

ccanetwork



newsletter of the children's craniofacial association

Cher—national spokesperson

2013: Issue 3

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israel's story

By LaShawn Carr

Israel "Izzy" Nekoda Bunkley was born on September 24, 2004, at South Georgia Medical Center in Valdosta, Georgia. When Israel was born, both of us were on active duty in the US Air Force at Moody Air Force Base. All of Mom's checkups and ultrasounds were perfectly normal, and we were ready for our baby boy to add joy to our family.

But when Israel was born, the medical center was not ready for him. They were a level II neonatal unit and had not seen a medical case of his kind. Israel was born with Goldenhar syndrome. He had Hemifacial Microsomia and a severe case of anophthalmia. Israel was missing his left eye, his left ear and the left side of his lower mandible. Otherwise he was very healthy, weighing a whopping 7 pounds and 4 ounces, the largest baby that night in the neonatal unit.

see **israel**, page 16



message from the development director

It's the time of year when everyone gives thanks. Here at Children's Craniofacial Association, every day is Thanksgiving Day! Our hearts are especially warmed by families who have been grateful for our help, so much so they have helped CCA in return.

We're touched by folks like **Heather** who successfully applied to have CCA benefit from a fundraiser at her workplace. This came only a couple of weeks after we helped her with travel expenses for medical care for her son, **Foster**.

see **development director**, page 10



ccakid

meet paula calderon



Paula was born in Arequipa, Peru, and moved to the United States when she was almost two. Her primary language was Spanish, and she began learning English by watching TV and talking to her kindergarten classmates.

Today, Paula's English and Spanish are both excellent. She's a third grader this year and loves school. She does well academically, and she has lots of friends at school as well as in her neighborhood.

Last year Paula took gymnastics classes after school and did very well.

She's looking forward to starting cheerleading and dance classes soon. Because she likes to dance and sing, Paula loves to watch America's Got Talent as well as other shows featuring singing and dancing.

Paula also loves her older brother, Daniel. They tease each other like siblings do, but they help each other and adore one another. They also enjoy playing with and taking care of Max, a dog they adopted last year.

Paula has Craniometaphyseal Dysplasia, a rare condition

for which there is no real treatment. Its progression cannot be predicted, and several other symptoms may develop because the overgrowth of her bones can compress nerves in the skull.

This past summer, Paula and her family attended

their first CCA Retreat. They had an unforgettable time in Orlando. Paula and her brother made friends and had lots of fun. Her family met other families, sharing information

and experiences. Most important, they learned they were not alone, that there were many other loving families facing similar challenges.

Paula and her family are counting the days until the next retreat in Missouri!



ccateen

meet hannah twedt



hannah is a sophomore at Red River High School in Grand Forks, ND, where she is a straight-A student. Yet just two years ago this incredible young lady was going blind and given only a few months to live.

Hannah was born November 2, 1997, with partial webbing of her fingers, an extra-large big toe, small low-set ears, beaked nose, poor muscle tone and digestion, difficulties eating and swallowing, bulging eyes that prevented her from being able to close her eye lids, and no nasal lacrimal

ducts. She had virtually no skull bones and no cranial sutures. Not knowing what to do, doctors decided to take a “wait-and-see” approach to see if Hannah’s bones and skull would grow on their own.

Her CAT scans at age five showed that her skull was slowly growing, but a large section on the top of her head was still wide open. When she was in kindergarten, she was diagnosed with autism. Despite all of this, Hannah excelled at school, working several grades above her level.

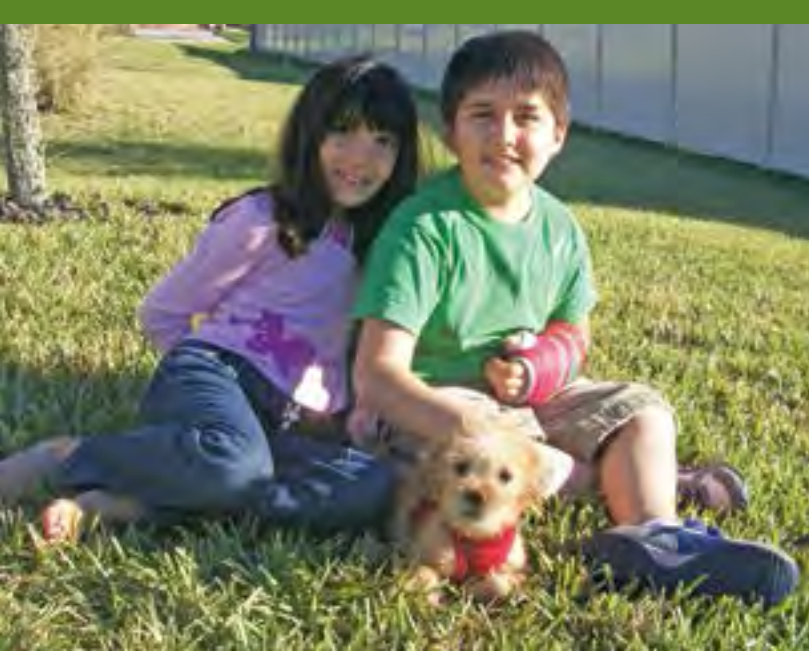
Throughout elementary school, Hannah went through multiple surgeries on her feet, ears, eyes and mouth. She began having severe headaches, but doctors dismissed it as stress, and later to puberty. She and her family regularly traveled to Minneapolis to see an orthopedic surgeon to monitor Hannah’s scoliosis and c-spine region. Her headaches were getting worse and were affecting all areas of her life. She also was losing feeling in her extremities and having vision difficulties.

In November 2011, Hannah was having routine

scoliosis x-rays done at Shriners Children’s Hospital in Minneapolis. Dr. Patrick Graupman, a visiting neurosurgeon from Gillette Children’s Specialty Hospital, walked through the imaging department, and noticed something even the radiologists had missed: Part of the base of Hannah’s skull had large, pitting holes.

