THIS ISSUE OF THE E-NETWORK IS DEDICATED IN MEMORY OF **JOHN MULLIKEN, MD – BOSTON CHILDREN'S HOSPITAL**

# cca e-network

newsletter of children's craniofacial association

2026: ISSUE 1

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*Left to Right: Chloe Ngo and Lainey Nguyen Tran*

# meet chloe & lainey

## Learning to be Seen, Learning to Give Back

*by Chloe Ngo | Bay Area, CA*

growing up with a unilateral cleft lip and palate in Vietnam, I was familiar with whispers, remarks, and stares. Some were warm and kind, while others carried a heavy silence or questions that had no easy answers. Moving to the U.S. was more than just a change of place. It was an opportunity to reshape how the world saw me and, more importantly, how I saw myself. It was a step toward confidence, opportunity, and purpose.

In Vietnam, community life was close and connected. This closeness brought both comfort and challenges. I was surrounded by people who unconditionally cared for and supported me, but I also had to undergo moments of quiet judgment and hurtful remarks. Moments of happiness followed by sadness, the circle repeated in a way that never seemed to end. see chloe & lainey, page 2

THE GREATNESS OF A COMMUNITY IS MOST ACCURATELY MEASURED BY THE COMPASSIONATE ACTIONS OF ITS MEMBERS.

- CORETTA SCOTT KING

## letter from the program director

**community**
*[ com·mu·ni·ty ]*

*a group of people with a common characteristic or interest living together within a larger society*

over the years, I've had the opportunity to share community with various groups. I love that my community is large and diverse — rich in lived experience, wisdom, and representing all walks of life. When I think about community, the definition above comes to mind, accompanied by a powerful image that radiates hope in my imagination and fills me with endurance, gratitude, and peace.

I remember what it was like growing up with Goldenhar and VATER syndromes, feeling the loss of what seemed like a world of communities passing me by.

see letter from PD, page 5

# chloe & lainey, continued from the cover

Hence, resilience became second nature, driven by the desire to feel truly recognized, included, and worthy.

Moving to the United States was a big change in my life. Everything felt new to me: the language, the culture, and the social norms. Honestly, at first, these differences overwhelmed me. But gradually, I realized that these differences let me tell my story in my own voice. I began to see my facial difference not as something to hide but as something that brought connection, understanding, and sympathy. I truly saw the power of shared vulnerability. When one person opens up about their stories, it encourages others to do the same. When I spoke openly about my experiences, I wanted those who were born with facial differences to know that they are not alone on this journey. This realization drove me forward with the initiatives I chose to create. Along with my friend, **Lainey Tran**, we started Bring Smiles Despite Miles, a campaign to advocate

for children born with clefts. From raising funds for children with cleft conditions, to receiving free surgeries and comprehensive care globally, to sharing educational and awareness content on social media, our goal is simple: to help others feel seen and loved. We aim to build spaces where differences are recognized, respected, and valued through community events or online platforms.

Honestly, I hesitated when deciding to start this campaign. I was afraid of doubt, judgment, and uncertainty if my voice mattered. However, Lainey always encouraged me to put aside those fears and just begin. Over time, each connection we made with cleft-affected individuals, advocates, and supporters proved

that we are doing something truly meaningful. Seeing someone feel understood and connected, witnessing the joy on parents' faces when their children finally received the surgeries they deserved, and knowing a child could smile confidently and proudly - truly strengthens our commitment to continue this work.

Living with a facial difference has taught me that a supportive community is built through empathy- and it doesn't always require big actions. It simply starts with showing up and sharing your truth.

Visit our YouTube Page to view an interview with Chloe & Lainey!

# chloe & lainey, continued from page 2

## A Journey of Belonging and Impact

*by Lainey Nguyen Tran | Bay Area, CA*

hello CCA readers, I am **Lainey Nguyen Tran**, a business student based in the Bay Area, California. I do not have a facial difference, but I do believe that your ability to advocate is not just limited to those with lived experience, but it can be learned from empathy, listening, and being present. I started our journey **"Bring Smiles Despite Miles"** with my amazing partner, **Chloe Ngo**, since I believe we can do something special and meaningful for this world, especially for children - our future generation. I always remind myself how lucky I am to have my smile and the power to spread it to

other people. Therefore, it motivated me a lot when Chloe asked me if I wanted to join her campaign that creates free surgeries for cleft children through **Smile Train**. This campaign gives me the chance to not only help other people, but also spread my positivity and support to those who need it. My family raises me up, they advocate for me to do volunteer work, charity, help

other people and be grateful for what we receive. Therefore, being a part of Bring Smiles Despite Miles is such a great honor for me to help **Smile Train** raise $50,000, which equals about 125 free cleft surgeries. We believe this is truly the best thing we have ever done in our life.

