

ccanetwork

newsletter of children's craniofacial association

2021: ISSUE 3

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meet the lockwoods

by Kevin Lockwood

The phrase "all things to work together for good" is part of a well-known Bible passage that brings hope and encouragement to many people as they face troubling circumstances. For us, that simple-sounding phrase has become so much more than a quote on a plaque, or something said to encourage a friend. Although it took us more than a decade to fully comprehend the profound truth in this passage, the words are now a constant reminder of the way our lives were transformed for the better through special needs adoption.

Our story of wanting a family started pretty early for us. We met at a church youth event and quickly became high school sweethearts. A couple years after high school, we got married and our life-planning kicked in to high gear. We didn't always know what jobs we would have, or where we might settle

see Lockwoods, page 2

letter from the director of development



In a year which started out often feeling like a continual Groundhog's Day to a time of re-emerging hope, 2021 has been nothing short of true growth for us all. I am so happy to share, with the help of so many donors and families like you, CCA has navigated these uncharted times with amazing results. Because of you, we have re-imagined how we fundraise and slowly and safely brought back a few in-person fundraisers. I am so very hopeful to see more blossom as we round out 2021 and head into 2022 with Retreat in our sights next summer, deep in the heart of Texas!

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down, but we were always certain about one thing: we were going to have a big family. We diligently worked though college and entry-level jobs while simultaneously planning, saving, and arranging every aspect of our life so we could be fully prepared to start the family we had always wanted.

Five years into marriage, we thought we had everything lined-up and finally began the process of waiting for a positive pregnancy test. It seemed to take a while, but when that day finally came, we were thrilled. After a typical start of the pregnancy, we were excited when it finally came time to have our first ultrasound. However, the day ended very differently than it started and we left the hospital that day with grief and sorrow instead of the traditional ultrasound photos most parents cherish. "Keep trying" is what our friends and family continued to tell us, so with steadfast resolve, we did just that, hoping and praying that our "dream" would come true if we just stayed the course.

After lots of disappointments and ongoing failures, we were finally advised to begin the process of testing and fertility treatments.

This news was detrimental to us since we had always dreamed about raising children, and the thought of forcing the issue through invasive and expensive procedures didn't feel like our destiny. Although we were completely heartbroken, we began praying, discussing and research-



ing what to do next. It didn't take long before the idea of adoption began to fill our minds, and especially our hearts. We still had a lot of questions about bonding and attachment with an adopted child, plus we were still processing the grief associated with having to forgo the joys associated with pregnancy and birthing, but we eventually began to realize that perhaps this was the real plan God had for our lives all along.

In 2005, we took what felt like the biggest leap of faith, and boarded a plane for Kazakhstan, a country we had only learned about months earlier. Our first experience with adoption was eye-opening, and after eight weeks in the country, we learned a lot about the plight of orphans in developing nations. We were completely heartbroken by the sheer number of children growing up in institutional settings, but what really stopped us in our tracks was the way children with special needs were hidden from public view, and valued even less than orphans.

After bringing home our first daughter, our lives were changed forever and we continued adopting, each time expanding the list of potential disabilities we felt like we could handle. With Kazakhstan becoming unavailable after our first adoption, we moved on to Vietnam, and then eventually to China, where a large amount of special needs children have been abandoned amidst the country's cultural stigma of disability and its former one-child policy.

By the time we started our fourth adoption, we had gained confidence about our ability to handle most physical disabilities



lockwoods, continued from page 2

but we were still not sure about how to raise children with intellectual disabilities. That changed the moment our adoption agency sent us the profile of a little girl who was listed as having club feet, a misshapen hand, and an "inability to respond socially." We didn't know exactly what that meant, but from the photos of her expressionless face, and the personal accounts of her not responding to her caregivers, we were convinced that she probably had an intellectual disability. This didn't bother us, we felt ready to help her with whatever she needed. We knew she was destined to be our daughter, so we quickly completed the paperwork to bring her home.

Upon meeting our new daughter, **Hannah**, we were thoroughly overwhelmed with emotion! She was adorable in every way, and seemed to have an inquisitive personality, but as her profile mentioned, her eyes didn't seem to move, and her facial expression never changed. It wasn't a concern to us and we were just happy to finally hold her in our arms. We figured that if she really did have an intellectual disability, it might be a while before we saw her smile.

Four days after receiving Hannah, we were feeling like she was really starting to warm up; she seemed to be enjoying all the interaction with us, however her eyes were still locked in an unblinking gaze, and her face continued to show no signs of emotion. Later that night, we were enjoying a few moments of bonding while playing a tickle

game on the hotel bed, and much to our surprise, Hannah suddenly burst out laughing. It wasn't just a giggle or a snicker, but a full on, roaring, belly laugh... and yet, her eyes and face remained completely motionless. We were so happy to see her laughing that we didn't think much about it. We knew our friends and family back home would be thrilled to hear her laughter as well, so we took a short video and uploaded it before going to bed. When we woke up the next morning, we had two separate emails from different friends who worked in the medical field. They wrote to let us know they noticed Hannah's lack of facial movement in the video and decided to start researching it. Much to our surprise, both friends independently stated, "she has a rare condition called Moebius syndrome."

We immediately began researching Moebius syndrome for ourselves and everything began to make sense about Hannah: her lack of facial movement, her eyes fixed in a forward position, her different hand, plus a number of other things we noticed were all textbook symptoms of this syndrome. The stoic face in her orphanage photos, and the observations of her caregivers weren't an indication of a cognitive disability after all; she just couldn't respond with a smile, or track people with her eyes.

When we returned home from China, Hannah's pace of life picked up very quickly.



She suddenly had three big siblings doting on her day and night. Siblings who immediately began to understand how to interpret her



lockwoods, continued from page 3

body language, vocalizations, and behavioral patterns, instead of relying on her facial expressions or words. The lack of facial expression, and the delayed speech didn't bother them one bit. At the time, Hannah's closest sibling, **Michael** (who also had some cranial and limb differences) had been going through a lot of medical procedures, so the two of them quickly bonded and became best buds. Because of the similarities of their needs, they would often share the same appointments as we traveled around meeting with specialists, surgeons, therapists, and geneticists. After a while, Hannah's club foot treatments were finished and she was able to start experimenting with walking, allowing her to participate in everything her big siblings were doing.

Hannah's radical transformation in those first couple years amazed and inspired all of us, and it wasn't long before we were talking about adoption again.



