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"I no longer give others the power to dictate how I feel..."

by LaDarius Davis

**H**ello, everyone, my name is LaDarius. I am 28 years old, and I am currently residing in Georgia.

I was born with Goldenhar syndrome. As a kid growing up, I remember just wanting to be friends with everyone, play with the kids, and have fun. Now, I always knew that I was different. My family instilled in me early that although I may look different from what people in my small town were used to seeing,



"Retreat is Canceled."

**N**ever in a million years did I think I would ever hear these words. In the 17 years I've been with CCA, for me personally, this was the hardest announcement we've ever had to make. It was heartbreaking, to say the least. However, HOPE is not canceled and so, we took the love online and held our first ever Virtual Retreat! We had first-time families join us as well as families from all over the United States and even internationally, which is always so wonderful. Over 220 families

See **programs**

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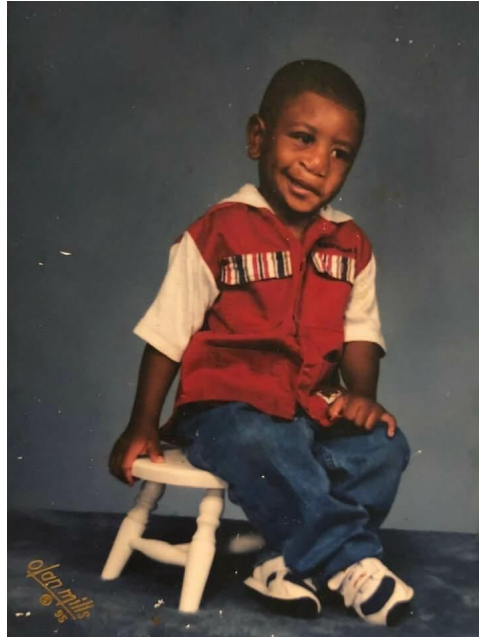
## LaDarius, from the cover continued

there was absolutely nothing wrong with me. It wasn't until I started school that everything my family told me got replaced by what my peers were telling me.



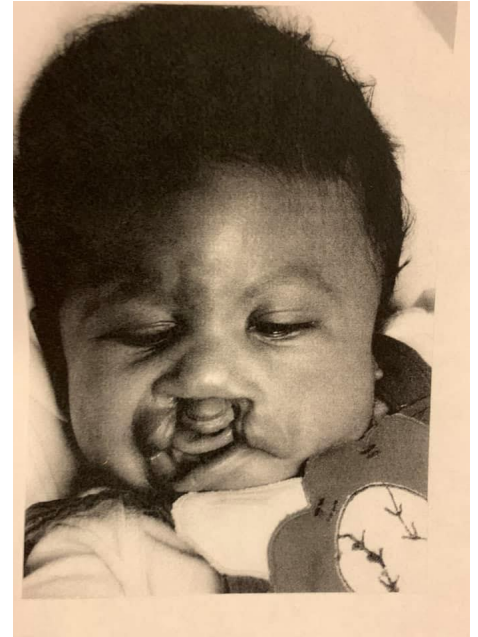
Going to elementary school felt like torture. From the time the bell rang, and until it was time to go home, it was nothing but bullying. Kids would call me names such as "smush face," make songs, would sing "one ear, can't hear," and would even go as far as creating rumors about me. They would say the reason I looked different was because I was involved in a fire, or that I had been in a car accident. There were even times that it would escalate from words to violence. Still, until this day, I can't wrap my mind around why someone would want to harm or hurt me because I looked different. **Don't we all look different from one another?**

My childhood wasn't all bad, though. I had a few friends who saw past my condition and loved me for who I was, and my family was so big that I never felt alone because I always had cousins to play with.