Moreover, Chloe inspires me with her real story and her passion to give back to the cleft community. What she has been through was a tough path which left her with so many emotions and memories. However, she was proud of that long journey, since she had her family and friends being around to support her. That touches my heart and I can imagine how hard it is for many other children in the world if they do not receive the same support and care like Chloe. This is why I am eager to make this journey more meaningful and help as many children as we can.

As young people ourselves, both Chloe and I want to make an impact on our youth and future generation. We have the shared goal to spread awareness about cleft and positivity to not only young teens but also people in our cleft community.

Bringing happiness to other people is what I always dream for, and I think Chloe does, too.

If there is a message to our readers, we want to say "be brave, be confident, be proud of yourself" and we are always here next to you and support you, cleftie!"

# gingertown 2025

*by Christine Andler, CCA's Director of Development | Dallas, TX*

On December 10th, 2025, hundreds of people from DFW's Design, Construction, Roofing and Architecture firms teamed together for the **16th Annual Gingertown Dallas!** This impressive build continues to be one of the biggest gingerbread house events in the nation. We are so lucky to be the beneficiary since inception of this amazing event at **NorthPark Center** in Dallas, Texas. Millions of people nationally and internationally visit the Center each year. They celebrated their 60th year in 2025!

*Left to Right: CCA Staff (Rasheera Dopson, Erica Klauber, Christine Andler, and Khadija Moten), the Hernandez family (Luciano, Brie, Abigail, and Liliana), and Sam Greer*

On the night of this event, teams compete in a live gingerbread building competition and exhibition to help spread joy and hope during the holidays! The theme was **"World's Fair"** and showcased the iconic buildings and structures of these historic expos across the world in renowned cities! This year we were tasked with a **1970s Japanese Tea Garden House** for the fair in the 1970's and it turned out to be one of our hardest builds for our CCA Kid's team, but with the help of our NorthPark team (**Glen** you are our hero!) and our CCA staff and families we made something beautiful! We are so grateful for all those that came out to support us and wanted to especially thank **Nancy Nasher, David Haemisegger** and their children for attending the build, and **RJ Ressig, Pam Mitchell,** and the entire staff for all they do to make this a huge success each year. A huge thank you to the **Hernandez family** and the **Greer family** for participating in the building process and working so hard to make our gingerbread build come to life. We had fun! A special thank you to **Glen Jones** and **Pritish Savant** from NorthPark for being our team leaders. We love this event and truly are so grateful to be the beneficiary of this each year. We cannot wait to see the total this spring when we do the check presentation!

# moebius syndrome foundation awareness day

*by Erica Klauber, CCA's Executive Director | Royal Oak, MI*

**CCA Kids** and the [Moebius Syndrome Foundation (MSF)] celebrated **Moebius Syndrome Awareness Day**, which is January 24, with a kindergarten class in Michigan.

CCA's Executive Director, **Erica Klauber** read the picture book **We're All Wonders** by **R.J. Palacio** to the class. The students explored images of people with facial differences and thought about how we are all unique. Thanks to generous donations to CCA and the MSF, each student received a copy of the book, a pair of sunglasses, and a purple Moebius Syndrome Foundation wristband.

CCA would especially like to thank **Jenny Whitman**, Executive Director of MSF, and **Laura Berge**, mom to **Harrison**, a student who has Moebius syndrome, for helping us organize this opportunity.

Invite a CCA Speaker to your school by visiting our website, here.

# letter from the PD, continued from the cover

It appeared as though everyone had found their space, their tribe, their niche in the world to claim as their own—and I was still searching, still wondering where I belonged.
And then I found CCA.

Here was a small-but-mighty group that made the conscious decision to link arms and build something extraordinary together—a fortress that would fortify themselves and others against the unkindness of society and its treatment of people with facial differences. While CCA is not my only community, it has become a critical refuge in my life. It represents a space where I can find safety and belonging in a world where difference isn't always greeted with acceptance.

