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mason hanbury

By Jessica Hanbury

"It is not our differences that divide us. It is our inability to recognize, accept, and celebrate those differences." — Audre Lorde

Mason Gray Hanbury was born on May 6, 2005, at shortly after 2 in the morning. Nine years later he has endured a tonsillectomy, eye surgery, two bone-anchored hearing aids, fat grafting, as well as countless adults and children staring at him. Each time he has shown strength and resilience that I never knew was possible for such a small child.

This was not the life I had planned for him before he was born. I was a single mother and had envisioned this "perfect" child that would make my life feel complete. What I got was the perfect child that showed me how complete my life was. My son Mason was born with a rare craniofacial disorder called Treacher Collins syndrome

see **mason**, page 16



message from the executive director

Now that 2014 is in the books, we at CCA are excited about the year to come. Before we move forward, let's take a moment to look at the highlights of last year.

The 24th Annual Cher's Family Retreat was held in St. Louis, Missouri. Our families have told us that the retreat is the most important program CCA offers, and that was validated by the numbers in attendance. It was the largest gathering yet, with 113 families.

CCA was able to help 26 families with retreat scholarships. In addition,

see **executive director**, page 6



ccakid

to sing all types of music. Her favorite artists at the moment are Alicia Keys, Kelly Clarkson, Taylor Swift and Bruno Mars.

Jessica also participates in swimming, and she volunteers her time at **Kids Care**, a service organization just for elementary-age children. She also helps her mom with her charitable foundation, **Project Angel Eyes, NFP**. And, in her spare time, she adds to her ever-growing snow-globe collection.

Last summer, she and her family went to the CCA retreat in St. Louis.

Her favorite parts were swimming and having the chance to meet other CCA kids. This summer will be different; Jessica, who has Crouzon syndrome, has a major, midface surgery planned.

We wish that all will go well for her and that she bounces back better than ever. And she offers these words of advice for anyone going through something similar: "Be nice, help them if they need it, and be understanding."

meet jessica jaskowiak

Jessica Jaskowiak is a budding scientist from Aurora, Illinois. She loves school and is doing really well, especially in her favorite subject, science, where she loves conducting experiments. She's even involved in an after-school science program called STEM.

Jessica likes to read as well, particularly the *Amelia Bedelia* series of books and books about dogs.

Speaking of canines, she has dog named Molly, a rescue dog she loves dearly. Jessica doesn't have any brothers and sisters, but, according to her mom, she talks about her Barry and Ben Lalaloopsy dolls as if they were her real brothers!

Like most fourth-grade girls, Jessica loves the movie *Frozen*, and she enjoys watching *Strawberry Shortcake* DVDs. She's also in a choir and loves



meet joshua whaley

Thirteen-year-old **Joshua Whaley** lives in Bowie, Maryland. He is in the eighth grade at the Harbour School in Annapolis. He enjoys gym class at school and loves watching wrestling matches on television and online.

Last October, Joshua was selected by a Florida-based nonprofit organization to receive an all-inclusive trip to New York City to meet World Wrestling Entertainment star **John Cena**. Not only did he meet John Cena, but he met a number of other wrestlers and divas too. He was also given the opportunity to watch a **WWE Monday Night RAW** wrestling event.

Joshua enjoys reading the Jeff Kinney book series *Diary of a Wimpy Kid*. In August 2012, Joshua and his older brother had the opportunity to meet **Jeff Kinney** at a book signing at the hotel where they happened to be staying—great timing, right?!

Joshua takes horseback riding lessons and swim lessons on Saturdays. In 2014 he won first place in the obstacle course at his instructor's horse show.

Joshua was born with Crouzon syndrome, which was inherited from his mother. His first CCA retreat was in Dallas, Texas, in 2009. He had a great time and plans on attending this year's retreat in Newport Beach, California.



Josh Whaley, 13, of Bowie (center) and his family met WWE wrestling celebrity John Cena through Florida-based Kids Wish Network's program for children with life-threatening disabilities.

Photo courtesy of Kids Wish Network

ccateen



meet robert whaley

hello, I'm **Robert Whaley**, and I'm currently a first-year student at a local community college. I plan to transfer to the University of Maryland-College Park, where I will major in Business Marketing.

Along with being a student, I intern for the Governor of Maryland. I am also pursuing my real estate license. During my downtime, I enjoy creating iPhone apps, watching real estate-related TV shows and just bothering my little brother, Joshua.

Even though Joshua has Crouzon syndrome, he's the same as everyone else! I'm very lucky to have such amazing friends who understand that just because my brother might not look like them he is still a great person!

We've attended two CCA retreats so far. At our last one, which was in Florida, I made a number of new friends, including **M.E., Wesley, Veronica, Shelby, Randy** and so many more! My family and I are very excited for this year's retreat in California. I can't wait to see everyone again!

ccasupersib



10th annual friends of jeremy golf tournament

The 10th Annual Friends of Jeremy Golf Tournament was held on Saturday, September 22, 2014 at the **Corning Country Club** in Corning, NY. We have had an amazing 10 years of support from family, friends and the entire community!

We are so grateful for our 117 golfers and more than 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-inch LCD TV and an iPad Mini.

The silent auction included autographed memorabilia, including items from the **New York Giants, New York Islanders, Buffalo Bills, Buffalo Sabres** and a **Derek Jeter** photo! The event was a huge success, raising **more than \$33,000** for CCA!

Jeremy was again joined this year by fellow CCA kid **Ryan Gulich** and his family. We were also very lucky to have CCA adult **Andrew Perry** and his family back to join us. And, CCA adult **Freddie Seitz** and his entire family made a surprise visit to be part of our last tournament!

We are so grateful to everyone who has supported this event and the kids from CCA. Thanks to your generosity, we raised **more than \$270,000** during the 10 years of the event! We want to especially thank those individuals and businesses who were a part of the event all 10 years!