Let's fast forward to high school. I think my high school experience was pretty average. I met some wonderful friends who accepted me for me. I dated, I hung out, and went to prom. Things were looking up, or so I thought. Even though things were better, I still dealt with insecurities from society. I always felt as if I needed to belong to a particular group. These people didn't give me a chance, though. It wasn't until later that I realized I don't need validation from anyone. I love myself. I know that I am worthy, smart, and a great person. I am worthy of being loved.

Today, I am a happily married man to a wonderful woman named, **Anna**. We have been married for 5 years. Anna never paid attention to how I looked on the outside. She fell in love with my heart, and so did I with hers. She was the one who pushed me to start writing on my blog: [www.thehealing-heart.com](http://www.thehealing-heart.com)



If you had told me a couple of years ago that I would be married, I would have laughed in your face and told you that you were crazy. Life is looking up for me now because I am in control of my own happiness. I no longer give others the power to dictate how I feel about myself.

If I had to leave a piece of advice for someone, it would be to **genuinely love and embrace every part of you because you are somebody special.** 🧡





## programs, from the cover continued

signed up. At our largest session, over 90 families were logged in.

Although it wasn't the same as an "in-person" retreat, we still had four amazing days of virtual FUN!

We started off our virtual retreat on Thursday with a modified version of our Educational Symposium which this year, carried over into Friday. Once again, we had expert speakers volunteer their time to host sessions for our families. We would like to thank the following team members and volunteers from:

- Nationwide Children's Hospital
- MED-EL
- ConnectMed
- La Jolla Country Day School
- Dr. Annie Drapeau
- Dr. Ibrahim Khansa
- Dr. Gregory D. Pearson
- Robert Shepherd
- Amanda Smith
- Cara Langdon
- Cashel Gaffey, MSW
- Dr. Azmaira Maker
- Rita Albert, JD
- Michael Douglas, MA, CCC-SLP, LSLS, Cert AVT
- Amanda O'Donnell, Au.D.
- Robert Wagner

These speakers spoke on technical and motivational topics, and we are happy to say that our speakers made an extra effort this year to connect with our families, since we had a barrier of distance. We really appreciate their dedication and preparation.

We would also like to thank our wonderful Motivational Speakers and Panel Presenters.

**Eduardo Verestegui and David Roche, Patricia Simon, Harlena Morton, Paula Guzzo, Liz Cox, Pedro and Karla Molina,** for opening their hearts to share their experiences with us.

Presenters discussed topics including "The Raw Realities of Relationships, While Parenting a Rare Child," "Your World Just Got Bigger: MED-EL Hearing Aids," and "Dare to Be Brave!" Connecting in this way can spark an idea or help tackle a problem the audience has, and we are so grateful to those who take on stage fright and present with passion and heart.

Friday morning was a fun surprise with a magic show by **Peter the Adequate** and he had quite a few tricks up his sleeve, literally!

