the 65-foot, arched ceilings, and during the day explored the original details in this vast structure.

Thanks to modern technology, many of our new families and those who had not attended previous retreats became friends on Facebook and through CCA's Yahoo Group over the past year, so the initial "get-to-know-you" period was taken care of before we even arrived at the retreat. Family members were glad to finally meet in person and immediately made connections.

Dr. Earl Gage of **St. Louis Mercy Children's Hospital** and craniofacial team members **DeAnn Wilson, Lauren Watson, Dana Kiley** and **Dr. Gregory Robinson** generously gave of their time and expertise to conduct the 6th Annual Craniofacial Symposium as did CCA family members, **Paula Guzzo** and **Rose Seitz**. Presenters discussed topics including esteem building, behaviors for friendships, caring for

a child with complex craniofacial conditions, positive communication and individualized educational programs. In addition, there were panel discussions for parents, siblings and affected adults. Panel members included: **Tommy Dale, Sarah Klinger, Anne Moore, Amelia Sanborn, Darin Dankelson, Eric Lucas, Alison Morrissey, Liz Prince, Rob Gorecki, Francis Smith** and **Meg Storie**. To close the symposium, CCA's Board of Directors held a welcome session that included an overview of the organization and future plans. Thanks to all for a very informative, productive day.

We kicked off the retreat on Thursday evening with an ice cream social. Families participated in an ice breaker, setting the stage and mood for meeting one another and making connections.

After meeting for breakfast bright and early Friday morning, we set out for a trip to the huge, 90-acre St. Louis Zoo. Families got up close and personal with lots of amazing animals such as lions and tigers and bears...OH MY! And, the fun continued Friday evening at the traditional family night and teen party. As usual, families from across the United States and beyond brought baskets of goodies from their areas for CCA to raffle. These baskets held everything from sports souvenirs and memorabilia, to local food specialties and everything in between. The generosity of our families never ceases to amaze us. While parents were buying raffle tickets and stuffing them in the raffle bags, the rest of the crowd was being entertained by a quirky clown. She really had the crowd engaged and even managed to pull a few of our CCA dads up on stage for a really cool



trick. Meanwhile, the teens were lounging by the pool, having dinner and hanging out.

Saturday the families gathered for the traditional big pool party. Several years ago a water-gun fight between two separate teams was started at the pool party. Each and every year more and more kids and over-grown kids (A.K.A. CCA parents) have joined one side or the other. You can only imagine the absolute chaos and fun that took place this year!

Saturday evening's dinner-dance is a family favorite, and this year was no different. But before the festivities began, we took a few moments to honor the memory of long-time CCA member **John Moulton** who passed away this past year. Many thanks to **Casey Deakins** who put together and presented a beautiful video tribute and **Elizabeth Erickson** who made a memorial quilt signed by CCA families and given to John's family.

This event was followed by a presentation for CCA's executive director, **Char Smith**. June 1st marked



reflections

By First-Time Retreat Attendee Lisa Brown

before I settled back into the daily routine of life, I took some time to reflect on the past five days of an amazing experience: my family's first CCA Retreat in St. Louis, MO. I have seen all the Facebook posts and pictures over the past few years of previous retreats, and have really wanted to go, but for many reasons I have been dragging my feet on planning this trip for my family. Some reasons were the timing of surgeries, Steve's work schedule and being able to take off the time that the retreat was scheduled.

But also it was my fear of the unknown. Apprehension seemed to have kept me from choosing to register, mostly because I didn't feel like I was ready. I knew that attending a retreat like this might force me to face and relive some emotions all over again and I was worried that it might not be what I expected, or wanted from this trip. Who wants to go on vacation with the possibility that it might turn out to be depressing and emotionally draining?

Luckily, this retreat was quite the contrary! And now that we have finally taken the opportunity,

and made the choice to be a part of this journey, I feel that my life has been forever changed.

So, what do I take away from this experience? I take away the sense of acceptance, being part of another family, a much bigger family with delightful people who have "walked the walk," if you will, and have felt the pain of witnessing their child's surgeries and struggles.

Even though we didn't necessarily discuss all of our surgeries and experiences with each other family-to-family, I felt there was an unspoken comprehension of what we've all been through. I thought to myself:



These parents get it... they've been on the front line and know what it's like to hear the constant beeping of the hospital monitors, the needles and IVs (oh, those dreaded needles!), the pain management, the devices, the tube feedings, the anxiety, sleeping on those awful hospital chairs (or not sleeping at all), the swelling after surgeries, (I know I'm leaving out a lot of medical events here), signing and

see **reflections**, page 8

registration is now open for 2015 annual cher's family retreat June 25-June 28 in Newport Beach, California

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

For more information,
please contact Annie Reeves,

ARees@ccakids.com

We hope to see you there!

Registration ends May 22, 2015.

a very special milestone. Char celebrated her 25th anniversary with CCA. To honor her for 25 years of dedication, CCA Board Chair **Bill Mecklenburg** called Char up on stage and presented her with a beautiful Tiffany-crystal vase and gave a heartfelt speech. It was a very touching night and there were tears flowing.

After everyone congratulated Char, the dancing began and continued long into the night! For the first time ever, the crowd was begging the DJ to play one more song!