Throughout my journey with CCA, I've witnessed the power of intentional community-building. I've seen families find their people, watched children discover they're not alone, and observed parents exhale with relief upon meeting others who truly understand their experiences. This is the heart of what we do—we create spaces where facial difference doesn't separate us, but rather connects us in profound and meaningful ways.

In my new role as Program Director, it is my mission to continue fueling the spirit of community that has blazed so brightly for the past 37 years.

I'm committed to fanning the flames of ingenuity that allow our community to shine even brighter for all those who are part of the world of facial difference. Looking back, I believe it was this very spirit that first drew me to CCA. It was this spirit—this unwavering commitment to acceptance, belonging, and collective strength—that beckoned me to explore my role in fostering this same culture of radical acceptance through a high-impact position such as Program Director.

Together, we will continue building bridges, creating safe spaces, and ensuring that no one in our community feels the isolation I once felt. We will continue to be that beacon of hope for families just beginning their journey, reminding them that they are not alone and there is a community waiting to embrace them with open arms.
This is our work. This is our calling. This is community.

See page 9 to view Rasheera's New Staff Announcement!

## sponsors needed: help support our annual retreat and let our families know about your company!

Promote your business at our Retreat in Orlando, FL and through our marketing channels! To learn more email our Director of Development, **Christine** at **candler@ccakids.com**

# ccaadult

## meet hannah

*by Hannah Artery | Plymouth, WI*

hello, my name is **Hannah Artery**, and I am an 18-year-old and I live with Apert syndrome. For those who don't know what it is, it is where your hands and feet are webbed together, and many parts of the skull are fused together. Even though it is incurable, many people with the syndrome have surgeries to help or fix some of the issues that it causes. My Apert syndrome is on the less severe side, but I've still had around a dozen surgeries and as a result, I have limited mobility in my ankles and shoulders and have trouble hearing sometimes due to chronic ear infections. I've had all my surgeries done at **Children's Hospital of Wisconsin** and I am extremely grateful for the care my nurses and surgeons have provided me for the past 18 years and counting.

A few of my favorite things are hanging out with family and playing games. At home with my mom, dad and older sister, **Grace** is one of my happy places.

Another one of my happy places is hanging out with my aunts, uncles, grandparents and cousins. Even though most of them live far away, every minute that I get to spend with them is priceless! I am always down for playing a card game or a board game, whether it be a

a quick game of Uno or an epic game of Monopoly, you can always count me in.

A recent hobby that I've picked up is baking. I love spending time in the kitchen making many different types of quick bread and muffins. At the start of 2024, I created a small bakery called **Hannah's Bakery**. Even though it has been hard making bread and muffins while going to culinary school, I truly enjoy it! My hope in the future is to expand my business and open a place where customers can come and smell the traditional bakery scent and buy my creations in person.

The **CCA Retreat** and community have really helped me find out who I truly am. In 2022, I attended my first **FACES Camp** where I started meeting true, and amazing best friends. After that, in 2024 I attended my first CCA Retreat and my family and I had an absolute blast! We met a lot of amazing people and families, and it was another place where I could just be

myself and not have to worry about being stared at or bullied. Overall, in the CCA community I have met so many amazing people and created friendships that I hope will last a lifetime!

Even though my life has been a roller coaster, I have still managed to find time to do things that make me happy! Whether that be trying to beat my family at a game or simply watching the **Baltimore Ravens** play an epic football game.

I always know where to find happiness one way or another. A true quote I live by is:

"Stand up for who you are. Respect yourself and ignite the divine sparks in you."
-Amit Ray

Visit our YouTube Page to view an interview with Hannah!

# ccasupersib

## meet grace

*by Grace Artery | Plymouth, WI*

My name is **Grace Artery** and I am the older sister of **Hannah Artery.** I have loved attending the Retreat the past two years and it has been amazing to get to know everyone. Everything that I have experienced at Retreat has been so fun and everyone just finds a way to make me smile. I didn't know what to expect when we first went but it has been one of the biggest learning experiences of my life. I am a senior at the **University of Minnesota in Minneapolis** and I am a huge lover of music.