Pat Alderson
Mike Cantando
George and Cathy Dale
Maureen and Charlie Dale
Marlene Deily
Mario Emiliani, Jr.
Mario Emiliani, Sr.
Bob and Pat Galietta
Dave and Ginger Henshall

William Horsfall
Bruce Kirk
Jackie and Paul Morgan
George Morgan
Dennis Naylor
Nick and Katherine Rossington
Ron Warunek
Chemung Canal Trust Company
Corning Dental Associates
Corning Incorporated
Dr. Maureen Gonta-Castellana
Simmons Rockwell Wegmans

For more information about the tournament, visit friendsofjeremy.com.

executive director, from page 1

Team Lentil raised funds to help six families attend, and **Medford Memorial Middle School Wonder readers** raised funds to send yet another family. As a CCA mom once said, “The retreat is like a booster shot that helps get us through the year.” CCA is dedicated to ensuring as many families as possible experience this life-changing weekend.

The 6th Annual Craniofacial Symposium was held on Thursday, kicking off the retreat weekend. **Dr. Earl Gage** and members of his team donated their time to lead workshops, as did CCA parents, teens and young adults.

During the year, we continued to focus on ways to keep CCA families, friends, volunteers and donors informed and aware through our publications. In addition to three newsletters, CCA published two more one-sheet overviews: “Responding to People in Your Community” and “As Your Teen gets Older: Preparing for the Next Steps.” CCA now has 14 syndrome booklets and 17

overviews available in print and at CCAKids.org.

In 2014, our online resources remained a priority. We kept CCAKids.org interesting and informative. Our website has a wealth of information available, including all of our publications, *Wonder*-related information, events, resources, craniofacial team information and more. Last year, CCAKids.org had 178,584 visitors. CCAKids Blog welcomed guest bloggers, **Jenny Ewing** and **Penny Loker**. We continue to seek avenues to spread awareness online through our Facebook, Twitter, Pinterest and Wikipedia pages. Additionally, CCA’s Yahoo Group of individuals and family members affected by facial differences has grown to almost 700 members.

The book *Wonder*, by **RJ Palacio** continued to make a huge impact on our abilities to spread awareness about facial differences. A program to discount or donate *Wonder* books for schools was implemented in 2014, with 2,810 books sold at a discounted rate and 364 books that were donated. Sixteen schools

interacted with real-life Auggies, sending letters and gifts to CCAKids. CCA families gave presentations at 23 schools and around 400 *Wonder* resource packets were mailed to librarians, teachers and other educators. And, thanks to Hollywood director **Edward Edwards**, teachers **Annette Manganello** and **Nancy Webb**, and CCA board of directors’ member and CCA mom, **Dede Dankelson**, we now have a *Wonder* Reader’s Theatre script available.

All of these accomplishments come at a price, and CCA is unique in that our families and friends raise a significant amount of our annual budget. In 2014, they held 19 fundraisers that raised from \$1,000 to \$67,000. Eleven more fundraisers were held that each raised between \$50 and \$1,000. Many others helped through online opportunities such as **Amazon Smiles**, **GoodShop**, **GoodSearch**, **iGive**, **Facebook birthday fundraisers** and **FirstGiving pages**. There are no fundraisers too small—each one is

greatly appreciated. We are amazed at your good works and thank you from the bottom of our hearts for your efforts.

As we look forward to 2015, we are especially excited about adding new programs for our young adults. Now that we have raised a generation of CCA Kids, we are looking at ways to help them transition to happy, productive adults. And we are excited to have them mentor our CCA Kids.

In addition, we will continue to provide ongoing programs and services that will empower and give hope to individuals and families affected by facial differences. Thanks to all who helped make 2014 a successful year. We hope we can count on you to move us closer to our vision of a world where all people are accepted for who they are, not how they look.

Char Smith

CCA Executive Director

grants received



CCA is proud to accept grant funds of **\$2,500** from each the **Servants Heart Foundation** and the **Maximus Foundation**. These folks found merit in our work and we're extremely grateful.

Additionally, the **Tony Stewart Foundation** granted **\$7,500** to our **Wonder Project**, placing our CCA *Wonder/Choose Kind* teaching packets and our special-edition *Wonder* by **RJ Palacio**, in classrooms across the country, teaching acceptance of all differences & to prevent bullying. Thanks "Smoke"!

Click on
DONATE
at ccakids.org

building awareness

By Haley Coghlan

Organizing the Choose Kind campaign for Heritage School, the local elementary school in our area, was a great way to spread awareness and acceptance about CCA. **Taylor Puckett** and I went in during lunch to talk to the students about the book *Wonder*, Auggie Pullman, CCA's Choose Kind Campaign, and asked questions to see what the kids already knew about



acceptance. It was very neat to see most kids raise their hands to say they are reading the book in class.

We told them whichever class raised the most money by the end of the week will win a popsicle party. The kids raised **over \$700** and it was a lot of fun to organize the fundraiser, especially since CCA is near and dear to my heart.

I am so happy we were able to pull it off and raise money for such a great organization!

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.

testimonial

I was born in 1952 with Sturge-Weber syndrome*, a birth mark that covers the left side of my face. It looked more like a bruise. The doctors wouldn't let my mother see me for a few days, and because I had such a rare condition the doctors weren't sure what it was.

By the time I was about a year old, my face had turned more pinkish and as the years went on, it became purple. I was diagnosed with glaucoma around age three or four. and although I am sure I probably had seizure activity, because of the type of seizures I have which only last a few seconds, I was not diagnosed with psycho-motor seizures until I was in my mid-20s.

When I hit puberty, the left side of my face, tissue and bones started to grow. In the early 1960's the doctors could not do much for my condition and my parents were told to wait until I had stopped growing before any surgery could be discussed. I was lucky to have my wonderful mom and dad who didn't take that advice lightly and from the time I was an infant continued to search out the best medical updates for the times.

By 1967, there was a procedure called derma-

tattoo. In theory, they were to make pigment to match the color of your skin and tattoo the port wine birthmark with the correct color. Unfortunately, it didn't work; when the pigment was put into the birthmark, the extra blood flow on that side of my face just washed it away.