Sunday morning is always the hardest. There were lots of hugs, promises of staying in touch and, as always, a few tears. We really enjoyed meeting all of the new families and catching up with our old friends who have attended in the past. We hope everyone had the TIME OF THEIR LIVES!

Registration is officially open for the **2015 Annual Cher's Family Retreat** in Newport Beach, and we hope to see you all there!

Now please enjoy reading about first-time retreat attendee, **Lisa Brown**, and her family's experience.

Annie Reeves

CCA Program Director

reflections, from page 7 attending hundreds of IEPs, and advocating for your child on so many levels.

Although our social media provides great tools for connecting with others, there's something to be said about face-to-face interaction, and perhaps this is what makes it so surreal. As a parent, it was therapeutic to finally connect with people in person who understand where you're coming from, regardless of which craniofacial syndrome or diagnosis your child has, and getting the chance to discuss not only the difficulties our children have faced or will be facing, as well as the ones we as parents face, but also celebrate the obstacles and challenges they have overcome.

I also take away satisfaction in seeing our kids take ownership, with confidence, in who they are and where they fit into this world, especially as other children who are "like" them, as well as their siblings, surround

each other with kindness. I'm certain that I am not the first parent to point out how empowering the retreats seem to be for our kiddos and their siblings, to know they are not alone.

When I asked my kids and husband how they felt about the retreat, this was their response: **Logan**, 12 (with Apert syndrome): "I actually just felt like a normal guy around here." **Landon**, 9: "I had so much fun, and I made so many new friends!" **Steve**: "I had a great time getting to meet so many new families. Being able to ask questions and also help by answering questions for others who had younger children was very rewarding."

I truly feel this was a pivotal moment in our lives. Going on vacation is always the highlight of the year, but to take a vacation surrounded by people whom I know I don't have to worry about the stares, or whispers or what they are thinking, and just being

able to really leave it all behind, is the ultimate.

To sum it all up, I take away a new sense of belonging; and as a first-time retreat parent, now I

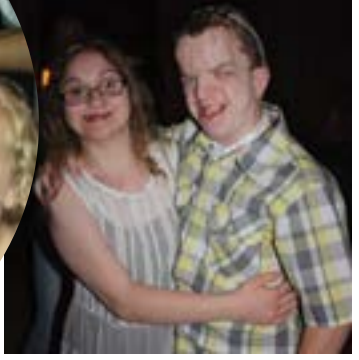


get it. We do belong! We do have something in common with other families! We do not have to feel like "that family" who has problems, with "that child" who has so many difficulties. **We are accepted! We are not alone!** Regardless of the miles in between us, we have made some lifelong

friends, and I cannot wait until the next retreat when we meet again!

Thank you Char, Annie and Jill for your dedication in serving all of the CCA families and the many ways you make a difference in so many lives!





2014



horseheads, new york school district brings *wonder* to students

When **Jeremy Dale** walked into his school library at the beginning of the school year and asked his new librarian, **Sarah Jones**, if they had any *Stars Wars* books, she was blown away. Sarah had read *Wonder* over the summer but she hadn't met Jeremy yet. One look at him and his similarities to Auggie (right down to his love of *Star Wars*) brought tears to her eyes. She instantly saw the possibilities of bringing this book to the **Horseheads Middle School**. With the help of a grant from **The Community Foundation of Elmira-Corning and the Finger Lakes, Inc.**, Sarah was able to purchase books from CCA for the

entire Horseheads Middle School.

Eight hundred seventh and eighth graders, along with the entire staff, read the book *Wonder* in February 2014. Live readings of the book were recorded by several staff members and broadcast throughout the school. During the all-school read, many students participated in discussion groups, wrote their own precepts, explored ways that made them "different" and signed the Choose Kind pledge.

The all-school read wrapped up with a final assembly, where Jeremy shared information about CCA and his real-life "Auggie" friends. Several students and staff were interviewed for a short

video that asked them their favorite part of the book and what character they most related too. Two hundred students attended the live assembly and sported their "I Read *Wonder*" t-shirts. The rest of the school watched the presentation through a live broadcast in their classrooms.

At the same time the middle school students were reading *Wonder* on their own, three third grade teachers at **Horseheads Ridge Road Elementary school** were reading the book to their classrooms. While reading the books to their students, **Kelly Murray, Kelly Wolf** and **Kim Balliet** were able to have great discussions with their students on what

makes them different and how to choose kind.

Then Jeremy visited their school to answer questions. One of the highlights was when Jeremy took off his prosthetic ear and passed it around! The kids were so inquisitive and curious about Jeremy and his likes and dislikes. They treated him like a celebrity! Their celebration ended with all of the students writing words of kindness on papers that were taped to everyone's back. Jeremy gave CCA Choose Kind bracelets to all of the students and they gave him a huge standing ovation!

Thank you to all of the *WONDER*ful students and staff at the Horseheads School District who choose kind every day!

all the way for cca



The **Texas Moms** held their third All the Way for CCA Golf Tournament April 25th, 2014 at **Battleground Golf Course** in Deer Park, Texas. We had a great day of golf with perfect weather. Our event included games on the course, silent auction and lunch with an awards ceremony. We also had a raffle for two Benelli Super Black Eagle shotguns. Top ticket sellers for those were **Jim Chapman, Cheri Bauman** and **Rick Dupuy**—they really got our fundraising rolling!