He performed the show for free, which was truly

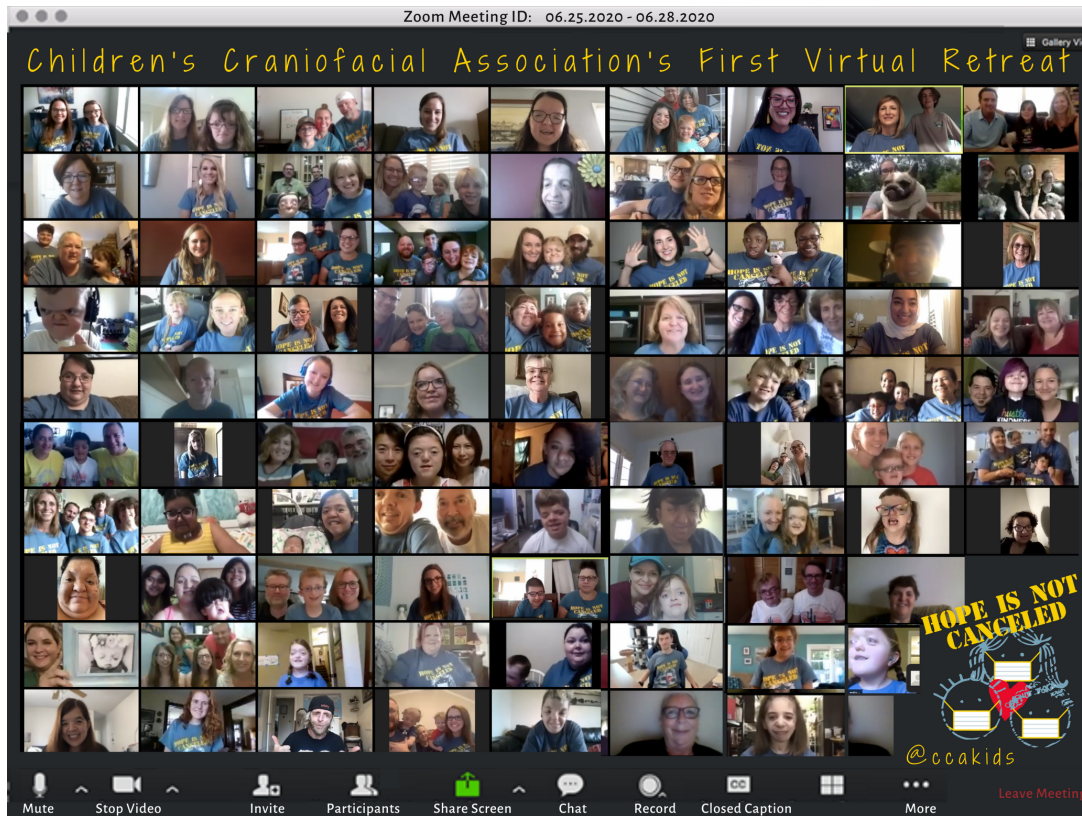
"magical!" Once the magic show was over, our families attended additional symposium sessions and we ended the day with one of our most popular events... the Talent Show, or as I like to call it, "CCA's Got Talent!" This year we had singing, instrument playing, signing, dancing, and poetry reading! Our emcee this year, **Chelsea Buyalos**, kept things moving along and was so entertaining. Not only did she feature costume changes and sport the cutest bow ever, but she closed out our show with an amazing performance. We hear Hollywood has been calling her since this hosting debut, but we hope she'll remember us as her star rises along with all our other amazing talent who performed!

Saturday morning we had a group of energized families join us for an intense and fun Zumba session from our CCA Dad, **Jerry Carchi**. He kept everyone engaged and let's just say we were all awake,



and maybe added a few scuffs to our living room floors from all that shuffling up a sweat! Following Zumba, we held Group Meet-Ups, one of our most popular parts of the Retreat. We believe this is one of the core experiences we offer, so we extended time together during these groups. What takes place within these small groups is priceless. Families are able to meet other families with like or similar syndromes/craniofacial conditions as well as others around their same age. It's always so wonderful to watch these families visit with one another in a more quiet and intimate setting - even though we recognize that is not always easy as our groups are still large. Fortunately, each group leader came up with an icebreaker for their group and they all did a great job of keeping their virtual audience engaged. We would like to thank everyone who helped with these group meet-ups, and we encourage your feedback. We are always trying to make these sessions even more meaningful and some of the suggestions you've given us are already in the works for more sessions going forward.

After the Group Meet-Ups, everyone put on their Retreat t-shirt for a Zoom style group photo. We weren't quite sure what to expect and how it would turn out. All I can say is "WOW!" Seeing how many people joined us for this photo was so touching



and it's such a wonderful memory of our weekend.

Saturday afternoon we all gathered for an Animal Show from Wild Things ZOOFar. The owner, Courtney Cortina-Pineda, went above and beyond during the show. She showed us so many animals and shared fun facts about each one. My personal favorite was Izzie the Otter and I'm pretty sure our Executive Director, Erica, wanted to adopt the Warthog. We even got to see her sloth - by special request - and he surprised us all by "actively" eating!