It would not have been too much of a problem if that was all that happened; however, in my case, my birthmark covers the entire left side of my face and they used 150 thousand needles each time. I had 7 treatments which left a lot of scarring because of all of the needles that were used—there was literally no skin left on my face when they were done and the healing process was horrendous.

Once the skin healed, the initial results showed temporary promise that it was going to work, hence the reason for the additional treatments. But with time, the pigment was washed away; leaving the skin very damaged, scarred and pitted. I had multiple derma-abrasion treatments over the following years but that didn't help very much to correct the scarring.

At the same time, the birthmark and bones were growing and becoming



more of an issue with my nasal passage closing and my breathing. My first rhinoplasty and debulking was scheduled at University of Michigan, Ann Arbor, somewhere around 1968. I lost my left eye to glaucoma at age 21. I have had to have debulking/reconstructive surgeries on the average of every two to three years, sometimes twice a year due to the rate of growth. I lost count of how many surgeries, procedures or laser treatments I have had at 70.

Until 2003, I used doctors in Michigan. Unfortunately, I had a few bad surgeries that caused some complications that

could not all be fixed by local doctors. It is a terrible feeling to be told that no one can help you at the best hospitals in your state or the top doctors that you have been going to tell you that they have done all they can do for you.

In 2003, I found out about **Dr. Milton Waner**, who is based in New York City. Out of desperation, I went to see him on my vacation from work. He accepted me as a patient and told me that with the help of **Dr. Aaron Faye** (based in Boston) they would be able to fix a problem that I had been living with since a disastrous surgery about 10 years prior which

involved a cranial cut and the dropping of my left eye socket. They told me I would need about four surgeries to help correct it. Unfortunately, I lost my job and insurance in August 2004.

I was unemployed and without the funds to get back and forth to New York. I had just started the treatment plan with Dr. Waner and Dr. Faye and could see some promising results. It was then that I started looking for help from agencies that might be able to help with flights for medical purposes, etc. I could find no one that would help an adult—all of the services were for children.

I stumbled across CCA, Cher's organization, and it didn't look like there were any stipulations about adults receiving funds, even though the name was Children's Craniofacial Association. So I called **Annie Reeves** for the first time and was greeted by the sweetest lady who told me to apply and that she could probably help me. With all of the graciousness in the world, I have been receiving help from CCA for my past three surgeries.

I just had surgery in November 2014 and need another one as soon as I am healed. The doctors ask that I stay in New York City about seven to 10 days, where a hotel room

can run between \$200 and \$300 a night. Plus there's roundtrip airfare as well as expenses for food, taxis or rental cars and surgery-related incidentals. And, even though I am an adult, I need someone with me because I cannot fend for myself after a major surgery.

CCA has been generous to give me funds toward my expenses. I want you to know how much I appreciate what CCA has done for me in the past—and to let you know that the child inside of this adult still hopes and prays that the next surgery will be the last surgery, and the one that will make me look "normal."

Thank you all from the bottom of my heart!

Sincerely,
Leslie Anne Trout

**Sturge-Weber syndrome is a rare congenital neurological and skin disorder and is often associated with port-wine stains of the face, glaucoma, seizures, mental retardation. It is characterized by abnormal blood vessels on the brain surface. Normally, only one side of the brain is affected.*



gingertown dallas 2014

The 5th Annual Gingertown Dallas build was held on December 2, 2014 and the wonderful gingerbread creations in the recent holiday's theme, "Gingertown Junction" were on display at NorthPark Center through December 15th delighting visitors of all ages.

The original Gingertown event, established by David M Schwarz Architects Charitable Foundation, began in 2006 and is held annually in Washington D.C., bringing together architects, engineers, and other design professionals to create towns built completely out of gingerbread and candy. All donations generated by participants and patrons of the event go directly to charity.

NorthPark Center, a premier shopping destination here in Dallas and a partner to local charities benefiting children and families, teamed up with DMS Architects to bring "Gingertown Dallas," which started in 2010 as a "branch" of the original, to the DFW area.

We are honored at Children's Craniofacial Association to be once again chosen beneficiary, and we were presented with checks for this year's total of **\$11,665!** We're so very grateful to event participants, sponsors, donors, **NorthPark Center** and to **David M. Schwarz Architects Charitable Foundation**. Thanks again!



dallas holiday party

CCA, together with **Drs. Jeffrey Fearon, David Genecov, Carlos Barcelo** and **Craig Hobar**, hosted its 25th annual holiday party at **Southfork Ranch**, in Parker, TX. The much-anticipated event was held Saturday, December 13, when around 400 attendees joined us for a morning full of fun!

Power House was the entertainment, and everyone really enjoyed participating in the fun, music and games. Parents had just as much fun as the kids, especially during the "wrap your parent" contest. Kids literally wrapped up their parent with wrapping paper!

Everyone enjoyed cake and punch as well as arts and crafts. The kiddos decorated their own cookies and picture frames, had their faces painted and much more! They were also able to see a real fire truck, thanks to the **Parker County Fire Department!**

Families went home with lots of door prizes, which were donated by several local businesses. Prizes included a gift card to the **Magic Time Machine**, **Cowboys Stadium Tour Vouchers** from the **Dallas Cowboys**, tickets to the **Dallas Zoo** and **Fort Worth Zoo**, signed merchandise from the **Texas Rangers**, passes to **Amazing Jake's**, tickets to the **Mesquite Rodeo** and more! As always, the highlight of the party was the big guy from the North Pole, **Santa Claus**. Children took their picture with Santa, and everyone went home with a keepsake photo and toy.

CCA would like to thank Southfork Ranch for hosting, as well as their wonderful staff! A huge thank you goes out to our wonderful volunteers from the **Italian Club of Dallas**, **Tyler Hanson** and **KLS Martin!**





midwest holiday party

The Annual CCA Midwest Holiday Party was held on December 6th, at the **Parkway Chateau / Brat Stop** in Kenosha, Wisconsin. As always, families lunched on a spread of pizza and "pop" followed by yummy desserts!