All in all, we raised **more than \$36,000** for CCA!

But, we couldn't have done it without constant support from our amazing friends and supporters, **Alisa Shelton** and **Lynna McGuyer**. For four years you both have given selflessly, and we are so very grateful. You raise

awareness and advocate for our kids as if they were your own. It takes really special people to do that.

Also, very special thanks to **Sarah Collins** with **Maddie Dean Photography**. For the second year in a row and third CCA event, Sarah has volunteered all the professional photography, and this year recruited her family to come 10 hours from home to participate in our tournament. Sarah is now officially another surrogate CCA Texas Mom. Thank you Sarah!

Lastly, we need to give recognition to **Brittany Severin**, at the **Craniofacial and Plastic Surgery Center Houston**. She has gone out of her way two years in a row to help us raise awareness in the community and volunteered countless hours for our event. Thank you so much, Alisa, Lynna, Sarah and Brittany—we are so grateful for all you helped us accomplish over the years!

We had a tremendously fun day with 22 teams of four generous golfers each,

who all said they had a great time! We want to give special thanks to our sponsors,

Diamond (\$3,000 or more): **USA Environment, Empowering Motivated Women;** Platinum(\$2,000-\$3,000): **J2S Services, Triple B Services, F.I.R.S.T., The Craniofacial and Plastic Surgery Center of Houston,** Gold (\$1,000-\$2,000): **Inflight Outfitters, Hufco, ISB Capital, Cima, Divicom Inc., Southwest Airlines, RS Graphics, International Long Shoreman's Association and Max Con Construction.** Thank you so much for supporting our kids.

Each golfer received a

goodie bag filled with coupons, a CCA newsletter and various other items. The **Houston Texans Cheerleaders** made an appearance and stopped for photos with all of the players. They were a great hit!

This year, three CCA kids joined us at the event—

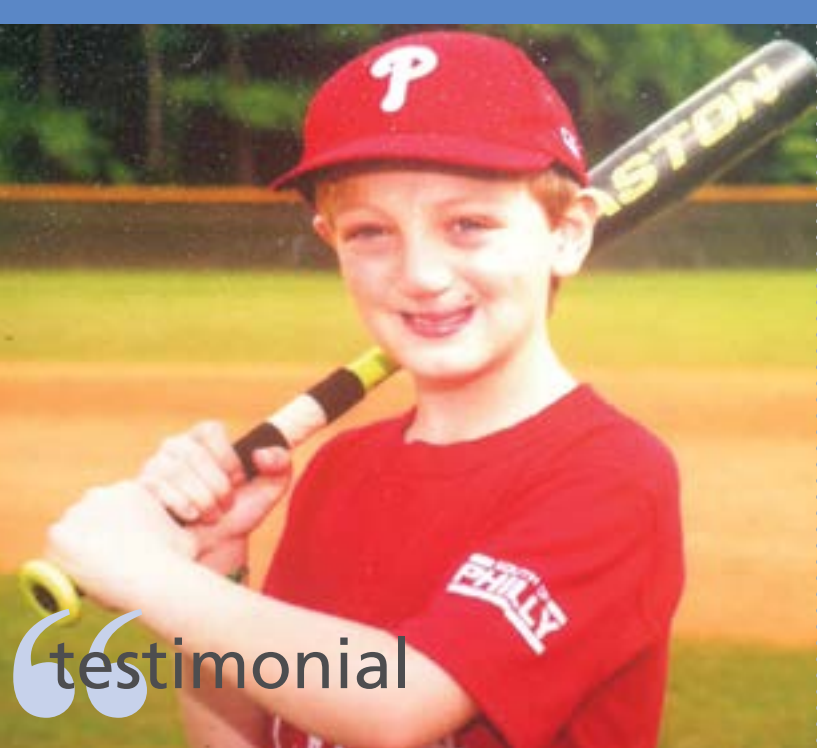
Wade White, Ashley Bock and **Jakob Happ**. It was nice for the golfers to see firsthand some of the kids they were helping. The CCA kids who were there assisted in



handing out awards and posing for photos.

Can't wait for next year!





testimonial

CCA has been a blessing in our lives. Jay was born in 2006 with bilateral cleft lip and palate. He also suffers severe hearing loss in his right ear due to cholesteatomas.

We moved to the panhandle of Florida a little over two years ago. The closest care we can find for Jay is in Gainesville, three hundred miles away. It has been financially difficult to get Jay to his specialists in Gainesville several times a month. Currently, we are seeing a plastic surgeon, a speech pathologist, an orthodontist and an ENT. Our social worker through our cleft team introduced us to CCA.

CCA has been an enormous help to our family, reimbursing us for fuel and meals as well as covering our hotel stays while we traveled to and from Gainesville. They have

made it possible for us to take Jay every time that he has an appointment or surgery. Without them, I don't know that we would be able to get Jay the care that he needs when he needs it.

It has been a great experience working with **Annie**, their program director. Any time I have questions or concerns, Annie is there to ease my mind. It has been such a relief to know that we have a group of people that we can turn to.

CCA has made it possible for Jay to do all things a seven-year-old little boy should be doing. By seeing his doctors on time and receiving the care that he needs, Jay is able to go to school and be an all-star on his baseball team. I cannot ever thank CCA enough for all they have done to help our family.