The last event of the day was our signature event of the Retreat... the Dinner Dance. Although we couldn't all be together in a ballroom, we all managed to dance the night away from the comfort of our home. DJ Jerry Carchi kept everyone on their feet for the night. He knows how to keep the

crowd engaged and kept the party going! We loved peeking into your homes and so many of you set up a true dance party with lights, glow sticks, and more! It was so fun to see how you made your home dance party a part of our collective Dinner Dance!

Sunday morning is always bittersweet and comes way too fast. This year we were very fortunate to have David Roche close out our retreat. David has the most amazing way to set the stage and honor the time we had spent together. There were touching stories, laughter, tears, and love shared. It was the perfect way to end our retreat.

We also want to thank our sponsors who stuck with us and helped us weather this




## programs, from the cover continued

economic crisis, while still serving our families. We want to thank:  
Kaiser Permanente, KLS Martin, and Orthomerica.

And last but not least, a HUGE thanks goes out to all of our amazing families who volunteered their time during our Virtual Retreat by helping with the Talent Show, Zumba class, Group Meet-Ups, Dinner Dance and for your love and support throughout the weekend.

Jeff & Whitney Dunn, Johnny & Jessica McMahan, Chelsea Buyalos, Dee Moss, Jerry & Virginia Carchi, Jennifer Dockter, Heather Figueroa, Carolyn Johnson, Patricia Simon, Courtney Vysocky, Dorina Watkins, Lisa Bock, Eric & Jennifer Lucas, Bobbie Quiroz, Stacy McAllister, Rose Seitz, Kristine Dale, Ed & Amy Kern, Dave & Liz Anderson, Taylar & Kalyssa Aumann, Paula Guzzo, Harlena Morton, Kristy Lund, Mindi Stowe, Kelsey Harris, Lisa Bowers, Megan White, Liz Cox, Kristen Roberts, Stacey Atkins, Erin Richmond and Emerald Demor.

Thank you all for attending and for being such a bright spot in my life. It was so refreshing to see all of you and to meet so many new individuals and families. My heart is full, thanks to all of you.

- Annie Reeves  
CCA Program Director 



## a HUGE thank you to our virtual retreat sponsors

We could not have made our First Ever Virtual Retreat a success without your generosity!



Interested in sponsoring our 2021 Retreat or know any leads?  
Email our Director of Development, Christine, at [candler@ccakids.com](mailto:candler@ccakids.com)

# meet CCA's newest ambassadog, Mr. Ed Ducky

by Brittany Kegley

This is Mr. Ed Ducky, distemper survivor, two-time shelter dog, now being fostered through Dallas Dog Rescue Rehab Reform aka Dallas DogRRR.

Ducky was brought to Dallas Animal Shelter as a very young puppy and adopted by a family in the Dallas/ Ft. Worth area. On July 11, 2020, Ducky was found as a stray and taken to the very same shelter he came from a year and half ago. This time he was a young adult dog with special needs, and looked quite a bit different than he did as a puppy. The shelter tried to contact Ducky's owners, but no one ever responded or came for him.

Patti Dawson, the president of Dallas DogRRR, felt a smile and tug in her heart after seeing photos and videos from the shelter asking for rescue help. She knew she had to save Ducky and get him the care and love he deserves.

The vet believes Ducky survived distemper, a viral disease without a cure that can affect multiple organs in the body and the central nervous system. Distemper has an 80% mortality rate, so Ducky is a living miracle! The disease caused his brain to swell, which in turn caused facial differences and neurological tics. Since he was still growing at that time, it also caused his nose to



turn up (resulting in the cutest snorts) and his legs to turn in a little bit. However, those things don't stop his love of playing chase with other dogs and splashing around in the pond! His tongue hangs out of his mouth because the virus stopped proper enamel formation on his teeth, causing them to decay or fall out. He'll have that all taken care of with dental surgery, and then this happy-go-lucky guy will be on the lookout for his "forever" home!