Her family is forever thankful that he was there on that specific day at just the right time. About three days later, and after many tests, Hannah and her family learned her skull

see **hannah**, page 12



meet daniel calderon

My name is **Daniel Calderon**. I am 11 years old and live with my parents and sister, **Paula**, who is three years younger.

Paula likes to play with our dog, Max, and she also likes to dance, sing and play with her friends. She likes to mess with me, but I know that she really loves me and I love her too. Paula was born with C.M.D (which is Craniometaphyseal Dysplasia, but I can't pronounce it). Even if she has this, it still doesn't make her different from everyone else.

I am in sixth grade. It is my first year in middle school. I like it and have already made new friends. I think it is very different

from elementary school in that I have to change classrooms and teachers after each period. My favorite class is science. I'm also reading *The Lightning Thief* by Rick Riordan, which I like a lot.

I love playing Minecraft, Black Ops and Grand Theft Auto. My favorite TV show is *Doomsday Preppers*. (Sometimes Paula doesn't like what I am watching on TV, so she changes the channel or hides the remote control.)

One of my favorite things I like to do is spend time with my dad. He teaches me a lot of things. He is helping me train for a triathlon (200 meters swimming, five miles biking and 1.36 miles running).

Sometimes Paula goes with us to the pool, and plays while we swim.

I like to do things with my entire family too. When I was nine years old, we went with people from our church to paint some houses damaged by a natural disaster. I painted an entire wall by myself.

Last June, our family went to the CCA retreat in Orlando. We really had a great time. My sister and I met other kids and siblings and made some new friends. We loved it and would like to go again next year.



ccasupersib



seth's stride 2013

After a two-year break, Seth's Stride for CCA came back better than ever! It is great to be "back in the game" with renewed perspective and focus as we continue our mission of raising acceptance for our CCA families.

As always, Seth's Stride kicked off with our 5K walk—it never gets old seeing all those awesome shirts walking in support of acceptance. Next, the family funfest! **Cowboy Steve** made his appearance to create balloon animals for the kids (and some adults). The kids also enjoyed the bounce house, face painting, lots of games and the hot air balloon! We had various vendors, entertainment, food, and of course, our incredible raffle/silent auction, which raised a

record amount of more than **\$7,000!**

To add to an already special day, **CCA kid Samantha Klinger** and her family joined us. The Klinger family faithfully continues to make the three-and-a-half-hour drive each year for Seth's Stride.

Ten-year-old **Lillian Castor** and her family drove hours from Columbus to attend their first-ever event. Lillian had no qualms helping announce the winners of our raffle! Thanks, Lillian!

Little **Jackson Diaz** surprised us all by coming with his family. Jackson, a one-year-old, stole the show

and grabbed the attention of many people with his cuteness! Thank you all for coming. It was such an honor and a wonderful surprise to have you there!

As always, it was a beautiful, special and successful day! It is proof that big things can happen in a small community, and I am so honored and grateful to play a part in raising support and acceptance for such an amazing organization.

~Stacy





raegan's rally

by Ashley Daugherty

Saturday, September 7, marked the third annual Raegan's Rally held at Deerassic Park in Cambridge, OH. This year's rally did not disappoint, as we were able to raise a record **\$9,000** to donate to CCA. Every year we learn more, add more and raise more!

This year the rally featured a raffle that included a beautiful, handmade quilt donated by **Laura Wade**, as well as a NASCAR Ultimate Fan package for Charlotte

Motor Speedway donated by Raegan's Uncle, **Matt Long**. With the help of friends and family, we were able to raise more than \$1,500 through pre-sale raffle tickets before the rally even kicked off!

The rally began at 9:30 am with the 5K walk/run. The White Elephant Raffle began inside the lodge of Deerassic Park at the conclusion of the race. Some of the items up for grabs included Origami Owl necklaces, Thirty-One gifts, Target gift cards, purses,

Ohio State memorabilia, car washes, oil changes, car detailing, primitive décor, Nike Golf apparel, and Stella-n-Dot jewelry. A silent auction also took place, featuring prizes such as water coolers, hunting items, a Bumble and Bumble gift basket, a primitive dough bowl, a handmade kid's quilt and a picnic table with "Raegan's Rally 2013" engraved in it. T-shirts designed by the family's close friend, **Lauren Gruenebaum**, were available, as were snacks donated by family and friends.

As Raegan gets older, her rally is becoming more and more meaningful to her. She was so excited to release the balloons to start the race, pull the tickets for the raffle winners and deliver the prizes. We couldn't be happier that this event is growing yearly. It means so much to us, for many reasons, to continue with this special event.

We would like to give a big thank you to everyone who attended Raegan's Rally 2013 and helped make the event such a success through your continual support over the years. In addition to those previously mentioned, we would like to extend special thanks to all of Raegan's family and friends who devoted their time to make sure this year's event was the best ever!





hartley golf outing for cca

by Nancy Michael

The fifth annual Hartley Company Golf Outing was held this past August. This event was a huge success. More than 56 golfers played under the beautiful blue skies of Ohio, and some 30 volunteers helped us out. We raised more than **\$17,000** for CCA kids.

In addition to a 50/50 raffle drawing, other prizes were awarded to golfers for games held on the course at special holes. After golf, the group moved indoors to enjoy a wonderful dinner. Raffle sales continued during dinner, along with a Chinese auction that created a lot of activity. All of the prizes for the auction were donated by Hartley suppliers and local businesses. Music, food, and support for this cause were flowing. Thanks to all involved!

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?!

Cher usually sponsors our pool party for the weekend event. 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.

owen's fundraiser

by Liz Anderson



and for donating 17 percent of the proceeds to CCA. We would also like to thank the **Anderson and Sheets families** for helping promote the event that turned out to be such a success. Thank you to

PKSA Allen Park

On September 18, 7-year-old **Owen Anderson** spearheaded a fundraiser for CCA to honor his little brother, **Nathan**, who was born with Treacher Collins syndrome. Owen set a goal of \$1,000, and he surpassed that goal with online donations before the event even began, raising a total of more than **\$5,000** by the time it was over!