We had learned a lot after immersing ourselves in the world of craniofacial differences, so we kept our ears open and soon heard about a little boy in China with facial palsy, global delays, and epilepsy. We didn't have a lot of information to go on, but he was absolutely adorable and we couldn't wait to bring him home. Ironically, when we arrived in China to adopt him, we realized his "facial palsy" diagnosis was actually a poor translation on his medical documents; in reality, he actually had cerebral palsy, which meant we needed to learn about a whole new set of symptoms, and find a new set of medical specialists.

We thought our hearts and hands were full after five amazing kids, and we had been going about life as usual for a few years, but one day, we got an unexpected call from our adoption agency. They remembered the story we shared years ago about Hannah's rare syndrome, and they wondered if we would be willing to consult on another little boy whose profile had just come across their desk. They said his photos and list of medical conditions reminded them a lot of our Hannah, so we asked them to send the info to us right away. Upon opening the email and seeing his profile, we instantly knew this little boy also had Moebius syndrome. We replied with an email saying "we'll take him," which shocked the agency's staff who had only expected to get some background



information to put in his profile. Nine months later we were on the plane again to China, this time with the entire family. The moment they brought our little **Josiah** into the room, he was immediately surrounded by five, adoring siblings, all of whom were fully accustomed to interacting, playing and communicating love, regardless of speech ability or facial expression.

Hannah and Josiah have come a long way since being adopted. Both have experienced numerous life-changing medical procedures, developed intelligible speech, and come up with their own unique ways of communicating emotion. Along with the rest of their siblings, they truly enjoy raising awareness about craniofacial differences far and wide. In addition to being involved with CCA Kids, they have also helped spread awareness through their videos on YouTube, their involvement with various Moebius syndrome organizations, and their appearances in disability awareness campaigns like "Joni & Friends" (the international outreach started by **Joni Eareckson Tada**). 🌈



celebrating craniofacial acceptance month

Craniofacial Acceptance Month (CAM) might be over but we will continue to spread the message of Acceptance and Awareness all year long! September was truly special, and we loved seeing so many of you turn Facebook yellow throughout the entire month, with frames, customized graphics from our Outreach Director, **Khadija Moten**, and sharing your stories and fundraisers with all of your friends.

It was a great way to mark the 17th year CCA has observed September as CAM. This year, our CAM theme was **"I Accept Me, I Accept You."** Our theme reflected both the need for self-acceptance, but also the need for us to be advocates for acceptance broadly. Families shared stories throughout the month on ways they accept themselves as well as ways they cultivate acceptance in their communities. We ended the month focusing on how to build those accepting communities and recognizing the support we have around us.

One of the things we appreciate the most are the innovative fundraisers which often launch during CAM and support our work all year long! This year, we added **Lasting Smiles Lip Care** (which runs through the end of the year), **Polish and Hooves by Allie Quinn** (featuring a **ColorStreet** profit share), a lemonade stand, a piggy bank funder, and an incredible number of Facebook Birthday Funders and CAM Funders - 12 of which surpassed the \$750 CAM Incentive Goal. Thank you all so very much - your support is not



only critical; but it is also so appreciated!

We also got to see and share interviews, podcasts, and videos on social media. We continued hosting our CCA Virtual Programming, including a Virtual Group Photo. Nine states proclaimed September as Craniofacial Acceptance Month.

Many states now require local families to sponsor the proclamations. If you are interested in helping with this process, please email: kmoten@ccakids.com. Your help will get that number up and beyond!



CAM, continued from page 5

For the 14th year, CCA held National Picnic Day in September. Though COVID continued to put a damper on our scheduled events, amazing picnics were able to be held in Michigan and Ohio!

Numerous organizations and hospitals also celebrated CAM along with us! We would like to send out a special thank you to **ConnectMed International** for hosting a Parent PopUp, and we look forward to our continued collaboration with our friends in San Diego.

We would also like to thank everyone who participated, with special thank you's to the following:

Abby McGowan, Manny Ventura, Iva Ballou, Christine Maier, Brianna Legner, Renne Fuganti, Lisa Bowers and Family, Rose Seitz and Family, Kellie Dowd and Family, Jesanne Roden-Reynolds, Summer Thomas and Family, Allie Quinn, Ron Shover, Balloon Artist, Spring Creek BBQ, Patricia K. Marik, PsyD from Children's Wisconsin, everyone who purchased marketplace and webstore items, those who requested and shared a custom social media graphic, and those who fundraised and donated to CCA Facebook Funders.

"The most useful asset of a person is not a head full of knowledge but a heart full of love, with ears open to listen, and hands willing to help."

-Anonymous

We couldn't have done this without all of you. Our hearts are truly full. Stay well!

- Annie Reeves
Program Director



thank you to our 2021 facebook fundraisers:

names are listed in alphabetical order by the fundraiser campaign owner

- | | | | | |
|-----------------------------|----------------------------|----------------------------|--------------------------------|---------------------------|
| 1. Alanna Hess | 32. Erica Klauber | 63. Karen Arnold Silfies | 94. Nancy Da Silva | 125. Tamara Nord |
| 2. Alisa Faber | 33. Eugenia Young | 64. Kary GB | 95. Nathan West | 126. Tami Litfin |
| 3. Amanda Sandoval | 34. Francis Menard | 65. Katie Hartke | 96. Nathaniel Newman | 127. Tammi Trude-Gonzalez |
| 4. Angela Hanrahan Eyer | 35. Graham Ormerod | 66. Keith Miller | 97. Nicole Cheri Clifford | 128. Tanya Tiger |
| 5. Angela Yurkanin Allen | 36. Greg Daniels | 67. Kelli Kelly | 98. Nicole Killeen | 129. Tenny James Philip |
| 6. Angie Batton | 37. Haley Holubec | 68. Kellie Lloyd | 99. Paige Michelle Edwards | 130. Terri Mlotek |
| 7. Anna Rogers Milican | 38. Haley Turner | 69. Kelly Cunha-Pokorny | 100. Patricia Simon | 131. Theresa Hospodka |
| 8. Annie Reeves | 39. Helen Parker Mills | 70. Kelly Williams Carlson | 101. Payton Parish | 132. Thomas M Lee |
| 9. Ashley Bock | 40. Honeybee Creations | 71. Khadija Moten | 102. Peter Dankelson | 133. Tisha Shellenberger |
| 10. Brooke Stragatz | 41. Ian Parkinson | 72. Kristi Cuddy | 103. Petty & Steven Weiss | 134. Torey Harrah |
| 11. Carol Ardelean | 42. Isabel Moreno | 73. Krystle Rizzo | 104. Rachael Blitvich | 135. Trashica R. Robinson |
| 12. Carrie Greer | 43. Jaci Samhammer | 74. Kyle Hoelting | 105. Rachel Fabre Johnson | 136. Tricia Elise Brusk |
| 13. Casey Deakins | 44. Jane K. Cook | 75. Lanique Fortune | 106. Robb | 137. Victoria Green |
| 14. Cassie Ayers Linnell | 45. Janelle Crystal | 76. LaTrisha Murphy | 107. Rose M. Seitz | 138. Whitney Sisney |
| 15. Charles Kinder | 46. Jeanie Ross | 77. Laura Vivian | 108. Russel Newman | |
| 16. Chelsea Buyalos | 47. Jeannelle Rivera | 78. LeeAnne Thompson | 109. Sam Sanchez | |
| 17. Cheyanne Sharpe | 48. Jeni Hines | 79. Lisa Bowers-Alters | 110. Sara Geller | |
| 18. Chris Sisney | 49. Jenie Kempert | 80. Lisa Singh | 111. Sarah N Mike | |
| 19. Christine Andler | 50. Jennifer Boyer Hedlund | 81. Lisa Stanford | 112. Sarah Suwalski | |
| 20. Cory Lloyd | 51. Jennifer Dockter | 82. Liz Griffin Cox | 113. Sasha Strasdat | |
| 21. Courtney Vysocky | 52. Jennifer Mau | 83. Liz Sheets Anderson | 114. Shannon Duzan-Fowler | |
| 22. Dawn Brand | 53. Jeremy Stowe | 84. Maddie Cameron | 115. Shannon Marie LaBarbera | |
| 23. Dawn Perkins | 54. Jessica Autumn | 85. Maricela Burns | 116. Shastina Hightshoe Kemper | |
| 24. Deb Wood | 55. Jill Laufbaum | 86. Markus Piskowski | 117. Shauna Abbott Huddleston | |
| 25. Deena Dyson | 56. JJ Henson | 87. Mary Ann Heston | 118. Stacey Egnor | |
| 26. Dianna Hill Hodges | 57. Joe Brooks | 88. Megan Mejia | 119. Stacy McAllister | |
| 27. Donna Marie Roberts | 58. Joel Brusk | 89. Melissa McQueen Benfer | 120. Stacy Needleman-Klein | |
| 28. Dorina Watkins | 59. Josefina Glykofrydis | 90. Melissa Reneigh | 121. Stephanie Marie | |
| 29. Ella & Anah Kryzanowski | 60. Judith Kemler | 91. Mena Stephany | 122. Steven Tyler | |
| 30. Emily Daisy Crabtree | 61. Justin Graham | 92. Michael Piacenza | 123. Sydney Rathbun | |
| 31. Emma Neal | 62. Kara Jackman | 93. Mitch Maltby | 124. Sylvia Brewster | |

create your own facebook funder

Facebook is a great way to raise funds for CCA kids. Facebook takes 0% in fees and you can set up your fundraiser with a few quick clicks.

- visit: www.facebook.com/fund/ccakids/
- click - Raise Money
- click - "Non Profit" and then search for "Children's Craniofacial Association"
- click: Children's Craniofacial Association
- select - a goal amount and end date
- click - Next
- enter - a title for your fundraiser - Birthday or CCA Fundraiser, etc
- enter - tell your audience why you are raising for CCA (We already have some words in there but it is all totally customizable)
- click - Next
- select - a cover photo - we have a bank of photos to choose from or you can upload your own
- click - Create

IT'S THAT EASY



meet august

my name is August Siegmund. My family calls me Auggie. I am 11-years-old. My birthday is actually this November! I was born with Treacher Collins syndrome. I've been fortunate enough to not have to have surgery. I know people mostly stare at me because of my ears and BAHAs. I don't worry about them staring at me because I think everyone else has differences, too.

One of my favorite activities is reading. My favorite books are "Wonder" and the "Spy School Series." I like "Wonder" because it reminds a lot about myself and what I've gone through and we have the same name! I enjoy spending time in the library and learning. My favorite subject is social studies, especially WWII. That time period really interests me because it is kind of recent. D-Day is my favorite battle in WWII. One of the fighters, Earl Rudder, was a war hero, and is a well-known local from my hometown of College Station, TX. I like to talk to my dad about history - he likes it too!

Playing video games is another one of my favorite activities. I like to play Switch and XBOX. I taught my little sister, Laurel, how to play Switch with me. She gets better every time we play. My youngest sister, Sutton, is a handful when Laurel and I play, and she wants to play with us!

I enjoy spending time with my family. We travel to see my grandparents a lot. We also like to take big trips. Last summer, we drove to Yellowstone and Grand Teton National Park. We also stopped at the world-famous Thermopolis Hot Springs along the way. It was a long, grueling trip, but it was so worth it!

I haven't been to a CCA Retreat yet, we were registered to go in 2020.

(darn COVID!) but I'm looking forward to next year's Retreat! I'm hoping to meet other kids who look like me and meet other people with Treacher Collins. 🥰



ccakid

ccasupersibs

meet laurel

Laurel says "Hiiii!" Laurel is **August's** younger sister. She can't wait to be 11, just like him. She has a few more years though. Her favorite colors (right now) are red, black, purple, and pink, but they might change by the time this story prints! She loves to color and uses all the colors in the box to embellish her drawings. Her family, cats, flowers, and hearts are mostly what she draws.



Even though she can't read yet, she likes to flip through books and make up stories based on the pictures. Playing ISpy is one of her favorite games to play with the whole family. Pink, red, black, and purple objects dominate her "I spy with my little eye" clues. She has a habit of changing the object she spies and adds a little giggle when she says "no, that's not it" when really it is what she spied with her little eyes.

Laurel adores her older brother, **Auggie**, and younger sister, **Sutton**. They love chasing each other on ride-on toys around the house and wrestling each other. She especially enjoys when she gets to play video games with her brother.