We had both new attendees and regulars who all added up to a pretty good turnout for ornament creating and visiting! And, of course, we took photos with **Santa** while the kiddos put in their wish lists. Special thanks to **Sonia Hanton** for bringing dessert, **Lynn Jaskowiak** and **Project Angel Eyes** for providing the toys & gifts and **Mary Beth Dalton**, for assisting with all the doings of the day. Thanks everyone for joining us and we'll see you next year!



as your teen gets older: preparing for the next steps

by Judi Tyler, LMSW

for every family and for every teen, the word “transition” can mean something different. For some, they will go off to college, while others will move out with a job or a work program. For others, transition will be more subtle, such as a change in a school program or a change to adult medical providers and benefits.

Let’s take a look at five different types of transitions: legal, financial, medical, educational and social.

Legal: The age of majority is the age when one ceases to be legally considered a child. These young people assume responsibility of themselves as well as their actions and decisions. Other rights, such as the right to vote, to drink alcohol, to leave school or to marry, may be given at other ages. For most states in the United States, the age of majority is 18, but in a few states it can be as old as 21.

Some young people can make decisions independently or with family input. Many states have **advanced directives**, which are documents persons over age 18 can sign. They

give a trusted friend or family member the right to make certain decisions for them if they cannot. Advanced directives are sometimes called a **health care power of attorney, mental health power of attorney, a living will, etc.** Depending on the directive, a young person may be able revoke that permission at any time. Some directives deal with health care and others deal with financial issues. Please check with your respective states.

For those needing more support, a **court-approved guardianship** allows someone else to make decisions for those declared unable to make decisions for themselves. It is serious because it takes away rights of the individual, but it is important because it can protect a vulnerable person. Guardianship can vary from state to state; however, it is important to begin setting up a guardianship before the age of majority.

Financial: If your young person receives SSI, be aware that after age 18, your income as parents is not counted. Contact Social Security at 1-800-772-1213 or ssa.gov for more information. You may be allowed to be a

representative payee. If the young person has more financial benefits than SSI, and they need a guardian, a **conservatorship** may be needed to manage those funds. A special needs lawyer who is aware of benefits your child is also receiving may be helpful. Visit specialneedsalliance.org to learn more.

If your young person is going to manage their own funds, you may want to discuss a **durable power of attorney** that allows you to assist in times of crisis. For example, if the young person was in an accident and was unable to make decisions, it would allow you to cash their paycheck and pay the bills. Remember to read the fine print before setting something like this up.

Medical: While the Affordable Care Act (or Obamacare healthcare.gov) changes have been made it possible to cover your child with your private insurance until age 26, be aware that pediatric providers may ask your child to transfer to an adult provider. Also be aware that state medical benefit coverage may vary between pediatric and adult benefits. Be aware at what age those benefits change.

Providers should be engaging the young person in conversations regarding their health care. If your young person is over age 18 and you have guardianship or your young adult has completed advanced directives, please give copies to your providers. Some young people wear a medical alert bracelet or put a copy in their wallet.

Educational: If your young person has an IEP (Individualized Education Program) under the IDEA law, they are able to stay in special education until their 22nd birthday. Check with idea.ed.gov or a local parent advocacy group if needed. Depending on the needs of the young person, vocational training or life skills classes might be the best fit.

If your young person is college bound, be aware of scholarships that might target scholars with certain medical conditions. While colleges and universities are not under the IDEA law, some colleges will have a Disability Resource Center that can allow supportive services to be given such as note taking or absences for medical appointments. Vocational Rehabilitation services also known as Rehabilitation Services of

America may be helpful in funding and looking at employment. Visit www2.ed.gov/about/offices/list/opers/rsa/index.html to learn more.

Social: Social activities are vital, especially as your young person may be leaving the familiarity of high school or their friends may be leaving. At age 18, many volunteer opportunities can open up such as working in animal shelters or volunteering at a hospital. Art and sport programs may also be available through your local communities.

For those who will not be going to school or working, day programs may be

available. Be sure to check them out unannounced or intermittently, so you have a good idea of the activities. Many of these programs try to include young people in the planning.

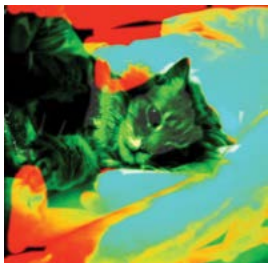
Most of all, remember that transition does not have to all be done at once. It is a process. Take it one step at a time in conversation with your young person and those who love them.

Judi Tyler, LMSW, is a social worker for kids with craniofacial differences and their families in Phoenix, AZ.

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.



Cher Crew Cher fans are supporting CCA Kids again, this time through a special Twitter effort that Cher's cat, "Mr. Big" was promoting. He held a drawing for a "pawtigraphed" Cher "Closer To The Truth" CD and raised **\$520** for

Children's Craniofacial Association! Thanks to all the fans who donated and congratulations to **Gloria M.** who won the special CD!

Big also gave a second-prize bracelet to **Terry H.** whose name was drawn next, and everyone in the drawing received a Cher tote bag for participating and helping CCA Kids. Thanks Cher Crew!



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.

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!



CCA Mom, **Angela Wojtyniak**, whose 2 year-old daughter, **Brooklyn**, was born with Crouzon syndrome, wanted to do something to help families with a craniofacial condition. Her friends and family spent an evening participating in a **Life Expressions** party having a great time working on artistic creations for themselves.

With the help of **Jill Allevato**, her representative with the company, who generously donated a portion of her sales, the group was able to raise **\$400** for CCA! Angela sent us a check to help all CCA kids in honor of Brooklyn. Thanks so much to everyone involved.