We would like to thank **Stevi B's Restaurant** in Woodhaven, MI, for helping to host the event

for providing a donation box in the studio to help bring in extra donations. In addition, we are thankful for the more than 40 families who donated directly and all of the families who came to Stevi B's to support us.

Finally, we would like to thank Owen for his love and dedication to his brother and CCA. Great job, Owen!

Thanks, Owen! CCA loves you, too!



This year marked the ninth year CCA observed September as **Craniofacial Acceptance Month** across the nation. CCA families, friends, volunteers and related support groups widened the circle of acceptance for individuals with facial differences. The goal is to create awareness that beyond the face is a heart and the true person within.



FLORIDA

Many of our CCA families were featured in their local newspapers and news stations. Radio stations also ran PSAs throughout the month of September. We mailed out more than 100 Craniofacial Acceptance Month packets to 35 states and Canada! And, for the sixth year, CCA held National Picnic Day in September as part of Craniofacial Acceptance Month. CCA families across the nation hosted picnics in Arkansas, California, Florida, Georgia, Illinois,

Michigan, Nebraska, Ohio, Pennsylvania, Texas and Virginia. This is the best turnout we've ever had.

We want to thank everyone for all their hard work in making Craniofacial Acceptance Month another great success!



VIRGINIA



WACO, TEXAS



PENNSYLVANIA



NEBRASKA



ARKANSAS



GEORGIA



student gives part of savings to cca

College student **Alida Boon** of Grand Haven, MI, has been sending hundreds of dollars over the years from what we thought were fundraising collections. We've since found out the money was from her own savings. She told us CCA became a part of her life when she and her older brother were both little, and he

was diagnosed with Craniosynostosis. She says our organization was a wonderful source of support for her parents. We're so happy to hear that, and we think it's pretty special and thoughtful of Alida to give back this way. Thanks so much, Alida, for helping care for our CCA kids in honor of your older brother!

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,

ARees@ccakids.com

We hope to see you there!

Registration ends May 23, 2014.



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

development director,
from page 1

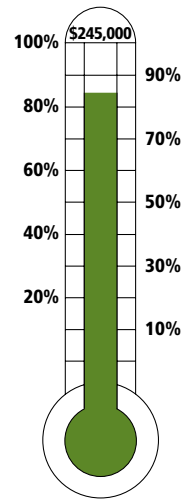
Also, we are thankful for the dad who called our office a couple of months ago to donate the exact amount his family had received in financial assistance from CCA. He said it took a few years but he was determined to pay it back so that we could use the funds for another family in need.

Some forms of Craniosynostosis are barely detectable after treatment, and a family could easily leave that chapter of their lives in the past and forget they ever heard of CCA. But time and again, these are the people who stick with us and continue to support the organization, “paying it forward” for other families.

One example is a family, originally from Dallas, who makes a donation to us via fax each December from Singapore. It’s their way to commemorate their son’s good surgical outcome along with his birthday, while helping other CCA kids. Or, there’s **Levi’s family** who rallied around CCA’s Dallas golf event this year and helped bump up that event’s gross income by some **\$5,000**.

We are amazed and inspired and thankful every day for these and all of

2013 FAMILY FUNDRAISER
GOAL THERMOMETER



our families who help us by selflessly putting their children "out there" to represent Children's Craniofacial Association.

Every year I go on and on about our family fundraisers.

Your efforts make up about half of our income budget each year!

Having only 3.5 paid employees makes our overhead low and our gratitude for volunteerism high! Not only do our families and their friends volunteer across the nation but our board of directors has a similar make-up. All are dedicated to our cause and put in much time and effort throughout the year to assist us in implementing our programs and services and continuing to spread awareness of craniofacial issues.

Most important of all, while it includes everyone I've mentioned, our donors stand out as our number one reason to be thankful every day, and we are! Our "Family" Thanksgiving table is a huge one indeed!

Jill Patterson

CCA Development Director

trevor's trip to triumph



What a great turnout this year! The third annual Trevor's Trip to Triumph motorcycle run began with a breakfast of bagels, donuts and coffee at the **Freehold Elks Lodge #1454** in Freehold, NJ. We had 46 bikes ride in our 67-mile scenic tour through New Jersey, ending up at a neighboring lodge and good friends, **Millstone Elks Lodge #2613**.

At the Millstone lodge, we enjoyed BBQ hot dogs, pulled pork and hamburgers with donated side dishes of potato salad,

pasta salad, black bean and corn salad, chips, juice, soda and water. The Elks from both lodges volunteered to cook, donate food and tend the outdoor bar for our afternoon festivities — all for the love of the children and this cause. We were joined by more bikers who didn't ride but came to enjoy the end festivities loaded with great food, great friends and great raffle prizes!

We would like to thank our sponsors. First and foremost, a big thank you to both Elks lodges, **Freehold** and **Millstone**, for hosting our event. And thank you **Kohl's** for sending associates from their **Associates in Action** program to help with setup and cleanup. We also would like to thank **Skip's Garage, Cycles at 117, Complete Security Systems, Inc., Leo's Mobile Mower Service, Carol Feldman**

of **CJLifeWorks, Harley-Davidson of Long Branch**, and all the people who sponsored our T-shirts as well as the event.

We appreciate everyone who donated raffle prizes: **Longhorn Steakhouse, Olive Garden, Silpada Jewelry Designs, ThirtyOne Bags** and about 30 others. And thanks goes to our large prize donators: **Wireless Zone of Freehold**, who donated \$200 in gift certificates; **Dr. Tara Gostovich, DMD**, who donated a \$1,000 gift certificate for Invisalign Services; and **Lowe's of Holmdel**, who donated a turkey fryer, lighted patio drink set and fire pit. Of course last, but never least, we'd like to thank all of our friends and family who helped support our efforts by loading and unloading that day, making baskets for our raffle prizes and moral support for our cause, Children's Craniofacial Association. CCA is so near and dear to our hearts because of our son **Trevor** and all children like him. This year so far the ride has raised over **\$4,000**, and we know next year we will do even more for CCA kids.