In the summer of 2020, just before her 3rd birthday, Laurel was diagnosed with type 1 diabetes. She gets multiple daily

injections of insulin to help control her blood sugar and wears a continuous glucose monitor (CGM) so she

doesn't have to prick her fingers every few hours. Sometimes she lets her big brother hold her hand and distract her when she gets her shots and changes out her CGM. Like Auggie, Laurel knows she's a little different (she said before: "Not everyone gets shots like I do, Mom.") She's been very proud of her CGM and likes to show it off to people. She'll even say she has diabetes even though she can't quite explain what it is yet. 🩺

meet sutton

Sutton is the youngest of the Sigmund kiddos. She takes notes from Laurel and Auggie. Those notes include climbing up slides, playing "Keep Away" and screaming and laughing as she's chased around the house. Two girls screaming and laughing make for a loud house but they have so much fun together (when they get along). It seems every week that passes, they get along a little better.

Sutton and Auggie on the other hand, get along all the time. "Auggie" is one of her favorite words. For a while everyone

was "Auggie." Sutton knows when Auggie's not paying attention to her so she'll grab his BAHAs. She knows he'll stop everything to save them and play with her. Her mischievous side definitely shows when she wants someone to play with her.

Since Sutton was born in March of 2020, she hasn't met many people face to face, but that hasn't stopped our video calls to family and friends. She likes to "boop" people's noses and hit every button on the screen to stay entertained. AJR and different kid's movie soundtracks stop her in her tracks so she can dance. She does a cute little shoulder shrug dance when she likes a song. Hopefully she can show off her dance moves at the next CCA Retreat. 🩺



letter from development, continued from the cover

I would especially like to highlight some of our biggest efforts:

Early this year we were the chosen corporate social responsibility project for **Tokio Marine Group**. Tokio Marine Group is a global conglomerate of multiline insurance companies and employs tens of thousands of people globally. We were connected to this organization by our selfless board member, **Bill Mecklenburg**. Bill was able to share our story and pitch with **Shawn Braun**, **Regional Sales Director at Reliance Standard**, who then championed us to be their corporate charity for 2021. We were able to engage their staff virtually with a movie screening of *Wonder*, hard copies of the books in two languages, and mailed educational material to their homes. What made the biggest splash was our personalized keynote address and subsequent panel discussion on diversity and inclusion, featuring **Jono Lancaster**. This video is still being used for their new hires and we are excited the impact has longevity in their corporate culture. Overall, we raised over **\$53,000** from this outstanding partnership!

I must share just a snapshot of the incredible news you will read and see more of on [page 11](#) about the **10th Annual Morgan Meck Golf Invitational (MMI)**. Our Board Member, **Bill Mecklenburg**, held the most successful MMI tournament in history: grossing over **\$155,000**! I was blown away how his network showed up and gave so generously. It was truly a few days of immense joy and

normalcy seeing new and old friends reunite to support our cause, share stories, and have fun together. We listened to speeches by **Darin Dankelson**, **Russel Newman** and **Manny Ventura** sharing how CCA has supported them and their families. The week was a true testament of the Meck Family's love and hard work for CCA.

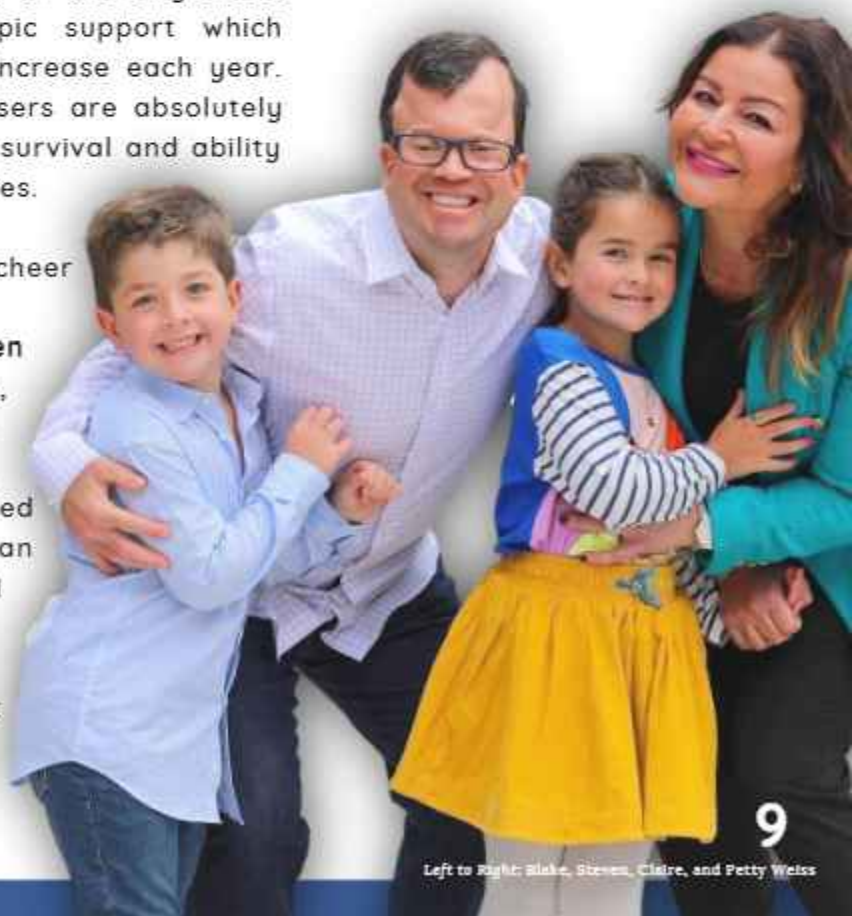
I am always so happy to highlight our Board Members and Staff who go the extra mile with personal fundraising efforts. **Annie Reeves**, **Kelly Cunha Pokorny**, and **Chuck Russell** dug into their own personal networks to raise thousands on behalf of their birthdays for CCA, along with so many of you who do this every month. We cannot overstate how important these fundraisers are. YOU are connecting us to your network and that support is one of the only areas of philanthropic support which continues to increase each year. These fundraisers are absolutely vital to CCA's survival and ability to serve families.

We owe a big cheer to our Board Member, **Steven Weiss**, his wife, **Petty**, and his mother, **Ellen**, who campaigned and delivered an incredible CAM fundraiser totaling over **\$14,000** in just a few weeks from their generous

friends and family. Thank you, **Weiss Family**, for this spectacular job and the wonderful inspiration you provide as mentors.

The **CCA Marketplace** continues to benefit CCA by finding friends and families to profit share a portion of their sales back to CCA. Please check our page regularly for codes or specials and continue to think of us for profit shares or shopping for a cause. While the amounts are small, we hope they provide you opportunities to weave financial support of our mission into your daily life. They are meant to be a convenience to you, and we appreciate everyone who utilizes these opportunities.

