THIS ISSUE OF THE *CCA NETWORK* IS DEDICATED IN MEMORY OF **STEPHANIE SUMPTER**

ccanetwork

newsletter of the children's craniofacial association

Cher—national spokesperson

2014: Issue 1

inside

are we ever really in control?

By Jackie Hafter

I blew it. Well, sort of. Saturday night, we were sitting around the table after dinner. Gabriel was talking about the curriculum that he is developing for his class when they read the book, *Wonder*. (This book is phenomenal, and focuses on a kid with a syndrome similar to Gabriel's.)

He was discussing the part when the main character, Auggie, describes the beginning of his life. I am listening. The other kids are eating and talking. In my mind, I'm still overwhelmed by a character dying in the book that I am reading. In addition, I haven't slept well in six weeks while we have been tending to Gabriel's recovery from his third jaw distraction surgery.

And then it hits me. I should have been expecting it. Gabriel has been very passionate about *Wonder* and his connection

see **gabriel**, page 16

message from the executive director

We are very happy and proud to announce that on February 24, 2014, Children's Craniofacial Association began its 25th year of serving individuals and families affected by facial differences. I remember my first two weeks working for this organization. I had never heard the term craniofacial and had no clue what it was about. I was a volunteer for another organization that had a direct impact on my family. When this organization's executive director left to become the first executive director of International Craniofacial

see **executive director**, page 8

ccakid

meet preston dubray

Preston DuBray is eight years old and lives in Nebraska. He's in elementary school, where he has a great time interacting with his friends and saying "hi" to everyone. His favorite subject is music class. Preston also likes to do his schoolwork—and play games, watch shows and just about anything else—on his iPad.

He is really close to his brothers, **Victor** and **Harry**. They like to play wrestling games, a lot, much to their mother's dismay. But Preston has a blast. When Harry has his little brother in a lock Mom says she just "looks the other way."

Preston likes to go to the park and visit a nearby farm, where he helps feed the animals, sometimes feeding the horses from his hand. He likes to watch some TV, and would watch the "Price Is Right" all day if Mom let him (which she doesn't). He loves the movie, *Monsters Inc.*, and has just about every toy, gadget, shampoo, etc. associated with the franchise. He loves to go to Walmart, most likely because he knows that's where the toys and all the *Monsters Inc.* goodies are.

He enjoys listening to music, and his all-time absolute favorite artist in the whole world is Carrie Underwood. He has multiple copies of all her CDs, and in 2009 got to meet her in person! Seeing Ms. Underwood and having his picture taken with her was a dream come true. In fact it was Make-A-Wish that helped make that magical event happen.

Preston and his family would like to go to the CCA annual retreat next summer, but he has to wait and see if he has surgery or not. (Preston was born with Pfeiffer syndrome.)

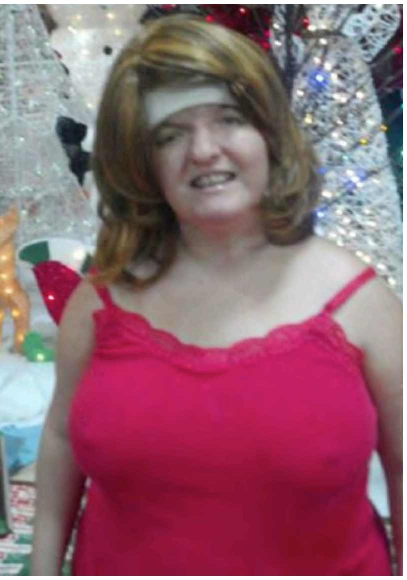
In the meantime, he is seeing a new team of therapists that are helping him enormously. He is learning to eat without a feeding tube; a big goal of his is to walk without his walker. He's getting there—he stood on his own recently, letting go of the counter. Way to go, Preston!

ccaadult

meet stephanie moore

By Vicki Moore

Stephanie was born in Tucson, Arizona, and was diagnosed with Craniosynostosis at birth. She was missing bones in her hands and feet and she was very small. Stephanie had her first craniofacial surgery at the age of 15 months. The doctors said she would have to wait until she was 19 years old to have any more surgeries because that would be when her skull was fully formed.



There was a long period of time in her childhood when it felt like there was nothing that could be done for her condition. When she was 17, she developed epilepsy and that was one of the most difficult times in her life to get through. She has not had a seizure since 2008, and they are controlled. She is really happy about that!

Stephanie has always been active in Sunday school and most people who meet her say she has a lot of confidence and is very friendly to everyone. She enjoys swimming and going for walks by the lake. There is a new program sponsored by a respite service here that offers free bowling on Sunday afternoons. She is planning on doing a lot of bowling this year!

Her favorite song is “Story of my Life” by One Direction, and her favorite movie this year was *Monsters University*. Stephanie loves to dance and go shopping and spends a lot of time socializing on Facebook. She is saving up for the CCA retreat in St. Louis and is really looking forward to meeting new people—and of course the dance! Right now, her hair is just beginning to grow out again after last year’s surgery and she likes to go to the hair salon and get it styled and have her eyebrows waxed.

Last year, she found an excellent doctor, Dr. Craig Hurst, at the University Medical Center, in Tucson. She is really happy with Dr. Hurst, and she knows that he will give her the best care possible. She has met a lot of friends on Facebook through CCA and church, and believes that anything is possible if you have faith. She works as a Sunday school aid at church, and she would like to get a job at Fry’s in a couple of months.

Stephanie has faced a lot of disappointments in her life, but she has learned that each day is a new beginning with new people to meet! Most people are inspired by her smile through all the obstacles, and they say they have learned one very important lesson from her and that is to never give up!

ccasupersibs

meet harry dubray

hi, I'm **Harry**, Preston DuBray's oldest brother.

I did not see Preston for about a month after he was born. But when I got to see him I just felt joy. The day he got home I was at my grandma's house, who lives next door. I can remember that day like it was yesterday. He was home and he was hooked up to a feeding tube. I was wondering what it was. My mom explained to me that he has to eat like that and then I asked why. She said because he can't eat with his mouth.