Thanks, everyone!
Erik Larys, Kim
Trzanowski and Trevor

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

hannah, from page 3

was way too small and had grown together as one solid piece, like a bowl. The pressure from a growing brain on a closed skull was so high it bore holes in her skull. Hannah had severe papilledema and was losing her vision. Without surgery to reconstruct her skull, Hannah would go blind within months and die shortly after that.

The doctors had about a month to plan the complex surgery to reconstruct Hannah's head and face and prevent further brain damage. The team used an artificial bone material called kryptonite. (Her family says Hannah is the only person they know who can defeat Superman.)

Recovery time took longer for Hannah because of her age and the extreme size change of her head, but her headaches were gone and some of her behaviors from autism improved. Just three months after surgery Hannah felt good enough for a trip to Hawaii to swim with dolphins and try surfing for the first time.

In April 2013, Hannah had surgery on her spinal cord because tumors were blocking the flow of spinal fluid. She and her family were planning to go to the retreat in Orlando that summer, which motivated



her to work extra hard to recover and walk again.

At the retreat, Hannah didn't worry about hiding her scars and dents on her head or people noticing her small hands and unique feet. She was really excited about wearing sandals and a bikini, which she would never wear anywhere else because of the curve and surgical scars on her back and what she calls her "funky" feet.

Since the retreat, Hannah has been working on raising money for CCA. She had a rummage sale and did pet sitting. So far, she has raised **\$600** and hopes to have more by the end of the year.

Recently she announced to a crowd of 5,000 during the Color Run in Grand Forks that "September is Craniofacial Acceptance month." She and her family reminded everyone that behind the face is a person just like they are,

and the crowd cheered and applauded Hannah for having the courage to share this message.

Hannah still has many obstacles ahead of her. She continues to follow up with her medical team and will need more surgeries on her spine, but for today, she is doing great.

When Hannah is at home she loves spending time with her dogs: Mudge, the Labradoodle and her constant companion; Stella, the feisty Cairn Terrier; and the newest addition,

Cowboy, a baby Great Dane. She has returned to riding horses after having to take a long break for her body to recover. Hannah also spends time doing volunteer work at the Humane Society and helps with the daycare at her church.

She and her family look forward to next year's CCA retreat to see the friends they met and to get that "wonderful boost of confidence to carry us throughout the year."



Peter Dankelson is our CCA Kid who read the part of "Auggie" at a *Wonder* book reading in California attended by the author, **R.J. Palacio** and where all the other parts were read by professional actors.

Since then, Peter has been on a bit of a speaking circuit and spoke at his own school as well, about craniofacial conditions. His **6th grade class** at **St. Patrick's School** in Highland, Michigan, took the "Choose Kind" pledge to a new level. They collected donations and bought *Wonder/Choose Kind* merchandise (from CCA) amounting to \$400 after Peter's folks gave them a little incentive—that they'd match whatever the amount the class donated! Thanks to these students, CCA Kids received \$800, and the school's Student Council also sent a \$300 check... for a total of **\$1,100** all in honor of Peter Dankelson! A real-life "Auggie"!

scott guzzo celebrates "30th" birthday!



about 75 friends and family members celebrated **Scott Guzzo's** 30th birthday at a CCA Fundraising Party hosted by Scott's parents, **Bob & Paula Guzzo**, at their home in Evansville, Indiana on August 4. Craniofacial Acceptance Month materials, *Wonder Choose Kind* information, and CCA and *Wonder* bracelets were available to guests. The effort raised **more than \$5,000** in Scott's name for Children's



Craniofacial Association!

Above, right: **Scott's** long-time friends and CCA supporters **Wanda Corn** and **Linda Vala** traveled from **Springfield, IL** to surprise **Scott** and his family.



Left, top: **Helping Scott** celebrate are his cousins **Klaire, Michael, and Kindal Scott** of **Dixon, KY**.

Left, middle: **Scott** is congratulated by CCA Adult, **Karen Wachendorf** and her father, **Marv Wachendorf**. They are from **Indianapolis, IN**. The **Guzzos** and **Wachendorfs** met 24 years ago through the **Riley Children's Hospital Craniofacial Clinic**. Both families attended their first CCA Retreat in 1994.



Left Bottom: **Scott's** cousins **Tracy and Layne Kraft** of **Mt. Vernon, IN** won the autographed football donated for the raffle by the **Indianapolis Colts**.

2013 miles for cca kids poker run



The 2013 Miles for CCA Kids Poker Run was held July 7, raising awareness and approximately **\$2,800** for CCA. Our event hosts were **Reverend Lewis Boykin**, his wife **Pastor Carla Boykin** and **Frank Leach**. The event was sponsored by **Aggressive Insurance**.

We would also like to thank our cosponsors: **2nd Sunday Biker Church** and its members, **Dixie and Darrell Brubaker, DWMC, Connect Insurance, Little Dragonfly Designs, Shooting Star Productions, The Allen Wicker Pub and Grill, Big Slicks Bar and Grill, Nick's Bar and Grill, Red Neck Heaven-Lewisville, Stokers Dallas** and **O'Riley's**.

Special thanks also goes to **Underwood**

Perkins, Attorneys at Law, as well as **Ekvall & Byrne, L.L.P.**, for their generous donations. And thank you to our stop volunteers: **Max and Danielle Screws, Isabel Nalley, Brittney Jacobs, Stephanie Pollack, Tommy Purtle, Jeremy Byington, Jack Holcomb, Larry Fava, Kenneth Johnson (KJ), Amy and David Curtis, and Myrna Tarango** for their hard work and dedication. And thanks to volunteers **Pat** and **Mike Becker**, who helped by spreading the word about the event. Many area businesses contributed raffle prizes, and we thank everyone for their generous support and dedication to a worthy cause. Join us next year on July 12 for the 2014 Miles for CCA Kids Poker Run!





testimonial

Jasmine doing what she does best, always climbing on things and posing.