Last but certainly not least, I am so honored to share, CCA is the humbled recipient of a bequest gift from the late



Left to Right: Blake, Steven, Claire, and Petty Weiss

letter from development, continued from page 9

Rosemary Mitchell. This wonderful woman left our organization nearly \$587,000 in the form of stocks and bonds. This gift has become a game changer that will help us replenish the reserves we've dipped into since 2019 and establish a fund to help our Retreat absorb the rising costs we are encountering each year. We will forever be grateful to Rosemary for her kindness. To learn more about how to leave your own mark on the world through supporting CCA Kids and Families, visit: ccakids.org/legacy-planned-giving/



We are so grateful for all the support you bring to CCA as donors, families and friends. May the year 2022 be full of light and all good things!

- Christine Andler

Director of Development



Simply put, planned giving enables you to make a meaningful gift to CCA that reflects your beliefs and values. Your gift will create an enduring legacy by supporting CCA Kids during your lifetime and beyond. We are happy to help you choose the program or services that mean the most to you, as you make your estate plans.

To learn more about how to leave your mark on the world through supporting CCA Kids and Families, visit:

ccakids.org/legacy-planned-giving/
or email Christine at candler@ccakids.com



2022 cca educational symposium and family retreat

Registration is open for the CCA's 32nd Annual Family Retreat & Educational Symposium, June 23rd-26th in Dallas, TX! Join us for an educational symposium, talent show, dinner/dance and much more!

Have questions or concerns about registration?

Contact our Program Director, Annie Reeves: areeves@ccakids.com

Interested in having your organization or company sponsor a part of retreat?

Contact our Director of Development, Christine Andler: candler@ccakids.com

View a list of our frequently asked questions answered at:

<https://ccakids.org/retreat-faqs-2022/>

- December 31st, 2021** Early Bird Pricing Ends
- December 31st, 2021** Retreat Scholarship Deadline
- January 1st, 2022** Registration Fee Will Increase
- March 22nd, 2022*** Registration Closes
*or when all spaces are filled

REGISTRATION

NOW OPEN

June 23rd-26th
DALLAS, TX



morgan meck invitational raises \$155,000 for cca

by Bill Mecklenburg

On September 8th and 9th the Mecklenburg family hosted the 10th annual Morgan Meck Invitational benefitting the Children's Craniofacial Association. There were 44 golfers from across the country and approximately 80 people who attended the dinners and participated in a significant way. The guests had the pleasure of listening to an inspirational speech by **Manny Ventura** on how he overcame his craniofacial challenges and is now dedicated to raising awareness for our CCA kids.



Manny Ventura, CCA Speakers' Bureau member & Christine Andler, CCA's Director of Development

CCA Dads, **Darin Dankelson** and **Russel Newman** also shared their stories with the group. Darin spoke to the impact of CCA on his family and the confidence CCA brought to

Peter Dankelson who is CCA's most active



#ChooseKind Advocate to schools throughout the country and is CCA's first true Rock Star. Darin's message was followed by Russel Newman's challenge for us to elevate our kindness initiative by creating a society of inclusion. In Russel's words: "It is easy to be kind, but it is difficult and uncomfortable for most people to be inclusive, so that needs to change." The message is one all CCA families know well, so hopefully this group and the overall CCA community will embrace his challenge!

We are so grateful for our committed friends and neighbors who joined us for this two-day event, and continue to raise the bar



each year. **Morgan Mecklenburg** also spoke at the dinner on Thursday evening to thank everyone for continuing to support the CCA. As she has grown, her speeches have evolved to include some serious wit (mostly at the expense of her parents) which was entertaining for all those that have known her since she was a child!

Darin Dankelson and his great friend and business partner, **Darren Bowden**, won the championship after years of disappointing performances.



Left to Right: Bill Mecklenburg, Morgan Mecklenburg, and Christine Condino-Mecklenburg

morgan meck, continued from page 11

Deb Van Horn and John Daybell captured the Ladies' Championship; however, the true champions of the tournament were our CCA Kids who inspired this small group of friends, corporate sponsors and auction participants to contribute over **\$155,000** to benefit Children's Craniofacial Association. A special thank you goes out to our Sponsors:

- Kaiser Permanente
- DUALNorth America
- Crum & Forster Insurance
- Bobby and Kristen Baillargeon
- Sean and Nancy McConlogue
- NFP Insurance
- Alliant Insurance
- SES Insurance
- Westchester Programs
- Metal Parts and Equipment
- Blair and Shelley Schrum
- Greg and Donna Bonnell
- Robert and Karen Reader
- Siwel Resources
- Sterling Floors and Zurich Programs

A special thank you is also deserved to **Shawn Craig** and **Holly Jaenichen** for providing incredible golf experiences for the

auction, along with TaylorMade Golf, for allowing CCA to benefit from its Charity Purchase Program.

Coto de Caza Golf and Racquet Club was the host venue and all out-of-town participants stayed at the **Balboa Bay Resort** in Newport Beach, California.

Private dinners were held at **Hanna's Restaurant and Bar** in Rancho Santa Margarita and at the **Balboa Bay Resort**. A fabulous pre-event dinner was hosted at **Harley in Laguna Beach** by **Greg Daniels**, CCA Dad and Executive Chef.

CCA and the Mecklenburg Family would like to thank all of the volunteers, participants, contributors, and auction item donors who made this a memorable and meaningful event, especially **Christine Andler**, CCA's Director of Development, who flew out from Dallas on her daughter's first day of school to help organize everything! 🍷



patty and abigail gather in maine

by Kara Jackman

Patricia "Patty" Simon, R.N., CCA Board member, and author is back at it again with two new children's books co-authored by CCA Kid, Abigail Grady, "Simon Says Mask On Mask Off: Be Kind Be Brave" and "Little Leo: Underdog to Superdog." Born with a cleft lip and palate, Abigail and Patricia share very similar life experiences. Together, they chose to channel those experiences creatively into two children's books, inspiring young readers with facial differences to find confidence and acceptance.



Abigail and her family hail from the great state of Maine. Patricia, a Chicago native, recently boarded a plane with her wife, Colleen, to surprise Abigail and the rest of the Grady clan in Maine. Patricia gifted to Abigail the first copies of the books they wrote together during the last year. To express their gratitude and excitement about the new publications, Patricia and the Grady family enjoyed a traditional Maine feast of lobster rolls and seafood at Ken's Seafood in Scarborough, ME. They also took part in some traditional New England fall fun, decorating pumpkin-shaped

cookies, while enjoying the stunning October foliage.