When he was three months old, he had to go to Denver for a surgery. I always felt sad when we went to Denver because I only got to see him for a little bit. Then, when he was two, we started going to Dallas for his surgeries; there I was able to spend a lot more time with him.

When I'm with Preston I feel like the luckiest big brother in the world. He is fun to play with and is a funny kid. He is my joy and the reason I want to wake up every morning. I help him get dressed and then we go to school. After school, we hang out in our room and play video games and just laugh over funny things. I'm proud to be his big brother.

My favorite movies are *Remember the Titans* and *The Blindside*, and my favorite TV show is *Duck Dynasty*. I love to play WWE 2k14 with my little brothers, and my hobbies include collecting football cards and watching and playing football.

meet victor dubray

hi, I am Preston's older brother, **Victor**.

When Preston was born, I could not see him for a long time. I did not care if he was different. He was my brother, and I loved him. Preston and I play games.

When we go to the store, people sometimes stare at Preston. I felt like just because Preston was different people thought he was a freak. Some kids smiled and liked Preston. At the store one time a little kid waved at Preston and shook hands with him. When I saw that I was very happy. This was the first time Preston made a friend at the store. I love Preston no matter what he looks like.

My favorite movie is *Star Wars*. My favorite sport is baseball. My favorite food is watermelon. My favorite video game is Star Wars.

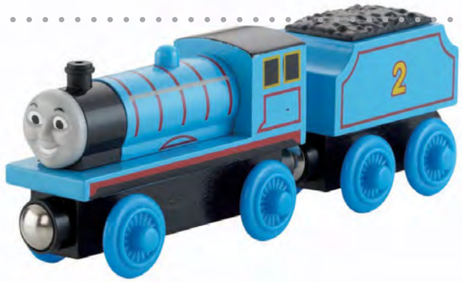
chocolate festival 2013

What an incredible event this year's Chocolate Festival became. Not only did **Chef Rick Chiavari** and his team of chocolatiers and volunteers raise funds for CCA, they set a new Guinness World Record for the largest chocolate mousse!

Along with tasting the regular fare of chocolate delights, folks at **Aventura Mall** on Sunday, October 6, 2013, were treated to a dessert cup share of the 496-pound mousse! The recipe included a whopping 24 pounds of egg yolk, 108 pounds of chocolate, 20 pounds of sugar, 66 pounds of butter, 50 quarts of heavy cream and five gallons of milk.

The successful day brought in about **$15,000** for CCA kids like Chef Rick's nephew **Seth**, to whom he and wife **Laurie** dedicate their involvement with CCA. CCA would like to thank them, along with their own grown and volunteering kids, **Kelsey** and **Brett** (Brett's restaurant, **B.C. Cafe** was also a sponsor), **Aventura Mall** and the many folks who helped make this, the Sixth Annual Chocolate Festival, possible: **Chef Danny Malone**; **Monica Glukstad** and **Aventura Mall staff**; employees of **Turnberry Resort and Ocean Colony** and volunteers: **Renee**, **Sarah**, **Amy**, **Robin**, **Harley**, **Jamie**, **Denise**, **Leo**, **Elaine**, **Paige**, **Edna** and **Sheree**; and, of course, all the other participating sponsoring restaurants and vendors: **Churro Mania**, **Clarabelles**, **Color Me Mine/Alisa's Painted Bistro**, **Crepemaker**, **Dolce Peccati**, **Florida International University**, **Ft. Lauderdale Art Institute**, **Mariners Sand Country Club**, **Munchcakes**, **P.A.C. Pastries**, **Porto Vita**, **Sugar Yummy Mamma**, **Sweet Tooth**, **The Daily Melt**, **Trazos Academy**, **Turnberry Isle**, **Turnberry Ocean Colony**, and **Veggie Express**.

Thanks so very much one and all. And congratulations Guinness World Record breakers!



rick's raffle 2014

the fourth annual Rick's Raffle is underway. Founders of the fundraising effort, **Ann** and **Doug Burgin**, established the raffle in memory of their beloved grandson, CCA Kid, **Rick Dornier**.

Thomas the Tank Engine toys were among Rick's favorites, so the raffle prizes always have a Thomas theme. This year's prize is another **Deluxe Thomas Train Table**. And, included will be a Thomas Wooden Railway Engine Happy Birthday Special—a "Birthday Thomas" and a "Cake Cargo Car" that plays the Thomas & Friends theme song!

In accordance with the Burgin's wishes and also Rick's family, all funds raised will go toward CCA's Patient Financial Assistance program in Rick's name, to help families defray expenses while seeking medical care for craniofacial conditions.

Tickets are still just $5 each, five tickets for $20, or 15 tickets for $50. Sales started February 14 and will continue through to the drawing of the winning ticket on Rick's birthday, Friday, April 25.

You may use our regular online donation site to make a purchase by indicating "Rick's Raffle." Or call CCA at 214-570-9099 or 800-535-4643, or email Jill at jpatterson@ccakids.com. And, please pass it on!

9th annual friends of jeremy golf tournament

The Dale Family, Back Row: Kristine and George
Front Row: Tommy, Jeremy, and Cody

L to R:
Frederick Seitz,
Jeremy Dale
and Ryan Gulich

The 9th Annual Friends of Jeremy Golf Tournament was held on Saturday, September 21st at the Corning Country Club in Corning, NY. And despite the very rainy weather, there was an incredible turn-out and overwhelming support from the community, our co-workers, friends and family. We are so grateful for the tremendous support of our 132 golfers and over 50 generous sponsors that helped to make the day a success! The tournament included a raffle, silent auction, closest to the pin 50/50, closest to the line prize and a skins game. There was a special raffle for a 40" LCD TV and a Microsoft Surface. The silent auction included many autographed memorabilia including items from the NY Giants, New York Rangers, NY Knicks, Buffalo Bills and a Derek Jeter photo! The event was a huge success raising over **$30,000** for CCA!