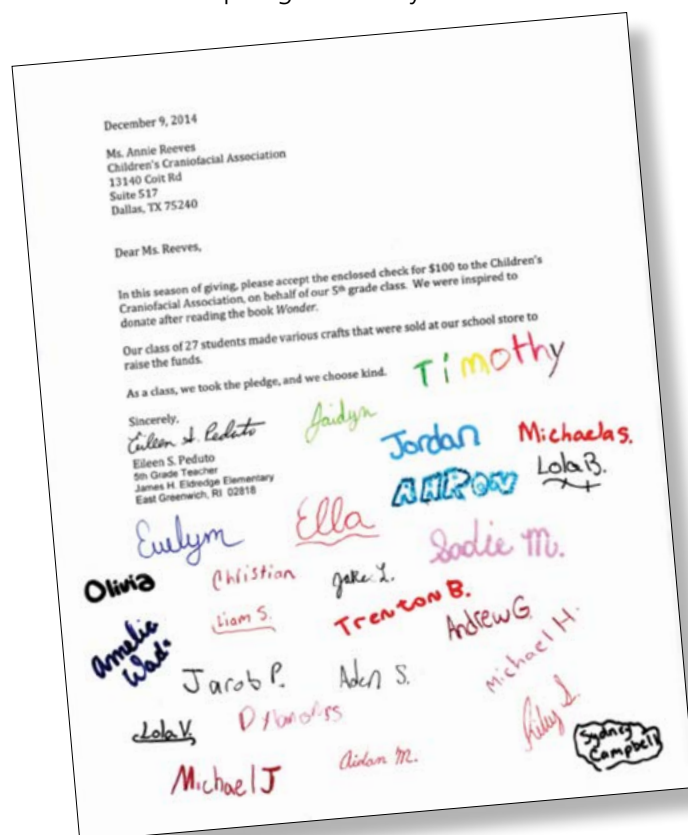


OP4G (Opinions for Good)

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Annie Reeves, CCA Program Director and our "Wonder Project manager" received a surprise holiday greeting in December!

5th Grade Teacher, **Eileen Peduto** at **James H. Eldredge Elementary** in East Greenwich, Rhode Island wrote us a letter signed by her 27 students who were proud to contribute a check for **\$100** from the sale of their crafts at the school store after reading *Wonder* and taking the "Choose Kind" pledge. Thank you!



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mason, from page 1

(TCS), a disorder I had never even heard of until after he was born. But little did I know that this small defect would change my life for the better.

The day I first held my son was the scariest day of my life. Not only did I have to struggle with the fact that maybe I had done something wrong that caused these defects; I also had to accept the fact that my son would never have an easy life.

It wasn't until a few hours later and after many tears had been shed that I learned I had done nothing wrong—my entire genetic makeup, in fact, was the culprit. I can still remember when the geneticist Dr. Zamora came into the hospital room and first told me about Treacher Collins. She told me Mason had all the characteristics of the disorder from his absent ears to his slanted eyes and small jaw. She also told me that with just one look at me she could tell I had the disorder as well and that I had a 50 percent chance of passing it to all my children.

This new information had both terrified and enlightened me. I had accepted many years ago that I looked different from my family. I had had a difficult childhood full



of bullies and self-doubt but then I thought most children grew up that way. So to learn that there was a reason why I looked different had me rethinking my entire existence. I decided at that exact moment that Mason would have something that I was denied growing up. He would have the understanding about why he looked different and the knowledge that there were others out there just like him.

By three months he had received his first bone conduction hearing aid provided by California Children Services (CCS). Along with Children's Hospital of California (CHOC), Mason was seen by a wonderful group of

medical professionals that dealt with children who had craniofacial disorders. The only real small hiccup we had was when, after a little over a year, I sent the hearing aid to be repaired and after more than a month I was still waiting for it to be returned. I realized during that time that one hearing aid would never work for a child as active as Mason. I worked hard and after a few letters of outrage and persistent phone calls I was able to acquire a second hearing aid. Never again would I allow him to go that long without clear hearing. And to this day I've been successful.

It quickly became apparent that Mason was not your normal child with

hearing difficulties. He was able to talk clearly and understand exactly what was being said to him. He was very outgoing and loved to be around people. His smile could light up a room and warm your heart. I wish I could say I was that way with all people but I can't. I struggled, those first few years, with people staring at him, or the children asking their moms why his face looked that way. In the beginning, I hoped parents would encourage questions or explain that all people look different—and that it wasn't nice to stare—but that hardly ever happened.

In many instances, I'd wait until I was alone and shed a few tears wishing people could look past

what was on the outside. Here was this beautiful boy and I just couldn't understand why others couldn't see it. But how could you make people understand his facial differences when every day we are surrounded by commercialized "beauty" on television and in magazines and billboards. Yet again, Mason remained unfazed and would go up to almost any kid and try to play, regardless of how they looked at him—a quality I hope he never loses.

When Mason was three years old, life brought us across the country to try and start our lives fresh in southern Connecticut. A huge change, but we had family in the area, and the chance for Mason to have a great education was

just too much to pass up. We were very lucky that I was able to find work almost immediately, and we were able to get our own apartment within just a couple of months after moving. I found a lovely preschool for Mason that understood his special hearing needs and seemed to genuinely care for his wellbeing.

We were both settling nicely into our new environment, and I was eager to start my employee health coverage only to learn that I could never afford the premiums with Mason on my plan. I applied to three major healthcare providers only to have Mason denied each time due to preexisting conditions. This was a hurdle I was not expecting,

and, after much trepidation, I applied for Mason to be on the state-run public assistance health plan.

I had my doubts that he would get the care he deserved, but all that went away when I met the pediatric plastic surgeon, Dr. Derek Steinbacher, and the ENT, Dr. Eric Baum, from the Yale-New Haven Hospital

and Connecticut Pediatric Otolaryngology. They had helped other children with TCS, and quickly we were able to put together a long-term surgical plan taking care of Mason's most concerning issues such as sleep apnea, eyes and his hearing.

I feel very fortunate that Mason's first surgery didn't happen until he was five years old. After researching about Treacher Collins, I know that most children had major airway issues, and in many cases needed surgery right away in order to breathe. Being able to wait also helped me find the strength to walk out of that operating room for the first time without him, knowing that I would have to put his safety and wellbeing in the hands of others, even if it was just a routine Tonsillectomy.