Brittany Postelwait

calendar of events

date event contact

2014

Aug 16	4th Annual Trevor's Trip to Triumph Motorcycle Ride for CCA Morganville, NJ	kimtriz@msn.com
September	10th Annual Craniofacial Acceptance Month Nationwide	ARees@ccakids.com 214.570.9099 800.535.3643
Sep 6	Raegan's Rally/Walk for CCA Deerasic Park Cambridge, OH	Ashley Daugherty adaugherty@mvesc.k12.oh.us
Sep 6 1-4P	Ohio Picnic Bexley Recreation and Parks (Memorial Shelter) Columbus, OH	Meg Storie megitect@gmail.com
Sep 12	7th Annual Links of Love Golf Tournament Bear Creek Golf Club at DFW Airport Dallas, TX	JPatterson@ccakids.com 214.570.9099 800.535.3643
Sep 13 11A-1P	7th Annual National Picnic Day Sandy Lake Amusement Park Carrollton, TX	ARees@ccakids.com 214.570.9099 800.535.3643
Sep 13 Noon-5P	Illinois Picnic Starved Rock State Park Oglesby, IL	Amber Harrold isabellajune12.ijh@gmail.com
Sep 13 1-5P	New Jersey Picnic 16 Gallant Fox Rd. Tinton Falls, NJ	Gary & Nancy Merrill gmerrill@commvault.com
Sep 13	Seth's Stride Canton, OH	Stacy Horne stacyhorne@gmail.com
Sep 14 Noon-3P	Michigan Picnic Hosted by University of Michigan Mott Children's Hospital Montibeller Park Pittsfield Charter Twp., MI	Coreen Abston cabston@med.umich.edu
Sep 20	10th Annual Friends of Jeremy Golf Tournament Corning Golf Club Corning, NY	gdale@stny.rr.com www.friendsofjeremy.com
Sep 28	Acceptance in the Park Vasona Park Los Gatos, CA	Deena Dyson deenstrick@aol.com
Oct 12	7th Annual Chocolate Festival for CCA Aventura Mall Aventura, FL	ChefRick2@aol.com
Dec 6 11:30A-2:30P	CCA Holiday Party—Midwest Brat Stop/Parkway Chateau Kenosha, WI	JPatterson@ccakids.com 214.570.9099 800.535.3643
Dec 13 10A-Noon	CCA Holiday Party—Dallas Southfork Ranch Parker, TX	ARees@ccakids.com 214.570.9099 800.535.3643

2015

Jun 25-28	25th Annual Cher's Family Retreat Newport Beach Marriott Newport Beach, California	ARees@ccakids.com 214.570.9099 800.535.3643
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ucf: awareness for social change

CCA sibling **Anne Moore** held an awareness fundraiser for CCA at University of Central Florida. Anne told us, "This year I am in the lead scholar program, and this semester we had to plan and carry out a social change project. My group decided to throw a CCA fundraiser!" Anne and her group raised about **\$50** in donations from fellow students. Group members **Lauren Polson, Anna Ly** and **Rachel Welborn** also placed CCA collection cans in the community to help raise more funds. Anne's sister, CCA kid **Katie Moore**, was guest speaker, helping spread awareness and understanding of facial differences. Thank you, all!



a living legacy



We wish we could thank those who thought ahead, arranging planned giving according to their wishes—many times without even telling us—all those who made the decision to champion CCA by leaving our charity in their will.

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

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

GO PAPERLESS and view the newsletter online in FULL COLOR! Email AReesves@ccakids.com and let her know you want to **save the environment and save money for CCA.**

OP4G (Opinions for Good)

help Children's Craniofacial Association by becoming a member of Op4G (Opinions for Good) and taking online surveys in your spare time. Op4G is a different type of market research firm. They're based on a private membership community of nonprofit supporters who anonymously participate in market research activities. They pay in cash, and a minimum of 25% (with the ability to be up to 100%) of your earnings goes to the nonprofit of your choice. Op4G has 340 nonprofit partners, and in 2012 gave over \$210,000 to their panel members, like you, for their insights. In return, their members have donated over \$79,000 of those funds to their Non-Profit Partners, like CCA. Give your opinions and help out Children's Craniofacial Association! Go to www.op4g.com to sign up and get started today!

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donors from morgan meck's match play See accompanying article on page 5.

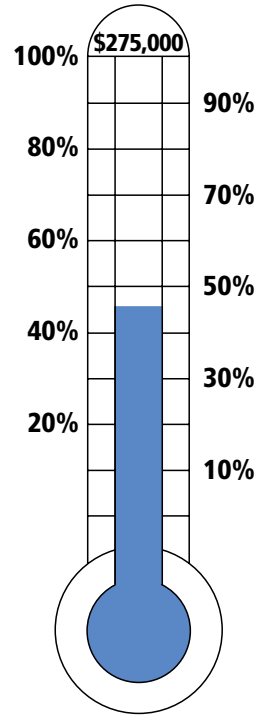
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www.ccakids.org/donor-list.html

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


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Buy and/or sell "Beyond the Face is a Heart" wristbands for Craniofacial Acceptance Month



BENEFITTING
CHILDREN'S CRANIOFACIAL ASSOCIATION

**Join us on September 12, 2014
at Bear Creek Golf Club in Dallas, TX
for the 7th Annual Links of Love Golf.
Tournament Don't miss the fun!**

Register now at www.ccalinksoflove.com

sponsors needed for cher's family retreat!