Jeremy was again joined this year by fellow CCA kid **Ryan Gulich** and CCA adult **Frederick Seitz**! It is so wonderful to have CCA friends join us for the tournament each year. The golfers really enjoy seeing the kids from CCA!

We are so grateful to everyone who supported this event and the kids from CCA. For more information about the tournament visit www.friendsofjeremy.com.

lily's dinner

Lily's Fourth Annual Craniofacial Awareness Dinner was a huge success! Of course, true to her diva personality, she planned what she was wearing for three months before her special night.

More than 130 people attended, including **Lily** and three of her adorable CCA friends: **Hope**, **CeCe** and **Hailey**. We held the event at Bella Vista Reception Center in Lindon, UT on Saturday, November 9, 2013. We had a delicious dinner catered by Urban Pioneer Catering.

We are so grateful for our generous sponsors this year. A big thank you to **KLS Martin Group**, **D.R. Horton Homebuilders** and **Rocky Mountain Power**. We could not have held the event without their support.

Dr. Rodney Schmelzer presented some information about craniofacial surgery and the importance of donating to CCA's cause. I had many comments about how caring, compassionate and sincere his speech was. It truly was an honor to have his presence and support.

The silent auction, as always, was the highlight of the evening. We had some fun items, such as artwork from Dowdle Folk Art, Southwest Airlines tickets, Little Giant Ladders, an autographed football from the Chicago Bears, many dinner gift certificates, stand-up paddleboarding, and many more fun and beautiful gift baskets. We raised **more than $7,000** for Lily's cause.

Thank you to the many family, friends, donations and supporters this year. We truly are in awe of the support and love of everyone. It would not have been the same without each and every one of you!

Thank You! Looking forward to next year!

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.

executive director, from page 1

Foundation (CCA today), she asked if I'd like to come to work with them. So, on June 1, 1989, I entered into the world that would become my passion, where I would meet some of the nicest, smartest, bravest and most resourceful people, and where I would spend the next 25-plus years.

It seems amazing now to reflect on those early years. Families affected by craniofacial conditions had so many unmet needs; it was hard to know where to start. We listened to our families and started to develop our programs and services.

The first thing we did was obtain a toll-free number on which our families could call and connect with us since long distance calls were so expensive. The Internet wasn't mainstream back then, so families only found us through word of mouth, by the few craniofacial healthcare providers who knew about us or the rare occasions when we received press coverage. Thankfully, in the early 90s, because of Cher's involvement, we had a couple articles in widely read magazines, and she also appeared on the *Maury Povich Show* with four of our families.

So, word spread, but it spread slowly. In September 1990, CCA's founder, two craniofacial surgeons and 10 families testified before the House Budget Committee in Washington, DC. While there, families met with CCA's Spokesperson, Cher. When she heard families talk about how this was the first time they had spent time with other families who shared similar circumstances and how comforting it was, she suggested holding an annual meeting or camp. The next June 1991 the first ever Cher's Family Retreat was held in Orlando, Florida.

There seemed to be a few common threads we heard every time we talked to our families: frustration over not having information about the various craniofacial condition(s) their family members had, not knowing where to turn for medical care, and how expensive it was when they *did* find quality care miles away from home. If they could find information at all it was in medical journals and papers found in libraries written in medical jargon they were unable to easily understand.

Not only did the families not know where to seek quality craniofacial medical care, neither did the healthcare providers at their birthing hospitals nor their pediatricians. In fact we heard many times that their pediatricians couldn't make a diagnosis and it was only because of the "gut feeling" of a parent, that they pursued answers. And, even when they did find medical care they often had expensive, long-distance travel to receive it.

So it became pretty clear what our first programs would be. CCA started by providing the families with a list of the International Society of Craniofacial Surgeons (ISCS). This society was started by the doctors who studied under the "Father of Craniofacial Surgery," Dr. Paul Tessier of France. Members had to have completed a fellowship under an accepted craniofacial surgeon, worked with a craniofacial team of doctors, and performed a certain number of surgeries each year.

The financial assistance program was started to help families with food, travel and lodging when it was necessary to travel to the relatively few centers in the United States. And, in 1993 CCA printed its first two syndrome booklets, *A Guide to Understanding Craniosynostosis* and *A Guide to Understanding Apert Syndrome*, as well as the first CCA newsletter.

In 1991 we changed the organization's name to Children's Craniofacial Association to reflect the need to bring families aboard while their children are young so they can fully benefit from our programs and services during each stage of their lives.

Now, 25 years later, we've come full circle. We've raised a whole generation of CCA Kids—many of whom continue to attend the retreat every year—and those young adults are now role models and mentors for the youngsters.

And, 25 years later, although technology has changed drastically, many fundamental needs for families affected by craniofacial conditions remain the same, and CCA continues to provide for those needs.

Cher is still CCA's Spokesperson, and in June 2014 we will hold our 24th Annual Cher's Family Retreat that now starts with a one-day Craniofacial Symposium where craniofacial team members in the retreat city, volunteer their expertise.

We now have 14 syndrome booklets in publication, have added 14 one-page overviews that describe syndromes and topics related to having a craniofacial condition, and our newsletter has grown from a 4-pager in 1993 with a distribution of a couple thousand, to 24 pages today with a distribution of around 14,000.

CCA is still providing a list of craniofacial surgeons who are members of the ISCS, albeit a much-expanded list, and we are still providing financial assistance for families who must travel for their care.

We have a newly redesigned website, a blog, Wiki page, and Facebook, Twitter and Pinterest accounts. We have an extensive networking list, a very active yahoo group, as well as young adults and families who stay connected all year long through Facebook.

As we move into year 25 and beyond, our goal is to bring many more families on board. We started with just a handful in 1989, and today we serve over 7,000 families. But there are still many families who need to be made aware of CCA and what we can do for them. So we continue to spread awareness through our website, social media and our over 420 volunteers around the country who distribute information packets to local hospitals, healthcare providers and schools in their communities.

Though we would prefer it was not necessary for CCA to exist, as long as we *are* needed we will strive to serve all families that are affected. All the while, we continue to envision a world where all people are accepted for who they are, not how they look.