After the first surgery I came to accept two facts: First, Mason was more remarkable than I realized when it came to pain and swelling. Second, I could remain strong and help him feel safe and secure even if he was in torment. The fear lessened and I gradually realized that everything would be okay.

We eventually started a tradition when it came

to surgery time. The day before, I would take Mason to the grocery store and he would be able to pick out anything he wanted to eat for the next few days (foods I never buy for him) but he couldn't eat any of it till he got back



from the hospital. Then that night we would make the long drive up to the Ronald McDonald house in New Haven—not before stopping for his last meal at Chuck E Cheese, of course—and stay the night.

After surgery, all Mason had to do was wake up, sit up and eat a Popsicle (this awesome bit of advice was given to me by another wonderful TCS Family, Laura Bell and her son, Ryan). Soon after, we would be on our way home to a house literally full of all kinds of yummy junk food,



see **mason**, page 18

mason, from page 17

so he could be spoiled silly while he recovered.

Today Mason is nine years old. His last surgery was more than a year ago. His plastic surgeon wanted to move forward with ear reconstruction, but I decided it would be best for Mason to have a little time off. Now I am faced with a decision as to what the next step should be.

Recently, when Mason overheard me tell his ENT that he'd probably start ear reconstruction this summer (a three-to-four-surgery process), he told me he didn't want to have the procedure. He said he liked the fact that his ears were different. I was stunned and a little unsure what to say. When do you start letting your growing child call the shots with his own recovery, when all the major surgeries were done and the rest would mainly just be cosmetic? But that is a decision for another day.

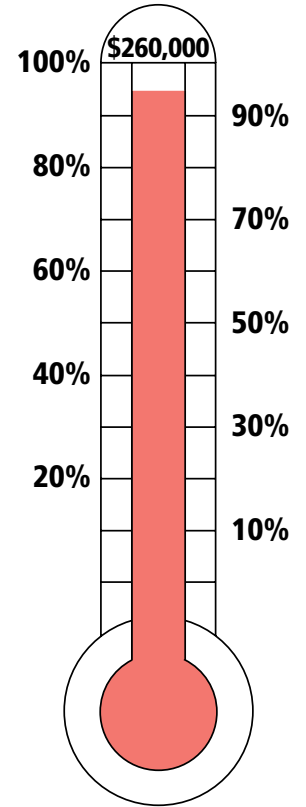
For today, I will just appreciate all we have been through and be proud of the young man Mason is becoming. He has had to endure more than most children around him, but I hope I have taught him that he is extremely lucky.



Because of Treacher Collins syndrome, we have been able to meet fantastic people from all across the United States, including the extraordinary team at CCA. Our very first Cher's Family Retreat was last year in St. Louis, and the outpouring of love and understanding was almost too much. I found myself feeling sorry for those who have never had a chance to experience feeling as welcome as we did. I believe one of the greatest benefits of growing up with a craniofacial

syndrome is that we have the "ability to recognize, accept, and celebrate [our] differences," and for that I am truly grateful.

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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

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calendar of events

date event contact

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Apr 24	3rd Annual Texas Moms' All the Way for CCA Golf Tournament Battleground Golf Course Baytown, TX (Houston area)	Becky White ledestiny@gmail.com
April 29-30	4th Annual Morgan Meck's Match Play Invitational Coto de Caza Country Club Coto de Caza, CA	BMecklenburg@redwoodsgroup.com
May 3 2-6P	Chase's Quest Zumbathon Richmond, VA	Carrie Ingram jicai@msn.com
Jun 25-28	25th Annual Cher's Family Retreat Newport Beach Marriott Newport Beach, California	AReeves@ccakids.com 214.570.9099 800.535.3643
Jul 11	2015 "Miles for CCA Kids" Benefit Ride	lewis.boykin@aggressiveusa.com
Jul 13-17	Ironman Triathalon in honor of Eli Dinsmore Lake Placid, NY	Amy Stone itriforgood.org/athlete-profile/amysayso/
August 8	5th Annual Trevor's Trip to Triumph Motorcycle Ride for CCA Morganville, NJ	kimtriz@msn.com
Aug 30	Seth's Stride Canton, OH	Stacy Horne stacy@hostetterskbr.com
September	11th Annual Craniofacial Acceptance Month Nationwide	AReeves@ccakids.com 214.570.9099 800.535.3643
September 12	Raegan's Rally/Walk for CCA Deerasic Park Cambridge, OH	Ashley Daugherty ashleyddaugherty@gmail.com
Dec 5 11:30A-2:30P	CCA Holiday Party—Midwest Brat Stop/Parkway Chateau Kenosha, WI	JPatterson@ccakids.com 214.570.9099 800.535.3643
Dec 12 10A-Noon	CCA Holiday Party—Dallas Southfork Ranch Parker, TX	AReeves@ccakids.com 214.570.9099 800.535.3643