Ducky's foster parents have fostered lots of animals and think Ducky is such a special pup with a huge heart. He is a well-behaved gentleman, and loves everyone from people to dogs, and even

cats. He also loves to cuddle and makes the perfect foot warmer while watching your favorite movie. His favorite things include tennis balls, his lamb chop stuffed animal, and any treats you give him! Mr. Ed Ducky is excited for all the new adventures in this next chapter of his life and grateful for the endless support around him now.

Ducky is so proud to be a part of this community, to share his story, and join in spreading acceptance and awareness that being different is cool!



photographs by:  
@rldphotographytexas



# Craniofacial Acceptance Month

by Erica Mossholder

**Y**es, this is another announcement that our “regularly scheduled programming” will be a bit different this year. Since many of you are still social distancing, we understand it is not possible for most families to host Craniofacial Acceptance Month picnics this year. However, we still intend to celebrate and honor this month! Please see our list of ideas and initiatives below that we believe will truly mark this special month.

## ONE:

We encourage you to display your CAM Yard sign if you were able to buy one. Put in your yard, apartment balcony, or at your medical providers’ offices! Weren’t able to grab one? Add your own chalk CAM art outside your house or turn your social media **YELLOW** using [CCA’s Media Kit](#).

## TWO:

We invite you to contact your local media and ask them to run a story on Craniofacial Acceptance Month. [Here’s](#) a handy guide to pitch your story.

## THREE:

Listen to our inspiring speaker series, the week of Sept. 14-18. Stay tuned for the schedule.

## FOUR:

Sport your favorite **YELLOW** shirt and participate in our first annual Virtual Group Photo for Craniofacial Awareness.

**We’ll meet on Sat., Sept. 12, at 11am CST, 9am PST, 12pm EST**

Sign up [here](#) for Zoom link.

## FIVE:

Kindness Rocks! Paint a rock and leave it to be found.

We encourage you to write messages of kindness on the rocks and leave them on a local trail or in a local park. Write [ccakids.org](#) on the back, to continue to spread awareness!



# #CAM2020

**Week of Aug. 24th:**

Contact your local News Stations, Radio Stations and Newspapers about being featured and announcing CAM Week of

**Sept. 12th:**

Join us for a group photo in your yellow shirt on Zoom at 11am CT

**Week of Sept. 14th:**

**Speaker Week**

Tune in on social media to hear from our speakers! (more info to come)

**Week of Sept. 21st:**

Paint Kindness Rocks & Share your photos!

**Week of Sept. 28th:**

Post photos of your CAM Yard Signs - close out September strong and united!

Just as you did with the picnics, please share your photos with us!

#CAM2020 #CCACAM2020  
#VirtualCAM

**FOR IMMEDIATE RELEASE**

**August 10, 2020**

**Erica Mossholder**

**Children's Craniofacial Association**

**(214) 570-9099**

**emossholder@ccakids.com**



### **Hope is Not Canceled – We Celebrate Craniofacial Families in September 2020**



Dallas, TX -- Children's Craniofacial Association celebrates its 16th Annual Craniofacial Acceptance Month this year and we are proud to keep this tradition alive, even with social distancing modifications.

This year our theme is “Hope is Not Canceled,” as our mission statement pledges “to bring hope and empowerment to individuals and families affected by facial differences.”

While we cannot gather in person, we still believe that knowing someone who shares your unique journey of living with a facial difference makes life easier and so much better. Thus, we have pivoted our family networking to offering our First Ever Virtual Retreat, hosting ongoing virtual support group sessions, engaging in art therapy hours, creating storytelling workshops, and more – so our members can still unite and connect from the safety and convenience of home.

Incidentally, going virtual has allowed us to reach more people than ever, including those who could previously not attend our regional gatherings. Now more than ever, we have hope and insight for a connected future.