Char Smith

CCA Executive Director

registration is now open for 2014 annual cher's family retreat

June 26-June 29
in St. Louis, MO

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

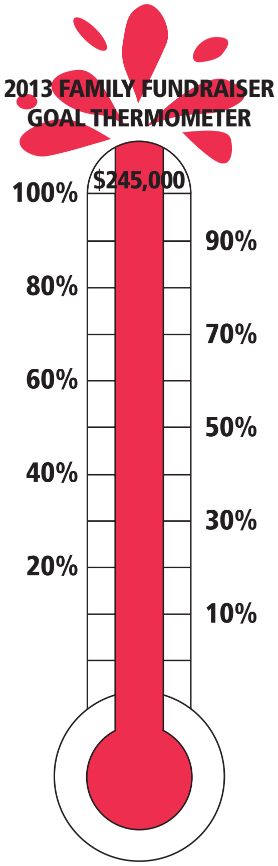
For more information,
please contact Annie Reeves,
AReeves@ccakids.com

We hope to see you there!

Registration ends May 23, 2014.

calendar of events

date	event	contact
2014		
Apr 25	**2nd Annual Texas Moms' All the Way for CCA Golf Tournament** Battleground Golf Course Baytown, TX (Houston area)	Becky White ledestiny@gmail.com
May 4 2-6PM	**Chase's Quest Zumbathon** Richmond Raceway Complex Richmond, VA	Carrie Ingram jcicai@msn.com
May 7-8	**3rd Annual Morgan Meck's Match Play Invitational** Coto de Caza Country Club Coto de Caza, CA	BMecklenburg@redwoodsgroup.com
Jun 26-29	**24th Annual Cher's Family Retreat** St. Louis, MO	AReeves@ccakids.com 214.570.9099 800.535.3643
Jul 12 8AM	**2nd Annual "Miles for CCA Kids" Poker Run** The Allen Wickers Pub & Grill Plano, TX	lewis.boykin@aggressiveusa.com
Jul 18-20	**11th Moebius Syndrome Conference** Bethesda, MD	www.moebiussyndrome.com 660.834.3406 plicht@yahoo.com
Aug	**Jaci's Fundraising Effort** TBA	**Jaci Samhammer** countrygirl28576@gmail.com
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	AReeves@ccakids.com 214.570.9099 800.535.3643



Click on

DONATE

at ccakids.org

thank you for choosing kind!

August (Auggie) Pullman was born with a facial difference that prevented him from going to a mainstream school—until now. He's about to enter 5th grade at Beecher Prep, and if you've ever been the new kid, then you know how hard that can be. The thing is Auggie's just an ordinary kid, with an extraordinary face. But can he convince his new classmates that he's just like them, despite appearances?

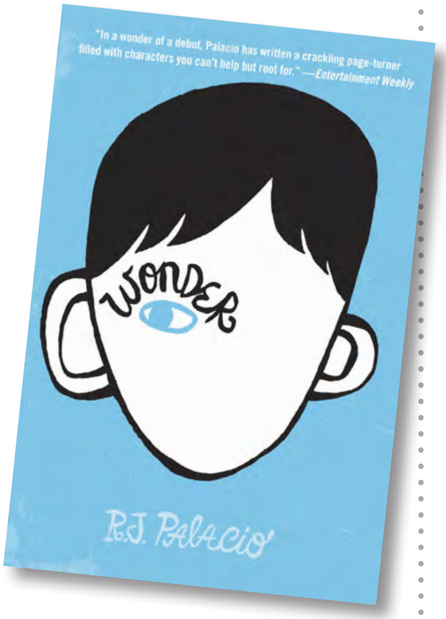
CCA is on a mission to spread the word about acceptance of facial differences and the book, *Wonder,* by R.J. Palacio has given us a perfect platform. The book promotes the message to "Choose Kind" and takes a stand against bullying.

CCA would like to see the "Choose Kind" campaign endorsed by schools across the country, and we are promoting a grass roots effort to make that happen. **If you have children between the ages of 9 to 13 we need your help.** First, please read the book, then share the book and supporting materials with your children's school(s).

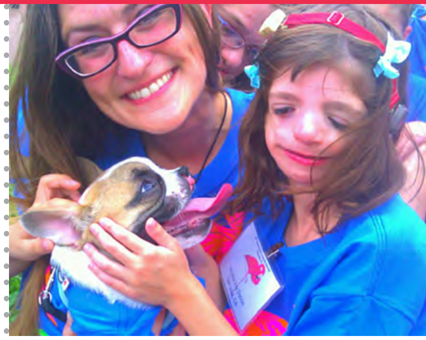
Educators are excited about *Wonder*, because not only does it have an anti-bullying message, but it also meets National Common Core Standards for K-12 Literature. In particular, the book meets the Character Component benchmark for 5th grade literature.

For more information on how you can help, contact AReeves@ccakids.com.

In addition to the book *Wonder*, "Choose Kind" Bookmarks, Buttons and Wristbands are available for purchase for personal use or to use as fundraisers. Order from CCA's Webstore or contact JPatterson@ccakids.com.



Wonder is available at ccakids.org/wonder.html for $12



Lindsay, Lentil and T.J. Dyson

go team lentil!

Puppy power and a simple request from "Momma Bean" moved over 1,000 members of "Team Lentil" to donate **over $27,000** to make sure more kiddos in local Philadelphia and all across the nation have an opportunity to experience our Annual Family Retreat. The program, considered by those we serve to be one of the most important services we offer, is held in a different city each June and the 2014 event will be in St. Louis, Missouri. Thank you **Team Lentil**, **Lentil Bean** and **Momma Bean**, **Lindsay Condefer**, for your caring support of our CCA Kids!

midwest holiday party

the annual CCA Midwest Holiday Party was held December 14, 2013, at the Parkway Chateau / Brat Stop in Kenosha, Wisconsin. Once again, the lunch fare included pizza and soft drinks followed by holiday desserts. Activities included holiday crafts lead by CCA mom, **Marla Verdone** from Janesville, Wisconsin, and plenty of visiting. Special thanks this year go out to **Lynn, Paul and Jessica Jaskowiak** for helping us provide toys for Santa to give and to **Jon Hansen** (Santa) and his helper **Erick Gorecki** for traveling miles through the snow to join us after a last-minute cancellation. A good time was had by all. See you next year!