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Memorials / In-Honor Gifts

Those with ten or more are subheaded

Beth Abel, in honor of Max Abel
 Stephanie Amsel, for the wedding shower of Christine Gorman/Steve Dyer
 Anonymous, for Apert syndrome, in honor of Grayson
 Anonymous, for Grayson Bisbing
 Anonymous, in honor of Daniel
 Anonymous, in honor of Sadie Bono
 Anonymous, in honor of Courtney Broome
 Anonymous, in honor of Ashley Compton and Tony Miglini
 Anonymous, in honor of Daniel
 Anonymous, in honor of Jeremy Dale
 Anonymous, in honor of Hope Evans
 Anonymous, in honor of Chrissie Marie Gorman
 Anonymous, in honor of Tate Gorman
 Anonymous, in memory of John Haycraft
 Anonymous, in honor of Amanda Hoika
 Anonymous, for Pfeiffer syndrome, in honor of Kaysin
 Anonymous, for Sam Welle Leonard
 Anonymous, in memory of Dolores Winters
 Carl Bach, in honor of the Mecklenburg Family
 Cora Bahr, in loving memory of Mary Kathleen Marchetti of Churchville, PA
 Michael Bannon, in honor of Jeffrey Fearon
 Sarah Blackburn-Renn, in honor of Aveny McCalla
 William Charles Bluman, in honor of Seth Swihard / Seth's Stride
 Judi Borchert, in memory of Dale Borchert
 Margaret Bordonaro, in honor of Zachary Bordonaro
 Marybeth Boucher, in memory of Carl Bundenenthal
 Geraldine Brill, in memory of Tobyn (check for combined gifts in memory)
 Brandi Bryan, in honor of Ashley Bock
 Christine Brocco, in honor of Lindsay Condefer & Lentil Bean
 Cindie Brooks, in honor of Gorman/Dyer
 Joe Brooks, in honor of Jill Patterson's birthday
 Michelle Buchanan, in honor of the Anderson Family; Dave, Liz, Owen & Nathan
 Ann & William Burgin, in memory of Rick Dornier
 Elizabeth Cacopardo, for Christine Clinton, 2015 Retreat
 Richard & Laurie Chiavari, in honor of Seth Swihart
 Shelly Chrisman, for families who can't afford treatment, in honor of Brakkin Chrisman
 Shari Ciarleglio, in honor of Ava Beeler
 Barbara Cravens, in honor of Scott Guzzo
 Mollie Cummins, in honor of Royal Gonzalez's birthday
 M.C. & Judith Cunningham, in honor of Robert and Erin Dinsmore
 Kristine & George Dale Family, in memory of Grace Diely
 James & Beverly Dalton, in honor of Elizabeth Dalton
 John & Jennifer Davis, in memory of Beatrice Sanborn
 Patricia DeMaria-Bocchino, in honor of Zach Bordonaro
 Directed Technologies, in honor of Jonathan Seitz' graduation
 Alyson Distel, in memory Debra Kassack
 Sheryl Dougherty, in honor of Ava Beeler
 Bridget Duke, in honor of Brooklyn Wojtyniak
 Dona Dunsmore, in honor of Jakob Happ
 Kyle Egemo, in honor of Sam Lemberg
 John Emminger, in honor of Sadie Bono
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Alysia Gray Painter, in honor of Kathleen Escalada
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 Arleen Heirly, in memory of Ed Einbeck
 Arleen Heirly, in memory of Bud DeLaughter
 Arleen Heirly, in memory of Jerry Kleis
 Arleen Heirly, in memory of Barbara Salins
 James Holbrook, in honor of John Gorman
 Janis Hood, in honor of Team Lentil
 Mary L. Hughson, in honor of Ryan Gulich, Jr.
 Elizabeth Hyder, toward Pfeiffer syndrome in honor of Avery Cooper
 Harley Jacobson, in honor of Seth Swihart
 Heather A. Jewell, on behalf of our friend, Amanda Hoika, one really brave girl!
 Gina Jones, in honor of Chase Ingram
 Vance & Judy Kemler, in honor of Luke Bowen
 Robert Koski, in honor of Ann LeDuc
 Kosmos Energy, in honor of Elizabeth Dalton
 B. Jane Lacaille, in memory of Beatrice Sanborn
 Mary Lancaster, in honor of Ron Micetic's birthday
 Rachel Lance & Dan Laugharn, in honor of Shierry Lance-Laugharn
 toward Retreat Scholarships for other CCA kids
 Bonnie Lichten, to help purchase the book, "Wonder to spread "not to bully" on behalf of Stuart Lazar's birthday
 Tony & Betty Lovato, in honor of Ryan MacLennan
 Sylvia & John Loving, in honor of Ryan Holliday
 Jefferson Lumber & Millwork, in honor of Avery Lytle
 Ann Lucas, for "Be Brody's Angel" in honor of Brody Lucas
 Ann & Don Lucas, in honor of Ann & Don's Anniversary, Ann's Birthday & Brody Lucas to be used toward retreat scholarships
 Emily Lukowski, in memory of Steven Haycraft
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 Michelle Neff, in honor of Royal Gonzalez
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 Heather Paul, in honor of all the kids you support & Lentil Bean's 1st Birthday
 Jana & Hugh Peace, in memory of Bruno
 Jana & Hugh Peace, in honor of Chase Ingram
 Florence Perrin, in memory of Jan MacDonald
 Florence Perrin, in memory of Beatrice Sanborn
 Larry Pomarico, in honor of Roann Bihir
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 Stephanie Pryor, in honor of Ashton Pryor
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 Annie & Tommy Reeves, in honor of Joe Brooks' Birthday
 Jennifer Reitmeister, in honor of Amanda Hoika
 Andrea Richard, D.O., in honor of Christine & Todd Redmann Family
 Richard & Arlene Richroath, in honor of Trevor Larys
 Michael Rodell, at the request of Jenna Rodell
 Perry & Linda Romley, in honor of Karen & Dominika Tamley & Kevin Irvine
 Jessica Schumann, in honor of Amanda Keeton and family
 Raymond Scott, in honor of Bill Mecklenburg