Abigail is featured as a character in the book alongside Patty and Simon in "Simon Says Mask On Mask Off." Abigail likes wearing her mask because it hides her facial difference. Through conversation and support from her mother and sister, she is able to understand that she does not need the mask to feel confident and accepted.

In "Little Leo: Underdog to Superdog," the story about Patricia's adopted French Bulldog, features how Leo, a dog born with a cleft lip, overcomes physical and emotional challenges through a little help from a caring community of friends.

The illustrator, Valerie McCord, brings Patricia and Abigail's words to life through brightly-colored, whimsical images splashed across the pages of these children's books.

Both stories are on sale at Amazon and through Patricia's website at: smilewithsimon.com

Read these two new additions in the Smile With Simon series, and explore the adventures of Patricia's other characters Patty, Simon, and Buddy, which round out her collection of stories.

You can request copies of these original books for your classroom for free from CCA. For more information, contact Khadija at kmoten@ccakids.com



The Grady Family, Colleen, & Patricia Simon, CCA Board Member

upcoming events

MAY 16th, 2022

Timarron Country Club Golf Course
| Southlake, TX

6TH ANNUAL PAR PREMIER GOLF
TOURNAMENT
BENEFITING CHILDREN'S
CRANIOFACIAL ASSOCIATION

CONTACT:

Christine Andler, candler@ccakids.com

JUNE 23rd-26th, 2022

Sheraton Dallas Hotel | Dallas, TX
(400 N Olive St, Dallas, TX 75201)

32ND ANNUAL FAMILY RETREAT &
EDUCATIONAL SYMPOSIUM

CONTACT:

Annie Reeves, areeves@ccakids.com

Registration is open for the CCA's
32nd Annual Family Retreat &
Educational Symposium, June
23rd-26th in Dallas, TX.

Please join us for an educational
symposium, talent show,
dinner/dance and much more!

Register by December 31st, 2021,
to get the early bird price.

Registration will increase on
January 1st, 2022.

Registration officially closes on
March 22th, 2022, or when all
available spaces have been filled.

If you would like to apply for a
Retreat Scholarship, the deadline
to apply is December 31st, 2021.

We hope to see you there!



SEPTEMBER 2022
Nationwide

18TH ANNUAL CRANIOFACIAL
ACCEPTANCE MONTH (CAM)

CONTACT:

Annie Reeves, areeves@ccakids.com

boston university SAFEBUGS find 'wonder'

by Kara Jackman

Chelsea Bupalos and Manny Ventura spoke at Boston University as part of the University's annual 'Learn More' series hosted by the Office of Diversity and Inclusion. During the 2021-2022 academic year, the students, faculty, and staff will explore disability. Kara Jackman, chair of the Faculty and Staff Community Network for persons with disabilities named **SAFEBUGS** (Staff and Faculty Extend Boston University (BU) Disability Support) invited the two CCA Speakers' Bureau members to share their experience living and working with a facial difference. The panel, moderated by Kara, explored ways to create inclusive environments, handle bullying, act as an up-stander for others, and the importance of allyship for people who look different or are disabled. Attendees engaged with the panelists on questions and comments around how to best support one another at work and in school.



Prior to the event, the Boston University community participated in a community read of either "Wonder" or "We Are Wonders" two books by R.J. Palacio. CCA kindly donated copies of "We Are Wonders" for BU to distribute to faculty and staff members with young children. Digital copies of the New York Times bestselling novel, "Wonder" were made available by the **Pickering Educational Resources Library**. Kara added some additional awareness items by purchasing #ChooseKind wristbands, bookmarks, and stickers to distribute at two

fairs hosted by the Office of sustainability. Speaking one-on-one with visitors to the SAFEBUGS tables raised awareness about disability and the work of CCA in the disability sphere. We even met some students who had craniofacial conditions, too!

Boston University looks forward to exploring more on the topic of disability through lectures, panels, and activities planned by various departments and individuals on campus. The goal is to raise awareness as the University moves towards increased inclusion of persons with disabilities on campus.

happy birthday chuck

On September 17, 2021, **Chuck Russell**, our Treasurer and Board Member, celebrated his 60th birthday! Family and friends surprised him with a heartfelt birthday party! If you know Chuck, you know one of the characteristics that distinguishes him is his desire to "Give Back" to his community through children's charities. The friends and family that surrounded him on his birthday celebration **collectively donated \$2,670 to CCA.**

The Russell family thanks everyone for making this wonderful donation and making a difference for our CCA Kids!

Thank you, Donors:

- | | | |
|------------------------|-----------------------|---------------------|
| • David & Brenda Kandt | • Donna Scott | • Nicole McClelland |
| • Patricia Rees | • Anne Mansfield | • John Koodrich |
| • Andrew Siegel | • Mark & Kate Crowley | • Karen Dealy |
| • Daisy Crawford | • Wendy Powell | |
| • Lorraine Brancato | • Sherry Buch | |



3 cheers

for volunteers!

by Gracen Smith

CCA has been part of my life since I was a baby. I was tagging along with my Grammie, **Char Smith**, to the CCA office and events for as long as I can remember. When I was old enough, I began volunteering. Over the years, I've put stickers on newsletters, assembled packets, participated in fundraisers, worked on the CCA database, even attended a CCA Retreat and numerous Annual Holiday Parties.

Fast forward 20 years, I am now a Junior at the **University of Arkansas**, double majoring in supply chain management and marketing. This past summer I had the privilege of taking part in a supply chain management internship with **Action**

Stainless & Alloys, Inc. in the Dallas area. It is a great company with a big heart. In addition to giving me the

opportunity to have hands-on supply chain management experience, they also went above and beyond by supporting a charity of my choice. I was happy to share the mission of CCA with the company President, **Lee Martinson** and **Richard Marabito**, CEO of the mother company, **Olympic Steel**. Both were receptive and strongly supportive, so **Dana Beard**, Director of Human Resources and I organized the project. We really wanted to make a direct impact on the kids, so we decided to collect new toys and games to be used in the care packages that are distributed to kids with facial

differences who are recovering from surgeries. **Action Stainless and Alloys** employees enthusiastically embraced the project. Not only did we raise funds and procure toys for CCA, but we also gave hundreds of people a glimpse into the lives of kids who have facial differences and their families.