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.

pete's oktoberfest 2014

Pete's Oktoberfest took place October 11, 2013. The **Dankelson family** of Highland, Michigan (seasoned CCA volunteers) hosted friends and family attending from Michigan, Ohio, Missouri and Indiana for the second consecutive year.

Dede and **Darin Dankelson** wish to extend special thanks to:

- **Shawn** and **Ellie Dankelson** for bartending
- **Doug** and **Patty Ogg** of **Watkins Flowers** for donating the beautiful centerpieces for the raffle
- **Dan** and **Jennifer Zamiara** for donating Pepsi beverages
- **Mr. Steve Suser** of **Sparkies Catering**
- **Prestwick Village Golf & Country Club**
- **Mrs. Helen Beaudry** for chaperoning **Peter** and **Jacob** and selling raffle tickets

The weather cooperated nicely, providing a beautiful fall night for what turned out to be a very successful party—netting **$5,000** for our CCA kids! Thanks, everyone!





good news

gingertown dallas 2013

The 4th Annual **Gingertown Dallas** build was held December 3, 2013. The Olympic-themed creations, "Gingertown World Games," were displayed at NorthPark Center through December 8. Donation receptacles were available throughout the effort. Once again, all net proceeds from the auction of the delightful Olympic Village benefited CCA!

Founders of the national one-of-a-kind holiday initiative, Washington, DC–based **David M. Schwarz Architects**, cut a check for **$8,211.61**, which was presented to CCA by NorthPark's management.

NorthPark Center, one of America's premier shopping destinations, prides itself in its ongoing commitment to the community and serves as host site for an array of important events throughout the year like this one. The Gingertown Dallas project brings together talent from more than 20 local design, engineering and construction firms to create a gingerbread town. Each handcrafted structure is auctioned to benefit a select children's charity.

The exposure and attention to our cause that CCA received during this effort helped us to spread awareness and understanding in the community, invaluable in fostering acceptance of facial differences and critical to our mission.

Everyone involved contributed toward this greater goal while raising much-needed dollars for our Patient Financial Assistance program.

Thank you Gingertown Dallas participants!

Find out more at Gingertown.org. Be sure to "Like" Gingertown Dallas on Facebook.

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 AReeves@ccakids.com and let her know you want to **save the environment and save money for CCA**.

stephanie lee sumpter

The Sumpter family attended some of the first family retreats in Orlando, Florida.Stephanie Sumpter passed away on January 27, 2014 due to complications from the H1N1 virus. Stephanie was talkative, witty and funny, and had a deep and honest sense of compassion for others. At her eulogy, Stephanie's mother Twyla read a facebook post Stephanie originally wrote in 2009, and updated from her hospital bed on January 22, 2014. Following is Stephanie's post.

May 14, 2009 at 1:18pm

To fully grasp the beauty of a person you have to feel it; you can't see it. Everyone is so very different than the next we have to take time out of our lives to get to know someone. Imagine what possibilities we could be missing if we didn't stop and get to know someone only based on their appearance. If this were true, I wouldn't have the friends I do. Life is more than color, religious preference, social status, and political views.

Through many trials and tribulations I have gotten myself to where I am. I am who I am today because of the love and support of those who took the time, who didn't walk past me and wonder or come to their own conclusions.

My downfall is I have always been too open and caring. I think sometimes everyone WANTS to hear my story, sadly they don't. However, I am compelled to tell it because I feel everyone NEEDS to hear it. No one's life is perfect and we all have faults. I was born with a birth defect. I cannot change it, but it has changed me and molded me. I often wonder if I hadn't gone through the 35 plus surgeries that I have, would I be no different or better than those who walk by me? Would I be as ignorant?

The funny thing is, I am now 32 and have reconnected with a lot of old friends. Some I have missed terribly and some that were mere acquaintances. They all talk about how they wish they had gotten to know me better, because I am such a cool person. I am the same today as I was then, only a little wiser. In high school my friends told me after my final surgery, "Just think of all the guys you will get and the ones who didn't want you then will want you now." But if my insides are the same but my outside is different and they now want to be associated with me, I don't want to be associated with them.

I have lived my life this way for 32 years. Endured more emotionally than some will in their lifetimes, I pray. I am strong, I will admit, but this is not for the weak hearted. My emotions run high. Sometimes I can't understand why people wouldn't want to "hang out" with me. Then I look in the mirror, and remind myself that tomorrow is a new day and a chance to make a difference and to tell my story.

Not everyone is ignorant. Don't judge a person by how many friends they have but by the quality of those friends. I will not name any names here, but my best friend and I met in High School. We can just look at each other and know if something is wrong or right. We have been through so much together. Births, deaths, heart break—you name it—and she accepts me and I her, and for that I truly love her.