2013 Miss Freeport 2nd Runner-up and Top Salesmanship Award

My family was introduced to CCA's financial assistance program in September 2012 when they helped with my daughter **Jasmine's** upcoming surgeries and doctor appointments. It was only days after I submitted the application when we got the best news ever: CCA was going to help with our trip expenses. As a parent, we all want the best for our kids and for them to get the best care. When there is financial hardship, those trips get really stressful. With the help of CCA, I was able keep my focus on Jasmine and her surgeries, appointments and her recovery. I always have that peace of mind knowing that CCA is there for our family.

Thank you for everything you do!

~Anita Massey

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.

t.j.'s spa day for cca

In honor of Craniofacial Acceptance Month, the **Dyson family** from San Jose, California, hosted "TJ's Spa Day for CCA." The raffle prize was a luxurious day spent at **Burke Williams Spa**, including a massage, facial, manicure and pedicure, luxury bath, and lunch. **Teresa Joy** was excited to pull the winning ticket and have the video of her doing so posted on Facebook! The lucky winner was **Carrie Lee**, a social worker and mother of two boys from Piedmont, California, who has supported CCA before. This crowd-pleasing event raised **\$1,400** and elicited those donations while also bringing awareness to Craniofacial Acceptance Month and CCA. The Dysons only wish that everyone could have won, since who doesn't deserve some pampering?! Congratulations, Carrie!



hannah Twedt spent her spring and summer doing various things to raise funds for CCA. Read more about Hannah, our featured CCA teen, on page 3.

kerry Carlisle gathered friends and family for a Thirty-One Gifts party/fundraiser in honor of her son **Connor**, raising **\$355** for CCA. **Laurie Carlson-Chalifoux** even donated her sales commission toward the effort! Thank you, everyone!



SRO officers and bracelet sale coordinators

wonder-ful st. rita's

CCA Mom **Melanie Howington** visited St. Rita's Catholic grade school to kick off the "One Read" celebration of the book *Wonder* by R.J. Palacio and to recognize Craniofacial Acceptance Month. Students in grades 4 through 8 attended the presentation and, along with the faculty, enjoyed getting to know a little bit about Melanie's daughter, **Leigh Ann**. They enjoyed her stories of Leigh Ann's antics as a child and her adventurous personality. Melanie gave fun demonstrations to illustrate craniofacial differences and acceptance.

In conjunction with this event, the student organization, St. Rita Outreach (SRO), held a fundraiser to benefit CCA. First, they organized a very successful bake sale for funds to purchase CCA's *Wonder/Choose Kind* wristbands. Then they sold the bands, with all of the proceeds going to CCA. Librarian **Bernie Mount** dropped off a check at CCA for **\$2,200!** Principal **Dr. Elena Hines** even adjusted the uniform dress code allowing two bracelets to be worn to school, a *Wonder* bracelet and one of their choice.

A big thank you to the *Wonder*-ful students and faculty of St. Rita's!



Melanie Howington (second from right) and a friend with Dr. Elena Hines (right), and Bernie Mount (left)



greenwich academy bake sale

by Rebecca Hatchett

This fall, **Greenwich Academy's Middle School** students held a bake sale to raise funds for CCA. Over the summer, every middle school girl read *Wonder* by **R.J. Palacio**, inspiring the student government to raise awareness and funds for the organization. The eighth grade brought in dozens of baked goods, raffled off a cake, and ultimately raised **\$532**. Organizing the bake sale to raise funds for CCA allowed the girls to feel a deeper connection to the book and pride in the impact of their collaborative efforts.



"i support lola's voice" walk

By LaTonya Williams

We would like to thank the **Columbus State University** ladies of **Eta Iota chapter of Alpha Kapa Alpha Inc.** for hosting the first "I Support Lola's Voice" Walk. Despite the weather, hundreds came out to stomp out bullying.

Lola's Voice is an anti-bullying campaign encouraging people to "Step Up and Speak Out," while educating the public about those with disabilities and the challenges they face. Special thanks to **Rachel Green** (VP of the Eta Iota Chapter) and Lola's Aunt, **Valarie Thompson** for all of their hard work and dedication. We would also like to thank **Lu Lu's Lunchbox**, and the other vendors and student organizations that came out. Big thanks to **M.A.S.E.** for their generous donation. Together we raised **\$1,264** in honor of **Lola Williams** for CCA Kids.

israel, from page 1

He stayed in the neonatal unit for two weeks before being allowed to come home. Israel was having difficulty swallowing, and we found out that his esophagus was not aligned in a normal position. He was sent to **Emory University Hospital** in Atlanta, where a craniofacial team developed a plan for facial reconstruction. In the first year of Israel's life, these pediatricians,

ophthalmologists, ocularists, plastic surgeons, oral-maxillofacial surgeons and otolaryngologist (ENT) personnel saw him monthly.

At just four months, he had his first of a multitude of surgeries. They started on his absent eye, in an attempt to create a normal looking eye socket. He had multiple eye expander implants to expand the inner orbit of the eye and prepare him for an eye prosthesis. To date, Israel has had 13 surgeries on his left eye.

He also had a severe case of scoliosis in his upper torso. He has a pronounced curvature around the heart area, which stunts his growth drastically. He was not even able to sit up until he was about 14 months old. Israel is 9 years old now, but at 43 inches tall, he has the stature of a 5 year old. He has been the smallest in his class since he started preschool.

He also has had multiple inner ear tubes to try and decrease the number of ear infections, which with the absence of his left ear, could be detrimental if he lost his hearing. On his right side, he has perfect vision and perfect hearing. With the support of an awesome family—mother, father, stepfather, sister, grandma, grandpa, a host of uncles and the United

States Air Force—Israel was on his way to an awesome start.

All of Israel's initial work started at Emory, but when he was three the family moved to his mother's home state of Michigan. Israel then started with a craniofacial team at the **University of Michigan CS Mott Children's Hospital** in Ann Arbor. With the assistance of **Dr. Steven Buchman**, a world-renowned plastic surgeon, and **Dr. Alon Kahana**, an eye plastic, orbital and facial cosmetic surgeon from **Kellogg Eye Institute**, his team of doctors are on a mission to ensure Israel is granted the best quality of life that he can possibly have.