I am majoring in **Sociology of Law, Criminology and Justice**. I have three minors on top of that including **Communication Studies, Youth Studies,** and **Intimate Partner Violence Prevention Studies**. I am on track to go into the **Police Academy** after I graduate and my dream job is to be a detective working in a special victims unit. I have always wanted to help people and I love working with others to figure out a solution to a problem. My favorite thing about college is getting to learn the things that make me excited about my future. It can be hard being a college student with the homework and the stress of life, but my biggest note is to just take it one day at a time. Another one of my favorite things about college is having my sister come and visit. She's also a college student now and I love having her come and experience the campus with me. I am a huge music lover as well. I was in band and choir in high school as well as a lot of other clubs including jazz band, German Band, and show choir. I also have taken piano lessons from third grade through junior year of high school. Now in college, I don't make music as much as I wish I did but I am an avid music listener. I would say I am listening to music as much as possible through out my day. I have also loved bonding over music with Hannah. We both took piano lessons together (which I am still amazed by since she has Apert syndrome but she has never let that hold her back) and she was in band with me in high school. We also share similar music tastes so whenever we have a good new artist that we listen to, we make sure to share with the other.

Throughout everything, I have found I enjoy everything more when I have my sister enjoying it with me. I love going to a hockey game at my college, but, it's always more fun when I have Hannah cheering next to me. I have always loved to perform music on stage, but, I have always enjoyed it more when I can get off stage and watch my sister perform exactly where I just did. We may have butted heads growing up, and still do occasionally like all siblings do, but, she has always been there during my huge moments and I will continue to be there for all of her big moments, as well. That includes the amazing Retreats which I can't wait to go back to next year. We have already been planning our trip and I am so excited to go to our third Retreat with my sister and best friend!

# HHI + ACCP gala for cca

*by Cari Moorse | San Antonio, TX*

The event this year was a **"Red Carpet Gala"** and was Hollywood themed. Costumes were encouraged and we saw everything from **Black Swan** to **Justin Timberlake** and **Britney Spears** to tuxedos and formal gowns! Everyone had a different take on the theme which made it really fun for everyone.

We had local Marines also invited and they helped with our annual **Toys for Tots** toy drive that compliments the rest of the night where the funds go to raise money for our favorite charity, **Children's Craniofacial Association (CCA).**

During the night a costume contest was held, Silent Auction items were bid on, we had a 50/50 Cash Raffle and Stretch Liquor Raffle. All these funds raised, along with Sponsorships and **Wetmore Beach House** contributing their Sweepstakes profits over the weekend, **we collected our largest amount to CCA yet: $17,873.91!**

Each year we aim to raise more funds than the previous year which keeps us on our toes and putting in the additional work to exceed this goal!

We love this charity and are so happy to help any way we can. **Christine Andler**, the Director of Development for CCA, once told me she is grateful for any donation amount but it's more about getting awareness to the public about their mission that means the most to her.

We, as **Alamo City Charity Partners (ACCP)** and **HHI** aim to do both year in and year out and we look forward to doing this again next year. Cheers to you all!!

**From: Cari, Carrie, Arlene, Heather and JJ (ACCP & HHI)**

# new staff anouncement

*by Erica Klauber, CCA's Executive Director | Addison, TX*

We are so pleased to announce the onboarding of our newest team member, **Rasheera Dopson, MPH**, who joined us as **Program Director in October 2025.**

Rasheera Dopson, MPH, is a Digital Storyteller and advocate who leverages multimedia platforms to promote reeducation and awareness of the intersections of race, gender, and Disability. As a nationally recognized speaker, author, producer, and host of the **Womanhood & Disability podcast,** she is dedicated to amplifying the voices and experiences of women and girls with disabilities.

In 2022, Rasheera received both the **David Roche Advocacy Award** from the Children's Craniofacial Association and the **Fearless Woman Global Community Impact Award**. In 2023, she published her first children's book, **Different Like Me**.

We are excited to welcome Rasheera to our team, with her impressive academic background in public health and interdisciplinary research, as well as her own invaluable lived experience, as a person with Goldenhar syndrome.

Ms. Dopson says, "The intersection of medical complexity and social support that characterizes craniofacial conditions resonates deeply with my advocacy work and academic research focus. I am particularly excited about the opportunity to support the Annual Family Retreat, having experienced firsthand the power of peer connection and community building. My research on healthcare engagement and intersectionality will inform my approach to ensuring CCA's programs are inclusive and responsive to families from diverse backgrounds."