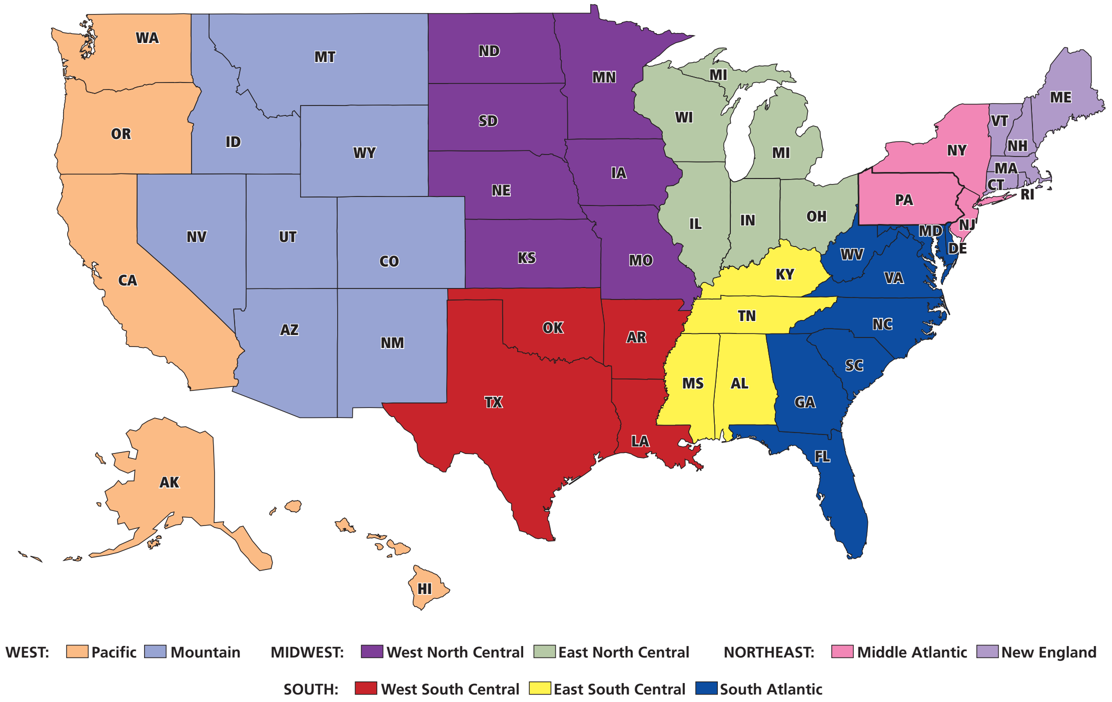
I remember growing up being embarrassed by myself. Having surgery after surgery, having to have my mom come to school to help me eat after another jaw surgery, or not being able to play in P.E. I think I was like in the 1st or 2nd grade before I truly realized I was different than everyone else. My difference is my heart is big, and my strength and determination were established at a young age. Pity is not what I want or look for, it's understanding, compassion for one another and respect. Don't look at someone and say what can they do for me but say what can I do for them. Pay it forward. A little act of kindness goes a long way.

My birth defect for those who don't know is not genetic, they don't know where or how it came to be. And if you think for a minute I don't or haven't questioned my existence once in a while you're nuts, but it's not up to me.

We are all like worker bees. Sent here for a purpose, but until that time comes we won't know what that purpose is or was. These are just random thoughts, not meant for anything or anyone. I just wanted to say what was on my mind at the moment.

Cherish those around you. You never know what tomorrow brings. Extend an invitation to someone you had been pondering about, you never know what joy you might find or might find you. Until next time, this is Stephanie saying, "Over and out!"

would you like to become a cca volunteer?



Public awareness about craniofacial conditions is important on several levels. It's important families find quality medical care, that healthcare professionals are aware of the special medical and emotional needs of children and adults with facial differences, the public understands and accepts facial differences and that individuals with facial differences are accepted.

CCA is looking for volunteers who will distribute educational materials throughout their communities. If you would like to help educate your community and take part in this National Awareness Effort, call or email CCA Program Director, Annie Reeves at 800-535-3643 or areeves@ccakids.com.

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gabriel, from page 1

to Auggie. He reads to me the part about Auggie's birth.

"Ima ('Mommy' in Hebrew), did you know I was different before I was born?" My eyes go wide. I sucked in my bottom lip and bit down so hard. I can't blink, I am straining so hard to keep the tears from falling, making everything in my line of sight go blurry. I see all the eager beautiful faces of my children just staring at me.

I think to myself. I have to respond. I have to hold it together. I have to not influence Gabriel to think anything that is hurtful or negative. I swallow hard.

I can't stop it.

I cover my eyes and the tears flood out. I'm trying to hide behind my hands, but the sights and sounds behind my hands deceive me. The kids all say, "What is wrong?" Aviva, his little sister, comes and rubs my back and says "Ima, take a deep breath" I laugh inside. Isn't that the same thing I have been saying to Gabriel, the same sentence I have used to coach him to cope over the weeks that have been passing by. I can't allow the laughter to escape me. I just choke out "Get Abba ('Father' in Hebrew)." I looked at the words blurring in my book and mumble about the book being sad and one of the characters dying.

Abba comes and hugs me. He tells Gabriel simply, "When you were born, we noticed that your ears bent over." Gabriel says, "Like Dumbo…." (He has always had a connection to Dumbo.) Abba continued, "Then we took you to a big children's hospital."

I studied Gabriel's face, took a deep unstable breath and began Gabriel's history like I remember it.

He was born and, yes, we noticed his ears and we noticed depressions in his face under his eyes, that we later learned was his lack of cheekbones. He was taken away to get cleaned and get oxygen. He looks up, questioning in his eyes. I told him he needed oxygen because the medicine that I had for the pain during delivery made his breathing slow down.

He was the first one with his birth defect (Treacher Collins) in that hospital. The doctors and nurses didn't know what it was. The next day, a female Indian pediatrician with wild dark frizzy hair and a deep purple shirt, walked into my room with a huge textbook with a faded cover, yellowed-pages and old-looking type. I didn't read the words when she put it on my lap, just noticed the picture.

The pediatrician was so cold, hard and devoid of emotion, just like the faded book. Jay's anger boiled as my fears grew. He sent her away asking her never to return.

My doctor was there and soon sat on my bed. He told me he printed some information for me to read. He told me we would have to take Gabriel to a children's hospital. He tried to be comforting and kind.

I was left with these sheets of paper to explain our future.

I remembered how we had to fight to get him released from the hospital. There was a neonatologist who had shoved a tube up Gabriel's nose without our consent. Jay was beside himself that this doctor could have harmed Gabriel and what had he been looking to find. Then, the doctor wouldn't release Gabriel without a CT scan. Jay started calling and fighting for what was in Gabriel's best interests.

Laughter formed inside me, as I relayed this information to Gabriel so many years later. This fight for Gabriel started just hours after he was born and has continued so many times to this day: Jay fighting. Jay finding the contacts to support his gut feelings and medical understanding. Jay advocating and taking on an added unnecessary burden to the emotions and fears that loomed inside of us.