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

From time to time we've had T-shirt sponsors. But, we are in need of more sponsors. If you know of anyone who might be interested in supporting this worthwhile program, please have them contact our office. Email contact@ccakids.com or call 800.535.3643.

matching gifts

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

financial assistance

do you travel to receive quality medical care? If you do, and need financial help, CCA has a financial assistance program that will help with food, travel and/or lodging. Call CCA for an application at **800.535.3643**. All we ask is that you **apply at least four to six weeks prior** to your next appointment.

NOW SELLING YEAR 'ROUND



"I read Wonder!" T-Shirt

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

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sarah, from page 1

two, **Ben** and I truly loved Sarah long before we ever met her, so no amount of genetic testing would have changed our minds about her.

After Sarah's birth, however, I ruminated over that decision and the possibility that we could have had some answers beforehand; what if we were able to receive a diagnosis prenatally? Would we have had time to prepare ourselves, do some research, educate and advocate? As a planner, my comfort zone is to prepare for everything, yet Sarah's birth was a stark confrontation of the reality that not everything in life can be planned or understood.

Sarah was born via last-minute cesarean, and from the moment I heard the on-call pediatrician frankly ask me, "Do you have any genetic disorders in your family?" my world was forever altered. We saw her pronounced forehead, her mitten hands and her webbed toes, and our hearts sank; it was a composite of emotions we neither anticipated nor desired, and yet our hearts were filled with a plethora of agonizing questions about her prognosis. None of the medical staff was certain as to how to diagnose Sarah initially, but within 24 hours, we learned that they suspected she had Apert syndrome.

Ben and I had never before heard of Apert syndrome,

and all we were given was a small Internet printout from a common medical website that included two informational paragraphs, both of which were unpromising and fairly fatalistic.

As we held her in our arms for the first time, we had no way of knowing whether she would live or die, or what quality of life she would have. We were completely in the dark, and yet thrust into this world we did not seek—a world we were forced to accept and even embrace. So we chose to simply love her. All else seemed so peripheral, as if researching potential problems associated with Apert syndrome would only keep her caged into a societal box labeled "Different." We had to somehow process that unique place in which we were proactive about her medical care and socio-emotional development without it becoming a crutch or hindrance to her being treated, simply and foremost, as a human being.

Sarah underwent the typical diagnostic testing, such as a renal ultrasound, echocardiogram, vision and hearing screening, CT scans and X-rays, and placement on an apnea monitor. Remarkably, all of her body's functioning was normal.

The only findings were that she tested positive for the FGFR2 genetic mutation that defines Apert, and that her bi-coronal cranial plates had been fused.

When I met **Dr. Annan**, the on-call obstetrician who delivered Sarah, for my post-partum checkup, I was caught completely off-guard by what she said to me.

"Jeannie," she began with no trace of trepidation and yet with a great dose of amazement, "what happened the day we delivered your baby was truly a miracle." She said the word miracle with emphasis, and I was taken aback as I listened further. She continued, "I've been practicing in obstetrics for many years, and I actually transferred here from New York not long ago. I've seen all sorts of things happen in much larger hospitals, but I will never forget the day I delivered your baby. The cesarean happened flawlessly, as if in a textbook, which was significant in and of itself. But when my hand reached in your womb to deliver Sarah, I felt this power overcome me, and it was as if God Himself delivered your baby instead of me. I felt His presence in that room that day; it was overwhelming, and the entire medical staff recognized this supernatural





Sarah has unknowingly given me permission to be my quirky self, all because I witness the love and simple joy radiating from Sarah. Quite possibly, this is the most astounding revelation of all: that miracles happen every day, not necessarily in extraordinary or dramatic healings, but rather in the quiet joy and simple beauty found in the heart of a child.



light. I truly believe Sarah is a special child of God.”

How can one respond after being told something like this, especially when this was the second encounter I had with Dr. Annan in my entire life? I did not know her as a person, and she barely knew me, but she spoke boldly and confidently, without a break in her spoken stride, and oddly, I believed her. I believed every word she spoke, and my heart was elevated from a place of exhaustion, despondency, and fear to a realm of hope and joy. It was then that I no longer viewed Sarah’s medical needs as being cumbersome, but instead I saw this fresh human life

in light of the beauty of her differences. Her differences, I was certain, were gifts rather than burdens, and I left the medical office that day considering the words of Scripture, “I am fearfully and wonderfully made” (Psalm 139:14).

Today Sarah has just passed her first birthday, and as I reflected over the past year, I realized how much she has inadvertently taught me about life. For one, she is not yet old enough to acknowledge that she is different, so the pure innocence about her elicits a joyful proclamation, “Hello world! Here I am!” Ben and I know that Sarah is simply Sarah, not a diagnosis, not a medical anomaly, but just a

little person who was molded and fashioned differently than we were. **Her differences have taught us that each and every one of us is unique in some way, and it is precisely our uniqueness that colors the world with what we have to offer. Ultimately, this life is not about blending and fitting in; rather, it is about standing out and owning what makes us special, gifted and valuable.**

*Jeannie Ewing’s Blog:
It’s Love Alone Creates,
lovealonecreates.com*



sadie's night at the ball park



Thank you to everyone who came out to the Lake Highlands vs Pearce, high school baseball game on March 28th in Lake Highlands, Texas, for "Sadie's Night at the Ball Park."