Ms. Dopson has spent over 7 years collaborating with CCA, from her time as a Retreat attendee, to a Speakers' Bureau member and mentor, to serving on the David Roche Award for Excellence in Advocacy committee, as well as being a David Roche Award recipient.

Rasheera will manage our programs including: Financial Assistance for Medical Travel, the Annual Family Retreat and Educational Symposium, and Family Networking.

**To connect with Rasheera Dopson, please contact her at RDopson@ccakids.com or call 214-570-9099**

Visit our YouTube Page to view an interview with Rasheera!

# upcoming events

**FEBRUARY IS BLACK HISTORY MONTH**

**FEBRUARY 24TH**

**CCA'S 37TH BIRTHDAY**

Consider making a donation in honor of our 37th! **Click here**

**MONTHLY AT 7:00PM CST**
**MAR. 4TH, APR. 1ST, MAY 6TH**
VIRTUAL
**CAREGIVER SUPPORT GROUP**
**REGISTER: HTTPS://QRCO.DE/CCACAREGIVERGROUP**

**MONTHLY AT 7:30PM CST**
**MAR. 16TH, APR. 20TH, MAY 18TH**
VIRTUAL
**ADULTS AND ALUMN GROUP**
**REGISTER: HTTPS://QRCO.DE/CCAADULTS**

**MONTHLY AT 7:30PM CST**
**MAR. 24TH , APR. 21ST**
VIRTUAL
**SIBLING SUPPORT GROUP**
**REGISTER: HTTPS://QRCO.DE/CCASIBLINGGROUP**

**MARCH 24-28, 2026**
HILTON BOSTON PARK PLAZA
BOSTON, MA

**THE AMERICAN CLEFT PALATE CRANIOFACIAL ASSOCIATION (ACPA) ANNUAL MEETING 2026**

**JUNE 26-28, 2026**
HYATT REGENCY GRAND CYPRESS
ORLANDO, FL

**36TH ANNUAL FAMILY RETREAT & EDUCATIONAL SYMPOSIUM**

**REGISTRATION IS CLOSED!**

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# woodall foundation grant for $4,000!

*by Christine Andler, CCA's Director of Development | Dallas, TX*

**the Woodall Foundation** has been a longtime grantor of CCA, and we are so grateful for their continued support to our organization year after year. **Martin Woodall,** Founder of The Woodall Foundation and **Adam Carriker,** who oversees all grants are always so kind to invite us to apply each year for a grant to their invitation only process.

We are lucky to be a part of this select group of nonprofits.

**This year we were granted $4,000! Thank you Martin, Adam and the Woodall Foundation for all you do for CCA!**

*Left to Right: CCA Staff (Rasheera Dopson, Khadija Moten, Christine Andler), the Greers (Carrie, Paul, and Sam) Adam Carriker from Woodall and Erica Klauber*

# 3 cheers for volunteers!

three cheers for our volunteer, **Carly McNiel!** Carly found CCA through our Adult Programs Coordinator, **Kara Jackman**, and has been so helpful to our programs over the last few months.

Carly has been helping us write thank you notes during our busy giving season (so many amazing donors!) so that everyone receives a heartfelt note of gratitude for helping us fund our work all year long.

Carly has also been a great connector, finding families in the community and plugging them into CCA – most recently, bringing our #ChooseKind programming into her local schools. Carly says:

**Hi. I'm Carly. I'm a volunteer for CCA in Michigan. I love it. It's the most rewarding work I've ever done.**

**Thanks for the opportunity CCA!**

**To that, we say, thank you, Carly, for making a positive impact on our kids, families, and staff with your support.**

# #givingtuesday 2025

*by Christine Andler, CCA's Director of Development | Dallas, TX*

thank you for making 2025 our biggest Giving Tuesday on record! We are so grateful for each of you who donated on this day and wanted to give a special thank you to our **Match Donors: Ron Miglini, The Italian Club of Dallas, The CCA Board of Directors** and **one donor who wanted to remain Anonymous.**

# children's craniofacial association

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https://qrco.de/cca-email

## financial assistance testimonial

"We received the check in the mail today. Thank you so much! I cannot express it in words. This time with the surgery, we felt supported through the whole process, it's financial help but somehow it makes me feel emotionally supported as well. We never expected that there would be anyone out there let alone any organization supporting the kids and families with medical needs. Your help means a lot to us.
Thanks Again!"

- Anonymous

*Houston, TX*


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