Dale Shephard, in honor of Megan Shephard
 Edward Shierry, in honor of grandchildren, Dan & Rachel Lance Laugharn & great-granddaughter, Shierry Lance Laugharn
 Edward Shierry, in honor of Dan, Rachel & Shierry Lance Laugharn from Uncle Ed
 Aaron Shotts, in honor of Nathan Anderson
 David & Susan Solomon, in honor of the Tate Gorman Family
 Stephen & Jennifer Sovik, in honor of Jeremy Dale
 Candace Stapleton, in honor of Tatum Stapleton
 Traci Stark, in honor of Team Lentil & my son, Hunter Stark
 who was born with a cleft lip and palate on 2/25/96
 Sharie Stephens, in honor of Mason Liebham
 Mark Stevens, in honor of Chase Ingram
 William & Nancy Suwalski, in memory of Anthony Pistello
 Linda Taylor, in honor of Brooklyn Wojtyniak, a brave little girl, for her 2nd birthday
 Priscilla Voss, in honor of the Bill Mecklenburg Family
 Priscilla Voss, in honor of the Morgan Meck Family, from Lolly & Clinton
 Carolyn & Paul Weber, MD in honor of Team Lentil
 Carolyn & James Werner, in honor of Scott Guzzo
 Paul Whiting, dedicated in honor of Roy L. "Rocky" Dennis & inspired by Cher Berhen Widjaja, in honor of Danatra Katherine Willis, on behalf of my buddy, Griffin; Love Molly
 Heather & Reed Willis, in memory of Don McClain
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 Deidra Wilson, in memory of James E. Carson for Luke Bowen
 David Wolfe, in honor of Channing Dickson
 Joseph Wolfe, in honor of the McKenna Family
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 Christopher Young, in honor of Chase Ingram

In Honor of Cher's Birthday

Anonymous
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In Memory of Phoenix Coleman

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 Baue Funeral Home-cash gifts
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In Memory of Rick Dornier / Rick's Raffle

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 Glenda Ballard
 Melanie Benedict
 Marsha Bennett
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Team Lentil / In Honor of Lentil's First Birthday

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 Pat Arlington
 Clancey Coffin
 Christi Farinash
 Mary Krause
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 Barbara Mann
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 Doreen Myers
 Heather Paul
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 Annie & Tommy Reeves
 Charlene & John Smith
 A Friend of Donald & Mary Zimmerman

In Honor of Annie Reeves' Birthday

Joe Brooks
 Michelle Gonzales
 Jodi Embleton Hillen
 Teresa Hirasuna
 Theresa Hospodka
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 Annie Martin
 Carl Martin
 Kelly Burks Mcdade
 Alison Morrissey
 Jodi Nafziger
 Stephanie Parham
 Jill Patterson
 Jana Peace
 Amy Plummer
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Naomi Abel
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Fundraising Events & Other Efforts

Up to \$1,000

31 Party for CCA / Liz Anderson w/Michelle Buchanan
A.J.'s Wristband Sales / Allen Coffey
American Legion Collection / Jaci Samhammer
Be Brody's Angel / Lucas Family
Beit Rabban Day School ~ Wonder
Bisbing Chili Cookoff / Kenzi Bisbing
Haley Coghlan & Taylor Puckett ~ Wonder Funder
Cher Fan Fundy / Josiah Torres w/ CherCrew fans
Ann Dolsen Elementary Wonder Funder
Eldredge Elementary Wonder Funder
Life Expressions Party / Angela Wotyniak
Munley Law PC Dress Down Day in Honor of Jeremy Dale
Nehanse Middle School Wonder Funder
"On The Border" Restaurant funder / Kellie Dowd
Sales of John Moulton's CDs / Mary Zimmerman
St. Patrick School Casual Day
Seaford Elementary Wonder Funder
Stevenson Elementary ~ Wonder
Thirty-One Funder / Liz Anderson & Michelle Buchanan
Trinity Catholic Elementary School Wonder
Wristband Sales

UCF: Lead Scholars Fundraiser / Anne Moore & Friends

\$1,000-\$5,000

Acceptance In The Park Picnic~Raffle / Dyson Family
Annie's Birthday Wish / Annie's Reeves, CCA Program Director
Chance Raffle / Retreat Attendee Families
Chase's Quest Zumbathon / Carrie Ingram & Volunteer Zumba Instructors
CherCrew Birthday Surprise for Cher to benefit CCA Kids / Jill Emerson
Dress Down Day @ Imagine Elementary at Desert West / Jill Laufbaum
Kitchen Shut-Down Raffle / Laura Beeler & Alicia Yost
Lawton C Johnson Summit Middle School Wonder Funder
Medford Schools Wonder Funders for CCA's Retreat Scholarship Fund
Miles for CCA Kids Poker Run / Lewis & Carly Boykin to Send a family to the 2014 Annual Retreat / thru Razzo Foundation
Quilt Raffle / CCA Families & Friends
Rick's Raffle / CCA by Burgin/Dornier Families
Round Rock ISD / Libraries Wonder Funders
Sadie's Night at the Ballpark / Bono Family, Gorman Family
Seth's Stride
Trevor's Trip To Triumph / Kim & Erik Larys

\$5,000 or more

Quilter's Guild of Dallas Miniature Quilt Auction / 2014 Beneficiary: CCA
Paula Guzzo's 60th Birthday Celebration Funder / Bob Guzzo
Raegan's Rally

\$10,000 or more

Team Lentil Effort toward Retreat Scholarships / Lindsay Condefer & Lentil

\$15,000 or more

7th Annual Links of Love for CCA

\$30,000 or more

All The Way For CCA / Becky & Wade White, Lisa Bock, Jennifer Kilmer
10th Annual Friends of Jeremy Golf Tournament / George & Kris Dale

\$50,000 or more

3rd Annual Morgan Meck's Match Play Golf Invitational / Mecklenburg Family

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

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donor in the spotlight

We at CCA would like to thank longtime supporter, **Robin Williamson**. Over the years, Robin has tirelessly given her time as a member of organization's board of directors, where she was instrumental in helping expand programs that empower and give hope to people and families affected by facial differences.

Although she no longer serves on our board, Robin continues to offer her graphic design and web expertise through her business, **Williamson**

Creative Services. She's the creative force behind our newsletter, information booklets and, of course, our awesome website!

Robin also has set up automatic donations to CCA via online giving. Plus she donates when she shops online through the convenient **iGive** program as well as **Amazon Smiles**, where a percentage of her purchases from participating merchants goes directly to CCA.

She's done so much to help us in so many ways. Thank you, Robin!



Robin Williamson, graphic designer and an avid quilter and quilt pattern designer, pictured here riding a giant sewing machine at QuiltCon 2015 in Austin, TX. RobinWilliamsonQuilts.com