I want to thank everyone at **Action Stainless and Alloys, Inc.**, for the wonderful learning experience and for their generosity and kindness toward CCA and the families we serve.



3 cheers

for volunteers!

by Khadija Moten

For the third year in a row CCA was approved to have a sponsored summer intern, thanks to the **Dallas Mayor's Education Initiatives at The Dallas Foundation**. This year we were so fortunate to have **Dhisha Kukalakuntla** as our intern. **Dhisha** played a huge role in CCA's **#ChooseKind** Initiative and outreach activities! She spent the summer writing proclamations to various state governors to proclaim September as Craniofacial

Acceptance Month (see page 5) and reaching out to schools across the nation about CCA's complimentary educator resources. **Dhisha** continues to

interns



advocate for children with craniofacial differences and recently assisted us on some CCA Blog content (ccakidsblog.org) through her Positivity club: **Positivity 101**

(positivity101.org) which she founded to promote mental health awareness and mindfulness among the youth.

.....
We would also like to recognize **Abbie Penn** and **Anya McCormack**



for also interning with us this past summer! The two are rising seniors of **Ursuline Academy Of Dallas**. They assisted us immensely with CCA's development and programming!

...

Thank you **Dhisha**, **Abbie**, and **Anya** for your hard work and dedication. All the best in your future endeavors!



meet hannah

by Kara Jackman

hannah Setzer is way more than a “Jill of All Trades,” -- and in her own words, she says she “does all the things,” -- with which we thoroughly agree! This fact makes her a wonderful profile for our CCA Adult. We also considered her for the CCA Athlete, and arguably Artist with her culinary skills, but as you read, we think you’ll see there is no categorizing Hannah, for when she says all the things, she means it! A quick Google search of recent news stories about Hannah reveals her work as a disability advocate, entrepreneur, farmer, Instagram adaptive exercise sensation, wife, and a foster and adoptive mother. Renaissance woman rings true here, but she is so much more than the next Da Vinci. She’s a nonstop freight train on a mission to make the world a better place for all people.

Hannah was born just outside of the Washington, D.C. area with cystic hygroma, a rare cranio-facial condition that causes cysts to form on her face, head, esophagus, throat, and neck. Some of the cysts have impacted her ability to swallow and breathe, so she has a feeding tube and tracheostomy to help her with those bodily functions. Never once did the cysts or surgical interventions hold her back thanks to her supportive family and very early on, support groups like CCA. Hannah attended a few Annual Family Retreats and CAM picnics (see page 5) between the tender ages of three to seven. As she grew, she invested in other groups of people for support.

When it became time to attend college, Hannah chose **Gardner-Webb University**, a small private, Christian college in North Carolina, earning a degree in Deaf Studies and American Sign Language.

After school, she took on many experiences including working in Colorado with kids who were deaf or experienced partial hearing loss, then heading back to North Carolina to work around her loyal college friends, and finally traveling to South America. She says, “I lived in Brazil teaching English” to kids in schools. After some life experience out in the world, Hannah returned to Richmond, VA, to pursue a Masters in Social Work earned at **Virginia Commonwealth University**.

Hannah met the love of her life, **Brandon**, while she was in graduate school. One year after she graduated in 2017, the two got married. She also started working as a disability rights advocate. Brandon and Hannah wanted to have a family, so they went through the rigorous process of becoming licensed foster parents. In 2019, they fostered a 14-year-old boy, then a few months later added a 12-year-old boy to their foster family. By 2020, both boys were fully adopted by Brandon and Hannah. The family fostered two additional boys, and they, too, are in the process of becoming fully adopted.



ccaadult

cca adult, continued from page 16

The family of six moved to the Virginia countryside in 2020. In the country, they have a farm filled with ducks, chickens, goats, herbs, and elderberries. Hannah says, this is the perfect place for her “boys to run wild and care for animals. It’s our little slice of heaven.”



Hannah is exceptionally skilled with social media, taking it by storm on both Instagram and TikTok platforms, raising awareness and galvanizing advocacy for inclusion of all people. Her first foray into Instagram began with a movement challenge that launched her into a viral sensation at the handle:

@feedingtube.fitness. Her fitness journey started in January 2018, when she took a 30-day movement challenge and never stopped. She documents her workouts and life on this channel which has nearly 40,000 followers around the world. She is also active on:

@hannahshandcraftedllc where she markets her own, homegrown, elderberry products. Her positive personal experience with the herb helped her recover from a sore throat. Hannah’s social media is full of inspiration. A post about her own

body image says it all, “None of my happiness is based on how I look. Yes, I have discovered how to have good hair at 30, and know I’m a babe; but I know my value and worth on days I got greasy hair and a swollen neck, too.”

Hannah is brutally honest on her social media channels which gives them an authenticity that keeps her thousands of followers coming back for more. She says, “People were saying, feeding tube, and a trach tube - ‘Wow what is this girl doing?’” Her audience grew slowly as people interacted with her, asked questions, made comments - both positive and negative. She, true to who she is, was her authentic self, sharing about her life, body, and movement goals.



Hannah quips, “No one cares about who I am. People are very interested in what I am doing.”

“People will always will say stupid things,” Hannah attests, but she is rock solid in her honesty that it can be intimidating having so many followers and people recognizing her at Target or Walmart. Self-described as a naturally positive person, she says about social media and any work in the public eye, that you must “trust yourself before putting yourself out there.” Further she advises, “Have a plan on what to do with it [your social media accounts], call out people being disrespectful, address it head on, because it is not okay for people to just get away with it.”

All of these statements are not easy standards to hold oneself to, but Hannah has what it takes to make her unwavering self-acceptance and confidence work for her, clapping back at the haters on Instagram Reels, or sharing self-care techniques that keep her grounded. She believes you can do the same. One of my favorite Instagram posts from Hannah’s **@feedingtube.fitness** is a still photo of Hannah brandishing a bicep while wearing a shirt that says, “proving people wrong since I was born.”