Dr. Kahana has gone above and beyond to use a technique of implanting a titanium rack into Israel's absent eye socket that will hold the eye prosthesis. He has also done an unprecedented job of reconstructing eyelids for Israel from skin and mucus membrane graphs. Israel was born with no eyelids and a contracted eye socket, but now he has an upper and lower eyelid made from his own skin and cells. Dr. Buchman also implanted a cranial plate into Israel's

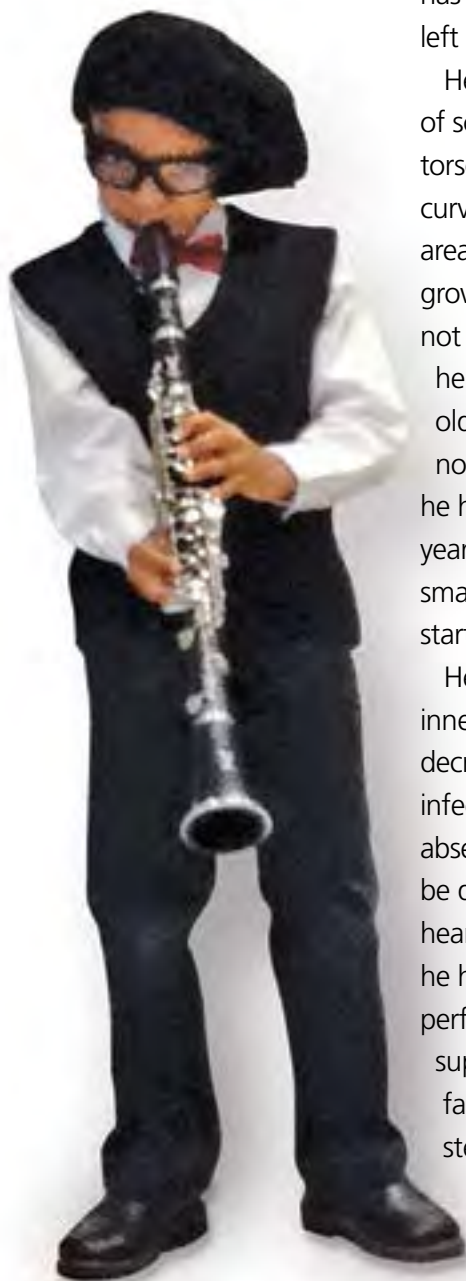


head in 2009, giving him a normal-shaped forehead.

In spring 2011, Israel had a bone graph using the technique of jaw distraction to correct his missing lower mandible. However, it may require multiple distractions to expand the jaw to a normal position.

After the procedure, his teachers and friends at **University Preparatory Academy** worked with him so he would be able to go to school. To ensure his safety, they made sure no one bumped the apparatus he had to wear. He would leave class five minutes early and leave school a few minutes early to avoid any mishaps.

Despite his strength and bravery going through the multiple surgeries, he is faced with the ugly issue of bullying. There are some children that don't understand his disability and find ways to tease him, stare at him and not treat him as a normal kid. Israel has a heart the size of Texas and loves to be a normal young man. He does have a group of friends that advocate for him and make him feel loved. His



two best friends in school are **Tyler** and **Tysin**, a set of twins who have been with him since kindergarten. They are a strong support system for him.

My son and I talk a lot about his upcoming surgeries and what the doctors have in store for him. He understands a great deal of what has gone on with him. He is constantly asking, "When will they have my eye ready?!"



While researching his disorder, I came across the CCA website and was able to find out more information about Goldenhar syndrome. I showed Israel, and he was able to see that there are other children dealing with similar issues. Next June will be our first trip to the annual CCA Family Retreat. I want him to see that he is not alone in his journey. (Because of past surgeries, we were not able to make prior retreats.)

In his spare time, Israel does normal activities like any other young boy. He loves gaming with his Nintendo Wii, riding his bike and his standup scooter. Israel loves going to church as well as singing gospel songs while riding along to and from school every day. He likes to attend the children's church on Sundays. He is always thinking about others and how he can assist them with the things they need.

Israel has chores around the house, including keeping his room clean, washing the dishes and taking out the trash. It is instilled in him that his disability does not change the fact that he has to be a responsible young person. He has to work for his allowance. He's also expected to get good grades in school, which isn't that difficult as he loves school and is a total math whiz. Israel is adamant about becoming a bioengineer when he grows up, so he can create artificial eyes that will move for children who may have similar issues.

Israel has been a member of the Michigan Y.M.C.A since he was five years old. He loves swimming and sometimes thinks he is a fish; I can never get him to get

out of a pool once he gets in.

His one passion is for music, and despite his disability, Israel plays the clarinet. He is in his second year with the Weekend School of Music at Wayne State University in Detroit. One would think this was not possible for him, but he plays very well and receives accolades from his music teacher. His goal is to eventually learn how to play the saxophone. His favorite music is jazz and for a youngster, he has an ear for music. His favorite jazz artist is Chuck Mangione. He also likes to listen to Earth Wind and Fire and George Benson. He has a soulful spirit.

Israel's backbone has always been his sister, **Kamayah**, who at two years old proclaimed "That's my baby" on the day he was born. She has been so supportive and an awesome sister, standing by his side, holding his hand, wiping his tears and helping him at times in school when he was afraid. If there was ever a "big sister," she definitely



Israel and his sister, Kamayah

holds that position in his heart.

Kamayah also attends the music class with Israel, assisting him in reading and learning his music. She is a fourth-year viola student and also plays the flute. They sit together in music class and play in their recitals together. She has had to learn a great deal of information regarding Goldenhar syndrome right along with the family, and she never misses a beat. She is his rock and his heart, and they are inseparable, like two peas in a pod.

links of love

The sixth annual Links of Love Golf Tournament took place on September 27 at **Bear Creek Golf Club** in Dallas, Texas, grossing more than **\$18,000**. Registration began with morning coffee and baked goods from **Starbucks** on Inwood, and golfers were treated to box lunches from **Corner Bakery** as they took practice shots and prepared to hit the golf course for the afternoon scramble.