We took Gabriel to Children's Hospital in

Gabriel with his siblings: Gabriel, 11; Judah, 10; Aviva, 8; Sofia, 5

Philadelphia. We met with his surgeon who informed us of the future surgeries to his jaw and what complications may arise along the way. We met with his ENT discussing his potential hearing loss. And we met with the geneticists who confirmed Gabriel’s diagnosis clinically. But we still needed a blood test to be sent to the only lab in the country that tests for his birth defect.

I explained the genetics to Gabriel. So boring to some, but so defining to our family. The lab needed to find the mutation (a feat compared to finding the one misspelled word in a random book in the Library of Congress). They were looking for a treacle protein deletion on the TCOF1 gene of the fifth chromosome, the one that defines the facial bones. My extremely science-proficient son drinks in this information and gets it.

Then we talked about percentages. Sixty percent of people with Treacher Collins syndrome get it spontaneously; 40 percent had it passed on by one of their parents. I didn’t anticipate the natural question that would follow: What is the percentage of me passing it onto my children? Eyes wide and with the pain in my chest digging deeper, I hear myself choke out: “50 percent.” I see Gabriel blink and calculate in his brain. He says, “Out of what?” I tell him 100 percent. I hear Judah, his little brother, say, “Wow! That is a high percentage.” I scrape something nonexistent off my skirt and while still looking down I somehow manage to say we will discuss that more later.

And I push that part—those fears, the emotions, the concern—deep down where it lives buried in my brain, tucked in so far that it will hopefully be a long time before it resurfaces. Gabriel, however, in those three seconds, processes this and says, “Well, that is a discussion you will have to have with my wife one day.”

I look up at him wide-eyed with my mouth gaping open. Months of postpartum therapy and antidepressants after Gabriel was born, fretting about how to manage his future and in three seconds, he taught me a brilliant lesson. If only I had had a crystal ball when he was born to see that he would be the one to teach me how to cope with the future.

And that is how the discussion unfolded, the one I knew for the last 11 years would one day happen. I was not able to process if I was upset that I cried, happy that I can put the anticipation behind me, fearful of Gabriel’s processing of this information or stunned as I so often am when reality stops me each time, even with 11 years of knowledge. What I am 100 percent certain about after our discussion is that Gabriel has grown to become an unbelievably confident, understanding, intelligent, determined, passionate, caring, kind and WONDERFUL kid, who just so happens to have Treacher Collins syndrome.

empowering children to cope with teasing

By **Amy Smith** • Child Life Specialist • Medical City Children's Hospital • Dallas, TX

teasing can happen to anyone, but some research indicates that children with disabilities are at a greater risk because teasing is usually about a visible difference. According to Ms. Joseph, social worker at Bloorview's neurodevelopmental program, "It's human nature to be curious, so from an early age children with disabilities need to be armed with the information to respond to questions, stares, and unkind comments." Parents and professionals play a critical role in preparing and empowering children with disabilities to cope with challenges of their chronic condition.

Talking with children about their facial difference can be a powerful beginning for more discussions regarding feelings and expectations for the future. It's important to use developmentally appropriate language and concepts children can understand. For example, preschool age children may learn about differences best by understanding differences around them. For example, parents can point out differences such as: some dogs have short legs and some have long legs. Whereas school age children may understand simple explanations, but have questions about the causes. Such as, "Do other children have these differences?" Is the condition permanent?" In order to come to terms with the condition, children need the opportunity to ask questions, take an active role in self-care, and learn how other children cope with their feelings and condition.

Adolescents need to make the decision about how much or little information they want to disclose to different people. Being involved in decisions regarding possible options is also essential for this age group because this control will foster relationships, increase compliance, and improve self-esteem. Children who learn, practice, and utilize strategies in teasing situations will cope more easily, and have less feelings of helplessness. Ms. Freedman, author of Easing the Teasing: How Parents Can Help Their Children says, "Teasing cannot be prevented, and children cannot control what others say; however, they can learn to control their own reactions."

The following are effective strategies developed by Ms. Freedman to be utilized in teasing situations, which can strengthen coping skills. The self-talk strategy encourages the child being teased to think of positive attributes about themselves. For example the child could say, "Whose opinion is more important, the teaser's or mine?" A teaser is seeking a reaction, so ignoring the teaser can also be very effective. Children should be encouraged to role-play walking away or pretending like they are invisible to show they are ignoring the teaser. Reframing is another way to cope with teasing. For example, if a teaser is calling a child "four eyes" that child can respond back with "thanks for noticing my glasses." Yet another coping strategy is using the "I" message in which children express how they feel and what they want changed. For example, "I feel upset when you call me brace face and I would like you to stop." Other strategies include visualization in which the child pretends to have a protective shield that makes the teasing comments bounce off. Sometimes adult intervention is necessary so children need to know it is okay to ask for help. Strategies that are effective in one teasing situation may not be in all situations. It is important for children to practice possible responses to teasing that they plan to utilize in teasing situations.

Tips for parents to help children cope with differences

- Show your love and acceptance of your child's facial difference by smiling, being physically close, touching your child, especially his or her face and by making eye contact.
- Tell your child about their facial difference in simple, honest words they can understand, emphasizing it's nobody's fault and at the same time pointing out strengths.
- Support your child's efforts in developing friendships by encouraging sharing, giving, fairness, kindness and consideration.