For the third year in a row, **Lake Highlands High School Wildcat baseball team**, led by **Coach Cory Tucker**, held a night to raise funds for CCA, promoting awareness and honoring event namesake, **Sadie Bono**. Sadie was on hand along with her fellow Lake Highlands

resident and CCA kid, **John Gorman**; each threw a first pitch at the game to start the festivities.

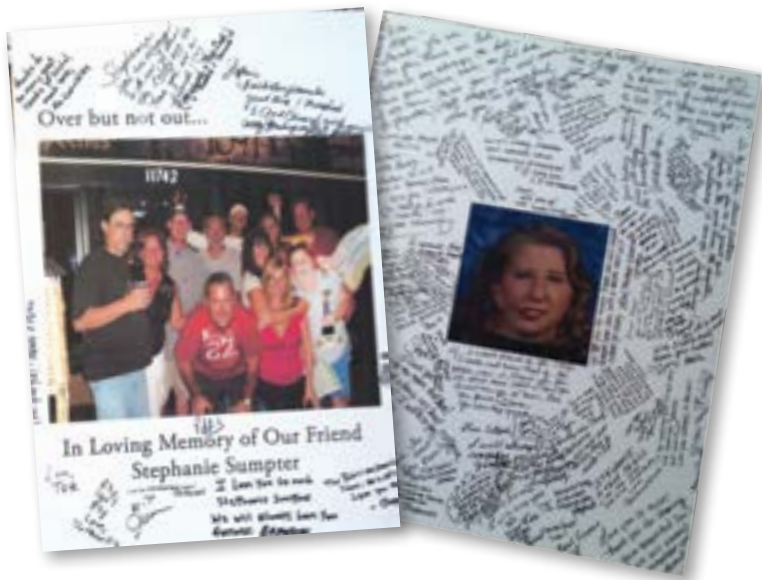
Funds were raised through concession purchases, bracelet and necklace sales (handmade by Coach Tucker's wife, **Ginny** with help from John's mom, **April Gorman**), passing collection buckets and this year, **Phillip Tilger Real Estate Group** donated and sold event T-shirts. As CCA mom **Debbie Bono**

said, "It was a magical night for Sadie, John and CCA!" Funds raised topped last year with **over \$2,500** for CCA kids!

Thanks goes to the **Bono**

Family, Gorman Family, Tucker Family, LHHS Baseball Team and Phillip Tilger and his wife, Robyn, and to everyone who volunteered, participated and donated! Thank you also Lake Highlands Community for embracing our CCA kids!





stormbringer for stephanie

Stephanie Sumpter was born with Goldenhar syndrome and was active with CCA as a child. Sadly, she was overcome by the H1N1 flu virus and passed away in January. Her friends and family (mom, **Twyla**; dad, **Chuck**; and brother, **Chad**) chose to honor her by raising money for others with craniofacial conditions. **Dale 1891** and pub owner, **Scott Edelman**, hosted the fundraiser held April 13th in memory of Stephanie, donating all food and beverage proceeds toward the effort.

Members of Stephanie's favorite band, **Stormbringer**, **John Vasalakis**, **Rick Moon**, **Dana Newcomer**, **Eddie Pecchio** and **John Zahner** as well as sound tech, **Robby Vassalo** and band photographer, **John Fazii**, donated their time and talent to the event. Stephanie's friend, **Donna Montagnino** (aka "Pittsburgh Donna") initiated the idea of the memorial funder and helped pull it together. Thanks all!

state assistance:

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



september is craniofacial acceptance month

this year marks the tenth year CCA will observe September as Craniofacial Acceptance Month across the nation. Each year CCA families, friends, volunteers and related support groups band together to widen the circle of acceptance for individuals with facial differences. The goal is to create awareness of craniofacial differences and to get people to see that "beyond the face is a heart."

As part of the 10th Annual Craniofacial Acceptance Month, CCA will hold its **7th Annual National Picnic Day** on **September 13th** (or other date in September of your choice). CCA families across the nation will hold picnics giving them a chance to get together with other families in their areas, while promoting awareness in their communities.

If you would like to hold a picnic, contact CCA Program Director Annie Reeves. CCA will invite all of the families in your area and help you organize your picnic.

In addition to raising awareness and acceptance, CCA is raising funds to support programs and services available to all individuals with facial differences and their families. Contact CCA Development Director, **Jill Patterson** for materials about this year's fundraising efforts.

We hope you will join this important effort! Please call 800.535.3643.