Featured at each tee box, along with sponsor signs, were photo signs of CCA kids and adults, which helped leave an impression about the many different craniofacial conditions. We were thrilled to have a personal visit from CCA kid **Sadie Bono**! Thank you to **Debbie**, her mom, for bringing her out to see her dad, **Justin**, before he played. Special thanks also to volunteers **Sarah Collins** and **Becky White**, who drove up from Houston for the day to help. Thank you,

Sarah, for donating all the photography for the event!

There were also a number of sponsored Pin Flags, each of which had a photo of a CCA kid emblazoned on one side and the sponsor name and/or logo on the reverse. These helped create a lot of awareness for CCA. Pin Flag sponsors included **Blanks Printing; C&G Boats; the Dalton Family; William Gorman, MD; Hudson & Marshall; Robert Morgan, DDS MSD; Haggar Clothing; Vance and Judy Kemler; Mr. and Mrs. Steven Weiss; and United Vision Logistics.**

The rest of our volunteer crew included **Rich Thomas, Clay Scroggin, Beverly Butera, Michelle Helton, Judi Freeman** and **Robin Williamson**—all helped with tasks from auction setup to registration to on-the-course contests and everything in between!



A late start reliably predicted a late finish, and hungry golfers arrived to another great **Spring Creek Barbeque** dinner, door prize raffles, awards

and auctions. We're so grateful for the help of **Cory Kruse** who handled the live auction portion of the evening, getting folks to bid high after listening to a moving speech by CCA mom Becky White. **Big thanks to all who helped make the 2013 Links of Love a success!**

Thank you to our volunteers, participants and especially to this year's sponsors:

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Auction Sponsors

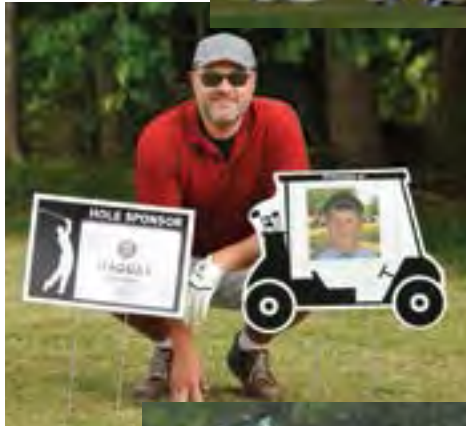
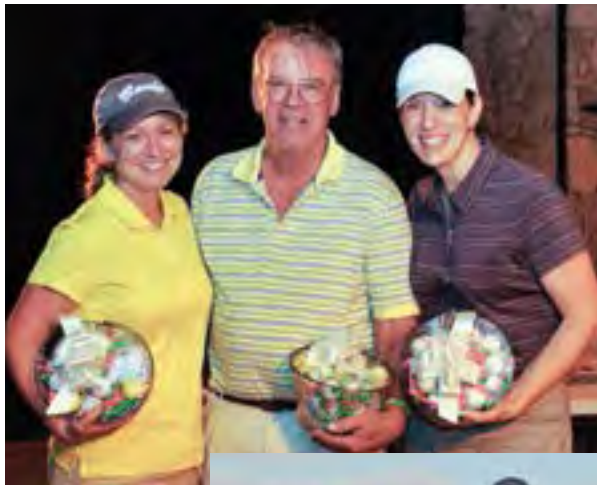
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a living legacy



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.**

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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!



donors in the spotlight

For this last issue of 2013, we honor the memory of **Paul Charles Mattison** of Horseheads, NY, his family and particularly his wife of nearly 63 years, **Joyce**.

Paul and Joyce are the maternal great-grandparents of CCA Kid **Ryan Gulich**. Ryan's mom, **Nicole**, told us: "We are very pleased that my grandma and family chose CCA! My grandpa loved Ryan, and it broke his heart every time Ryan had surgery. Grandpa, too, would be very pleased with this choice of charity."

Thank you to **Joyce Mattison**, her seven children, 17 grandchildren and 27 great-grandchildren—our Donors in the Spotlight!



waco picnic to raise funds and awareness

Once again, **Carmen** and **Ron Mickley** were joined by folks at the **Central Christian Church (CCC)** in Waco for a Craniofacial Acceptance Month "picnic" that raised funds for our CCA kids—and lots of awareness. Also, for the second year, children enjoyed pets from **Angel Paws Waco**, who came out to support the effort. Thank you, CCC, for a raising more than **\$800** for CCA!

birthday celebrations to raise funds for cca



As always, we wish to send out a big thank you to everyone holding Birthday Wish campaigns on Facebook to raise funds for CCA! We're especially excited about the birthday of our own **Annie Reeves** whose "wish" garnered **\$1,500** for our CCA Kids! Thanks, Annie!

Sydney Rose Ford turned six and again this year she asked for donations to CCA! Thanks, Sydney!





The **Jurek Family** of Andover, MN, surprised us at the retreat in June with a generous **\$1,000** check from their friends at **Bell Mortgage**, in honor of their daughter, **Madelyn**, and to benefit all of our CCA kids. Thank you to the Jureks and to their thoughtful friends and neighbors at Bell!

CCA Grad, **Rachael Morrissey** and her mom, **Alison** were guests on "The Doctors" TV show in order to share their life experience dealing with Rachael's bilateral cleft lip and palate.