- Help your child make a simple plan to respond to questions or comments. A simple, matter of fact explanation such as "I was born this way" or "This is just the way I am" is sufficient for most children.
- Brainstorm together a list of possible questions to anticipate from children: "How did it happen?" "Can I catch it?" "What is it?" "Will it go away?"
- Help your child understand they are not alone by introducing him/her to other children who share similar experiences.
- Children need the control of how much or little they want to disclose to different people depending on how they feel at that time.
- Communicate with your child's teacher throughout the school year to explain any medical limitations and ways to enhance learning.
- Discuss with your child why some children ask questions or make comments about their differences. Help your child to understand for the most part other children are just curious and do not mean to be hurtful.
- If your child is teased, help him or her to problem solve how to handle the situation with a positive response.
- Practice and role-play with your child different strategies to use in teasing situations.
- Allow older children an active role in surgical decision-making to help your child feel he or she has a say and that their opinion is valued.
- Your young child may want to present information such as a show and tell session in their classroom about their facial difference.
- It is human nature to protect your child from stressful situations; however, when children try new things they gain confidence and obtain the skills necessary to be successful in life.
- Consult with a child psychologist or social worker for additional support and resources.

Books for children and parents

- *The Berenstain Bears and Too Much Teasing* by Stan & Jan Berenstain
- *Chrysanthemum* by Kevin Henken
- *Anansi and the Talkling Melon* by Eric A. Kimmel
- *Princess Penelope's Parrot* by Helen Lester
- *Snail Started It* by Katja Reider & Angela von Roehl
- *Easing the Teasing: Helping your child cope with name-calling, ridicule, and verbal bullying* by Judy S. Freedman
- *Bullies are a Pain in the Brain* by Trevor Romain
- *What to do...when kids are mean to your child, Parenting Guides*, vol. 1 by Erin McCoy
- *How to Handle Bullies, Teasers and other Meanies: A book that takes the nuisance out of name calling & other nonsense* by Kate Cohen-Posey, & Betsy A. Lampe
- *Stick up for yourself. Every Kid's Guide to Personal Power and Positive Self-Esteem* by Gershen Kaufman, & Leu Raphael

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- Pope, A., 2003. *Advice for Parents: Helping Children to Tell Peers.*
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Anonymous, in honor of Randi Rush
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Street Tails Animal Rescue, Inc.
The David M. Schwarz Architects Foundation
Triangle Community Foundation: Bill Mecklenburg & Christine Condino Mecklenburg Family Fund of TCF

Fundraising Events & Other Efforts

Up to $1,000

American Legion 50/50 Raffle / Jaci Samhammer
Thatcher Bartlett's Birthday / Bartlett Family
CCA Wristband Sales / Lucas Family Kids
Connor's Birthday Donation / Connor Carlisle
City of Shelton Mohegan School / Wonder Funder/ Students
Dannemora Credit Union Jean Day / Heather Rancour
Greenwich Academy Bake Sale / Wonder Funder / Students
Indoor Flea Market / Anjolene Whaley
Jaylin's Birthday Donation / Davila Family
Lake Highlands Wonder Funder in honor of Sadie Bono
Lake Highlands Book Club Cluster Wonder-gram Sale
Pampered Chef Funder / Jennifer Lucas, Hostess
Scentsy Funder / Bev Grim
CF Picnic Funder for CCA / Central Christian Church, Waco, TX / Mickley Family
Lila's Lemonade / Lila & Ethan Plummer
31 Funder in honor of Connor Carlisle
Blue Jeans Funder toward 2014 Retreat / Team Lentil
Hannah Twedt's Summer Fundraising / Hannah Twedt

$1,000-$5,000

Arleen Heirty's 75th Birthday / Sheila Romano
Chance Raffle / Retreat Attendee Families
Lovelies Birthday Surprise for Cher / Jill Emerson
"Miles For CCA Kids" Poker Run / Lewis Boykin, Frank Leach
Primrose School of NE Flower Mound Spring Fling proceeds
Quilt Raffle / CCA Families & Friends
Rick's Raffle / CCA by Burgin/Dornier Families
"I Support Lola's Voice" Benefit Walk / LaTonya Williams
Sadie's Night at the Ballpark / Bono Family, Gorman Family
T.J.'s Spa Day for CCA raffle / Teresa Joy & Deena Dyson
Annie's Birthday Wish for CCA / Annie Reeves, CCA Program Director

$5,000 or more

Owen Anderson's Fundraising Effort at Stevi B's Restaurant / Owen Anderson & Family
Lily's Dinner / Tosha & Nathan Walker
Raegan's Rally / Ashley & Boz Daugherty & family with Raegan Daugherty
Scott Guzzo's 30th Birthday Celebration Funder / Guzzo Family
Seth's Stride / Stacy & Barry Horne with Seth Swihart
3rd Annual Trevor's Trip to Triumph Ride / Trzanowski-Larys Family

$10,000 or more

6th Annual Chocolate Festival / Aventura Mall / Chef Rick & Laurie Chiavari
Lentil Fest / Lindsay Condefer & Lentil Team Lentil

$20,000 or more

All The Way For CCA / Becky & Wade White, Lisa Bock, Jennifer Kilmer
6th Annual Links of Love Golf Tournament
9th Annual Friends of Jeremy Golf Tournament / Dale Family

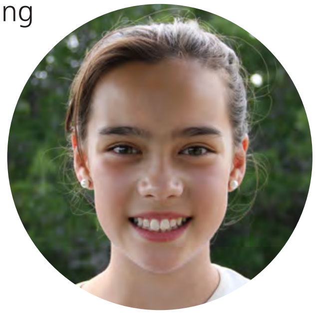
$50,000 or more

2nd Annual Morgan Meck's Match Play Golf Invitational / Mecklenburg Family

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

donors in the spotlight

this first issue of 2014, we want to call attention to new donors for Children's Craniofacial Association, the **Carney family**, of New Canaan, CT, who sent a year-end gift around the holidays and then surprised us by having it matched **200%** by Mr. Carney's firm, **The Warburg Pincus Foundation**! We just had to ask how all of this came about and upon inquiring, found out that each year they let one of their children pick a charitable cause for the family to support. This time, their daughter, **Emma** chose CCA after having read the book, *Wonder*, at her school, **Greenwich Academy**, and having helped with a bake sale for which the proceeds were donated to CCA last fall! In fact, Emma didn't realize it, but her image had already graced our pages in the photo that accompanied that article in our last issue! Special thanks to Emma and her family, our 2014, issue one, "Donors in the Spotlight."



children's craniofacial association

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