Don't forget to **TURN FACEBOOK YELLOW** during the month of September by using a CCA Craniofacial Acceptance Month avatar, downloadable from our website at ccakids.org/acceptance-month.html



chance raffle / quilt raffle

Once again for this year's Annual Family Retreat, our families outdid themselves, bringing baskets and goodies from their hometowns and states to raffle to one another. Also again this year, **Mrs. Janie Thurmond** graciously donated her time, talent and treasure toward two fabulous quilts for raffle, one large queen-sized and another smaller, lap-sized. Total sales of tickets on both raffles set a new high reaching over **\$3,000**... about \$800 more than last year's tally. Winning the large quilt AGAIN this year was **Cheryl Smith** of Mustang, Oklahoma. (Apparently, your odds of winning DO go up when you buy more tickets!) And, the winner of the small quilt was the **Gonzales family** of Bloomfield, New Mexico. Executive Director, Charlene Smith drew the winning tickets. Thanks again to all who participated in both raffles by bringing items to raffle, buying tickets, and helping with the raffle in any way! See you all in Newport Beach, California in June, 2015!



quilt miniature quilt auction

around 110 miniature quilts at the **21st Annual Miniature Quilt Auction** were auctioned to benefit CCA. This special event was held at Dallas Market Hall during the **33rd Annual Quilter's Guild of Dallas Quilt Show** in March.

CCA was proud to be the chosen 2014 beneficiary, and we helped spread the word ahead of time to garner online bids for

the quilts as well. The event raised both funds and awareness of our cause, and net proceeds of **\$7,220.85** were presented by check to CCA.

Thanks to the auction committee, **Bonnie McElearney, Mary Lord, Donna King** and **Glynnis Wood** and especially to all the artistic quilters, who donated their fabulous "minis" to benefit CCA kids. Thank you all!



happy birthday cher!

Cher Crew fans and others donated to one of Cher's favorite causes in honor of her birthday, May 20. Cher Crew's **Jill Emerson** and CCA's **Jill (Gorecki) Patterson** got together to tell our honorary chair the sweet birthday surprise—**more than \$1,500** was raised for CCA! Thank you, all!

Click on
DONATE
 at ccakids.org

how to raise funds for cca

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

- **www.goodsearch.com** (Powered by Yahoo) Enter Children's Craniofacial Association as your beneficiary charity. (You only have to do this the first time. You may add others if you wish.) CCA will receive up to a penny each time someone uses the GoodSearch search engine.
- **GoodShop.com and iGive.com** Go to GoodShop.com or iGive.com, online shopping sites, both featuring hundreds of great stores including Best Buy, Macy's, Apple, and more. It's easy! Just shop as you normally would! You get the same prices, but a percentage comes to CCA!
- **Cash for Trash!** Save your discarded cell phones, empty laser / ink cartridges, GPS devices, digital cameras, MP3 players and old laptops. Call CCA for more information.

- **Matching Gifts** Many companies offer a matching gift program that could double—or even triple—your gift to CCA! Contact your human resources office to find out if your company has such a program.

One family donated \$2,500 and had it matched in order to get their free retreat hotel stay!

- **Planned Giving** Tax preparation time is also a good time to consider long-term tax savings. When you consult an attorney or investment professional regarding your wishes for distribution of your assets in your will, consider a provision for CCA. Your planned gift in the form of an endowment will live on after you.
- **CCA Web Store** You can shop at www.promotes.me/cca for your T-shirts, mugs, caps and more. So shop now and shop often!
- **Clubs / Hobbies** Have your club organize a benefit for CCA. Use your hobby or something you love to do to raise funds.
- **Denim Days** Raise funds at work for CCA. Establish a special day or days for employees to make a designated donation (cash or check) to CCA in return for wearing

blue jeans. The donation is usually \$1 to \$5, depending on how often the event takes place (for example \$1 for a weekly donation, \$5 for a monthly donation). Any higher amount would be at the discretion of the donor.

- **Civic Organizations** Public awareness leads to contributions. Contact and solicit opportunities to speak to your local civic organizations such as Rotary Clubs, Kiwanis Clubs, even HOG organizations (CCA has many 'biker' supporters). Distribute brochures and/or newsletters or other CCA-sanctioned materials for awareness and information. Ask for contributions.
- **Friends / Family Letter Appeal** Draft a letter to family, friends and acquaintances—anyone who has met or encountered your child. Contact CCA for a sample letter.
- **Kitchen Shut Down** Raise funds by raffling off chances to win meals for every day of the week, so the winner can "shut down" their kitchen. Local restaurants can donate meals or coupons. This idea could also be used for a week of entertainment, such as movie rentals or theater

tickets. Call CCA for more information.

- **Collection Cans** Ask local businesses to place a can or box (provided by CCA) to collect donations.
- **Get On Board!** Read our newsletter and learn about and participate in the events, raffles and funding efforts of CCA and our supporters. And, when you are finished with your copy of our newsletter, spread the news! Pass it along or leave it in a waiting room. (Remember to remove your address label.)
- **FirstGiving** There is a free customized CCA "firstgiving" site for anyone who wants help raising funds for CCA. Log onto firstgiving.com/ccakids and tell your personal story or post an event you're having. You can even set a goal and track success! When you tell your own story about your CCA Kid or why you are involved with CCA, folks will respond because they know YOU!

good news



Lawton C. Johnson Summit Middle School

The students and faculty at Lawton C. Johnson Summit Middle School in Summit, New Jersey, raised **more than \$4,000** via their annual "Hoops for Humanity" basketball game. Children's Craniofacial Association was chosen as beneficiary after the students read *Wonder*. CCA "Wonder" kid, **Trevor Larys** and his parents, represented CCA at a school assembly check presentation. Thank you ALL!