But, it was also a plan cooked up by **Lindsay Condefer** and "Lentil Bean" so they could finally meet in person! CCA helped with the top secret surprise—The Morrisseys introduced Lindsay to Children's Craniofacial Association, and her Team Lentil "Bean Stalkers" have provided much funding support for our families. We're extremely proud of Rachael's network debut and of Lentil's, too!



calendar of events

date event contact

2013

Dec 7	CCA Holiday Party—Dallas	ARees@ccakids.com
10A-Noon	Southfork Ranch Parker, TX	214.570.9099 800.535.3643
Dec 14	CCA Holiday Party—Midwest	JPatterson@ccakids.com
11:30A-2:30P	Brat Stop/Parkway Chateau Kenosha, WI	214.570.9099 800.535.3643

2014

Jun 26-29	24th Annual Cher's Family Retreat	ARees@ccakids.com 214.570.9099 St. Louis, MO 800.535.3643
Jul 18-20	11th Moebius Syndrome Conference	www.moebius syndrome.com 660.834.3406 Bethesda, MD plicht@yahoo.com



After bidding successfully and winning this beautiful huge photo of "Lentil Bean" during Lentil Fest last Spring, generous Team Lentil member and "Bean Stalker," **Liz Schweizer** immediately donated the photo back to Children's Craniofacial Association and asked us to present it to one of our CCA Kids. We checked with Liz when we drew **Connor Ford's** name and she agreed wholeheartedly! Thank you Liz!

Click on
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at ccakids.org

welcoming a child back to school after surgery

By Kim Seifert, RN and Richard Redett, MD

Children with a craniofacial condition may have as many as 30 or more surgeries before they reach adulthood. These surgeries may change the appearance of the child and will often occur during the school year. Going back to school after surgery can be difficult for both the affected student, as well as his/her classmates. Taking steps to prepare students for these changes will alleviate much of the anxiety they may experience.

Returning to school following surgery can be an exciting and anxious time for children with craniofacial differences as well as their classmates.

As a parent, you are looking for all of the resources that will help you and your child adjust as he/she returns to the classroom. As a teacher, you want to make the student's return comfortable for both the affected student and his classmates. Preparation and communication on the part of teachers and families help children make a smooth back-to-school transition by:

- Teaching classmates respectful and appropriate ways to ask questions about the surgery
- Providing classmates with a better understanding of the medical condition and surgery, making them more accepting and less likely to tease or bully the child
- Sharing ideas on how classmates and friends can be supportive
- Preparing classmates for the physical and emotional changes that might be present after surgery

Sometimes a student who has a craniofacial condition undergoes [surgical] procedures that might cause him/her to come back to school looking different.

General Craniofacial Surgery

Children with craniofacial differences often need surgeries that require them to be out of school for extended periods of time. After surgery, they may return to school looking different from when they left. Some changes may include:

- Sutures or staples on the face or in the hairline
- A shaved area of the hair
- Swelling around the eyes and face
- Following surgery on the ear, a cup, soft dressings, or headband may be used for a few weeks as protection
- Frequent visits to the nurse for post-surgical care
- Needing extra help with school work due to extended absences

Tracheostomy

A tracheostomy is a small surgical opening in the neck which allows air to go in and out of the lungs. The opening in the neck may have a tube inserted through the opening. Some changes may include:

- A change in voice quality or volume
- The child may bring a nurse to school to help or may require frequent visits to the school nurse

Rigid External Distraction (RED)

Sometimes children need RED. This device is used to treat children with certain craniofacial conditions affecting the growth of the jaw. The RED device (which is actually purple, not red) pulls the face forward very slowly by a set of screws that are turned daily. It is usually on for 6 weeks.

Common questions students may have about the RED are

• **Can you breathe and talk with that on?**

The device should not affect the patient's ability to speak or breathe.

• **Does it hurt?**

It should not hurt and the child should not require pain meds.

• **Can you do regular things with the RED on?**

Children may go to school and participate in their regular activities: but may not swim or play contact sports.

• **Can you eat normal food?**

No. Children need to be on a soft diet during this time.

Preparing students for the return of their

classmate will help make the transition easier

Returning to school after craniofacial surgery is potentially challenging and overwhelming for both the student and his or her classmates. Open and honest communication can facilitate the transition back into classroom and give the child a sense of normalcy and routine.

Tips for Teachers and Students

How can teachers and classmates make the transition back to school easier for a child after craniofacial surgery?

- Prepare the class that the student might be out for an extended period of time.
- While the student is out, keep in touch with cards, phone calls, e-mails. Tell the student about class activities and try to keep him/her connected with the class.
- Prepare a class discussion with a simple but accurate description of the surgery and what to expect when the child returns. (For example, a shaved scalp, swelling, bruising, the presence of a RED or trach). He/she will not be able

to participate in gym class and certain school activities. Encourage classmates to ask questions and clarify misconceptions.

- As a class, brainstorm ideas on how you can support the returning child. Remind the class that their friend is the same person, but that they may notice some changes. Open discussion and communication is key.
- Ask the class questions such as:
 - “Do you think that it will be difficult for ____ to return to school looking different?”
 - “Do you think that ____ should get teased for looking different?”
 - “What will you do if you see other kids teasing ____?”
 - “How can you help ____ when they return to school?”

Allotting time for planning and preparation will make a student’s return to school after surgery, a smooth, comfortable transition for both the student and his/her classmates.



A Young girl after placement of the RED device

donors, january 1 – september 30, 2013

To see Children’s Craniofacial Association’s list of donors as of September 30, 2013, please go to our website. The list can be found at

www.ccakids.org/donor-list.html

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

3 cheers

for volunteers!

We're so very grateful for two busy nurses, **Rebecca White** and **Sarah Collins**, who traveled from the Houston area to Dallas for our 6th Annual Links of Love (LOL) golf tournament in September. They juggled their and their families' schedules for CCA, and we are truly thankful!

CCA mom Rebecca helped host the inaugural "All the Way for CCA" golf tournament in Houston last

spring with fellow "Texas Moms" fundraisers **Lisa Bock** and **Jennifer Kilmer**. That's where we first met Sarah, an extraordinary photographer, who donated her talents to the effort. At the time, Rebecca and Sarah, with plates already full, were classmates in nursing school.

Both of these wonderful ladies made their way up to Dallas to help make LOL



one of our most successful tournaments yet! A sampling of Sarah's work is found on pages 18-19, along with the follow-up of the event. And Rebecca gave a moving testimonial during dinner, really expressing to our golfers what CCA is all about. Thanks again and Three Cheers for these awesome volunteers!