Every single day Hannah does just that on the farm, with her boys, and through Hannah’s **Handcrafted LLC**. She sells products ranging from jelly and syrups to candle wax and lip balm. Business is booming with products sold online and in local, brick-and-mortar stores in the Richmond, VA area. Hannah

remembers the sore throat that went away instantly thanks to elderberry. After that positive experience, Brandon and Hannah started their Hannah's Handcrafted LLC, in January 2020, just months before the COVID-19 pandemic took hold of our globe. Hannah says her husband "likes to experiment," so "he did a lot of research and tried a bunch of recipes." He made his own elderberry syrup, first giving it to family and friends, and then opening their own online store. Their elderberry syrup and other products got the attention of customers across the United States, Australia, Mexico, and Canada. Hannah admits they are "trying to take over the world" one elderberry product at a time.

Through their business, and social media accounts, Hannah and Brandon enjoy hearing other families' and individuals' stories online and in person. After listening or seeing things in the world that need improvement, they feel the need to act as change agents in their community. Their next adventure involves creating an accessible community center with a playground for children, a laundromat to clean clothes, and businesses that will employ adults with disabilities in Central Virginia. According to a recent Washington Post article, the couple has raised \$61,000 in a GoFundMe and

18 began planning the features of the play-

ground that would allow children of all abilities to play together. In the eyes of Hannah Setzer, the world can always use a little more motivation, authenticity, kindness, and acceptance. And that little more, adds so very much for so many.

To view Hannah's interview visit CCA's YouTube page.

Follow Hannah and her ventures with Brandon and the boys on Instagram at @feedingtube.fitness and @hannahshandcraftedllc or on TikTok at @hannahvaughnsetzer.

You can follow their nonprofit @growinginclusivity on Instagram and Facebook and learn about their accessible community center at www.growinginclusivity.com



gingertown dallas

BENEFITING CHILDREN'S
CRANIOFACIAL ASSOCIATION

DECEMBER 8, 2021 - JANUARY 3, 2022

The annual Gingertown Dallas is one of the biggest gingerbread house events in North Texas with proceeds benefiting Children's Craniofacial Association.

Originally founded in 2006 by David M. Schwarz Architects, Gingertown is a unique holiday initiative which brings together talent from local design, engineering, and construction firms for a live gingerbread building competition to help spread joy and hope during the holidays.

Scan the QR code to learn more and to donate to Children's Craniofacial Association. For a full list of holiday activities at NorthPark, visit northparkcenter.com.



financial assistance testimonial

by Kelly Beck

In February 2006, Hailey and Madison surprised us with their early arrival. They were born

just short of 32 weeks. From the mo-

ment of Hailey's arrival, we knew she was special. When your child is born you count their fingers and their toes and hope they are healthy and everything is 'perfect.' Hailey had 10 fingers, 10 toes, one ear, one mouth, and one tiny nose! In the operating room on this day, there was confusion and whispers. Naturally there was a little panic, but in the end, all I saw were two beautiful, healthy, teeny-ty, four-pound babies, one just happened to look 'different.' In those moments following the birth, I didn't know exactly what that would mean, but I did know that this little girl was going to be special, and no matter what, I was going to stop at nothing to make sure that she had everything she needed.

Hailey was born with Microtia and Aural Atresia. This is a rare condition in which the outer ear does not form, there are skin tags, some minor facial deformities, and and in some cases, there is complete hearing loss. This was the case for Hailey.

Hailey was born with Microtia and Aural Atresia. This is a rare condition in which the outer ear does not form, there are skin tags, some minor facial deformities, and and in some cases, there is complete hearing loss. This was the case for Hailey.



Her journey, which we nicknamed "Help Hailey Hear," started just a few months after she was born.

Through the years she has had nine reconstructive surgeries, multiple dental issues, implants and hearing aids.

When your child is born with a disability, it is amazing how quickly you become an expert. In the early years, through some research and determination, we were fortunate to meet **Dr. John Reinisch**. How lucky were we to have been paired up with the pioneer of the surgery that Hailey needed? However, this miraculous pairing came with a few obstacles, one in particular was that his practice is located in California and we live in Pennsylvania. This was a travel nightmare with three, small children, not to mention the out-of-pocket expenses and the countless arguments with insurance companies. We knew that California was where she needed to be, and we were going to get her there. However, what we didn't know was that after that first meeting, we would be seeing a lot more of Dr. Reinisch and taking several trips to California for multiple surgeries. Because of the distance and the nature of the surgery, our visits to the West Coast are lengthy and grueling. Most of the time she is treated in an outpatient setting, so we pay out of pocket for hotel, flights, and accommodations for multiple days. There are just so many travel expenses! A lot of coordination is needed to fly from Pennsylvania to California. Without CCA's support, we

wouldn't have been able to make this recent trip happen. As parents, we want nothing but the best for our children. It is through the generosity of others, such as CCA, that we are able to give the best to Hailey. Despite her obstacles, Hailey has grown to be an amazing woman. She is a star athlete. She plays soccer, surfs, and snowboards. She is a caring and wonderful sister, and an 'A' student in the National Honor Society. Her disability has not, and never will, define Hailey. If anything, it has made her stronger and more determined to succeed. This journey is far from over, and it has been a humbling experience and a blessing to see the generosity and support from people. It really does take a village to raise a child.

Thank you CCA and to all of the donors for being a part of our village. We are so grateful for all of the support Children's Craniofacial Association has provided to our family. We truly feel blessed to have been able to give Hailey the best. Thanks to CCA's resources and financial assistance program we can give this to her. CCA made it possible and we hope to pay it forward one day.

Until that day, we would like to thank, **Annie Reeves**, for all she has done!



children's craniofacial association

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ron shover lifts spirits

After cancelling our DFW area picnic, we wanted to send our families something to brighten their day. Thanks to a donation we received for the picnic, we were able to send all 49 families who RSVP'd a Sonic gift card!

In addition to the Sonic gift card, families also received another special surprise. CCA Mom, **Brittany Denison**, shared a very powerful post on her Facebook page about her son starting Kindergarten, which ended up going viral. After being featured on a variety of local news stations in the DFW area, they were contacted by **Ron Shover** who is a master balloon sculptor and three time Guinness World Record holder. He ended up making **Brittany's** kids balloons and wanted to become more involved with CCA. He was scheduled to attend our picnic and make balloons for our families. Once he found out the picnic had been cancelled, he reached out to let us know he wanted to make balloons for the families who were scheduled to attend AND deliver them! He even delivered balloons to a family that lives over 3 hours from Dallas!



Aiden and Aaron Kimberlin with Ron Shover

Ron has delivered balloons to over 40 families! We can't thank him enough for his kindness, generosity and time he put into making all of these balloons & deliveries. Our families appreciate him as well! Thank you for brightening their day!



Mia Zani