Cedar Valley Middle School

Cedar Valley Middle school in Round Rock, Texas, sent CCA a check for **\$220.65**, proceeds from their cocoa and donut sale. The effort was held because they took CCA's Choose Kind challenge to read, *Wonder*, take the Choose Kind pledge and support the cause! Thanks so much, everyone involved!

Caraway Elementary School

by Julie Cooper
After a district-wide reading of the book, *Wonder*, by **R.J. Palacio**, Caraway Elementary school in Austin, Texas held a fun run to raise funds to donate to CCA. Each donated any sum they chose and did laps around the track. It was a fun-filled event and we are pleased to contribute **\$207** to support Children's Craniofacial Association. Thank you for all you do. Thank YOU Caraway Elementary students and staff!

Seaford Elementary

Seaford Elementary school of Seaford, Virginia also held a *Wonder* project fundraiser and sent in a donation of **over \$600!** Thanks to coordinator, **Kimberly Stratton** and all who participated!

Holly Academy

Holly Academy in Holly, Michigan held a Jean's Day fundraiser and raised almost **\$400** for CCA, after a visit from CCA *Wonder*kid, **Peter Dankelson** and mom, **Dede!** Thank you!

Round Rock ISD Librarians

by Carlyn Gray
An initiative was planned around the promotion of reading the book *Wonder*, by **R.J. Palacio**. Our district librarians planned and implemented many activities to encourage students to read the book, to provide writing opportunities, and to increase our students' understanding of the struggles that children with

craniofacial differences experience and how to be more empathetic and kind to others. The culminating event occurred on February 10, 2014, when the author visited our district and spoke to 2,500 students about her writing and the book, *Wonder* and spoke later in the evening to the public with about 500 more from the community in attendance. Students, teachers, librarians and administration of the Round Rock Independent School District in Texas, presented Children's Craniofacial Association with a check for **\$6,608.98**. Thank you!

Medford Memorial Middle School



After 8th graders read *Wonder* in the fall, we celebrated our 2nd annual "Choose Kind" day on December 13th. Upon return from winter break, the 8th grade began to work on their goal of raising **\$2,100** in order to send a local family to the CCA Retreat in June. They sold "*Wonder*grams" during lunchtime. Additional donations were gathered through change jars set up at various locations in the school, a schoolwide pajama fundraiser, a *Wonder*-inspired scarf fundraiser and through a generous donation by Student Council following their annual charity basketball tournament. Thank you Medford Memorial!



Dolsen Elementary

by Laura Weakland

Our Dolsen Elementary Helping Hands Club is proudly displaying a very large check of what they raised with our bookmark sales! The students raised \$175 through bookmark sales and then our PTO matched their efforts for a **\$350** donation to Children's Craniofacial Association. Such a positive experience for my students to be involved in! CCA Kids say thank you one and all!



zumbathon for cca

The first-annual **Chase's Quest Zumbathon** was held Sunday, May 4, 2014, in Richmond, Virginia. Hosted by CCA Mom **Carrie Ingram** and named for her son, **Chase Ingram**, the event took

place at the Richmond Raceway Complex at the Old Dominion Building. There were 20 plus Zumba instructors who led participants for four hours of Latin American dance moves performed to mostly Latin American dance music. Seventeen vendors came out to support Chase's Quest, each giving a gift (or gifts) for a door prize drawing—30 prizes



Nehaunsey Middle School

by Cathy A. Tortella, RN

On Friday, June 6th, we held our 2nd annual "One Book, One School" event at Nehaunsey Middle School. Every student and school staff member received and read, *Wonder*. The day's activities included a presentation from the **Children's Hospital of Philadelphia's Division of Plastic and Reconstructive Surgery**, several of their patients and parents, and of course, **Lentil!** Other events included team-building activities on trying a difference, writing *Wonder*-Grams, a quiz show game on the book's content and much more. It was an exciting day and we are happy to contribute **\$210** in donations from some of our students' parents. Thank you Nehaunsey Middle School, students, staff and parents!



in all—that were presented throughout the event.

A huge thanks to all who sent donations, participated in the event and volunteered to help make this event a success! Carrie especially wishes to thank two awesome ladies, **Donna Carver-Bolan** and **Carol McDonald** for helping put the event together

and making sure it was successful. She says it wouldn't have been possible without you!

This inaugural Chase's Quest Zumbathon grossed **\$3,400** for CCA Kids! Thanks again, everyone!



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Cher

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

rick's raffle 2014

The drawing for our 4th annual raffle, held in memory of **Rick Dornier**, was held on Rick's birthday, April 25. **Pat Arrington**, who had 30 tickets in the raffle, was the winner. Pat generously donated the deluxe Thomas Wooden Railway "Grow with Me" play table and "Happy Birthday" Thomas engine back to CCA to raffle again at our Annual Family Retreat, saying "It sounds like a great idea; a fun money-maker that will still mean that this wonderful toy will go to a CCA child." The raffle brought in **\$1,180** prior to the retreat. Thank you to all who participated! The lucky winner at the retreat was **Jesse Bridgins**. Congratulations to Jesse, one very happy boy!