We encourage families to contact their local media and state government offices to recognize the amazing strength and resilience of our kids by proclaiming September as Craniofacial Acceptance Month. All month long, we will have an awareness-raising sign campaign. Look for our signs on a front lawn near you. From Mon. Sept. 14 through Fri., Sept. 18, we will feature inspirational speakers each day on our social media platforms. And finally, during the last week of September, we will participate in Kindness Rocks: a fun project where kids decorate rocks with motivational sayings and leave them for others to discover in parks, on trails, and even in offices and classrooms!

All of these efforts are to bring awareness to those who look different, but who feel love, hope, and hurt just like you. Please join us because together, we can end bullying and break down the barriers of discrimination. It takes a sustained effort to educate the public to work together to build and develop compassion, tolerance, and empathy. This year – we’re doing it virtually!

Children's Craniofacial Association, a 501(c)(3) nonprofit organization based in Dallas, Texas and founded in 1989, serves over 20,000 families per year and an additional 10,000 unaffected students in schools across the country. CCA's mission is empowering and giving hope to individuals and families affected by facial differences. CCA envisions a world where all people are accepted for who they are, not how they look. To request free educational curriculum and additional resources, visit <http://www.ccakids.org>.





My first time to attend a CCA Retreat was in 2006 in Hershey, PA. My parents have a lot of memories of the retreat. I don't remember a lot because I was only a baby. We love to go to the retreats. I especially like to go to the retreats because I get to feel like myself and feel comfortable.

When I am at home, my hobbies are filming and writing short stories. Also, I like to meet with friends, watch movies with my brother and use my iPad for short films. Ever since the pandemic started, I have been reading, writing and watching movies more often than usual with my brother. I can't wait until the pandemic ends so my family and I can attend another CCA retreat!



**m**y name is Gabriela Lenia Lopez-Magne. I am going to be 15 years old on September 16th and I will be in 9th grade.

diagnosed with Apert syndrome. My parents were shocked, including the doctors because nobody expected me to be born with it.

My brother's name is Favio, he is very smart and kind. When I grow up, I would like to be a detective or a teacher because I love teaching and investigating things. I'm teaching my brother to be nice. 🍷

My first surgery was when I was 6 months old, and I have had more than 15 surgeries. We went through hard times but we overcame them. Our friends and family support us a lot.

When I was born I was

# ccakid

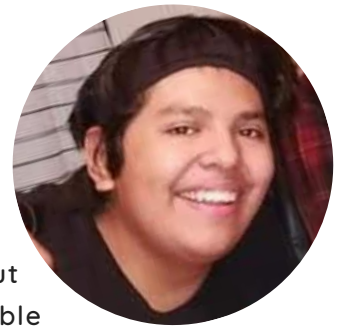




# ccasupersib

## meet favio

**m**y name is Favio Lopez-Magne. I am Gabby's big brother and I love her very much. I always help her try to be a better person and she ironically helps me more than I help her. I love my family. I don't have any interesting hobbies, but my hobbies are watching movies, going to the theater, writing short stories and screenplays, reading screenplays, and reading some books, listening to music, and hanging out with friends.



meet with my friends. But we were able

I was a little bit glad since the pandemic started because I got to do these things more often than I usually would get to do when I was in school. However, it got pretty boring after a while, especially since movie theaters are closed I can't watch anything new.

to attend the Virtual retreat. I always go with my family when there is one and I end up having a lot more fun than I usually expect. I enjoy going out to the retreats because they are so much fun and it made me appreciate being a sibling of my sister. She's so special and she shows me that being nice and smiling is the best way to act! 🧡

Another unfortunate thing about the pandemic is that the retreat was cancelled and I couldn't





# healthcare transition: a q&a guide for parents

**Dr. Judy Lu Kim, MD** and **Dr. Jordan Kemere, MD**

Assistant Professors in the Department of Medicine at Baylor College of Medicine

## 1) What is healthcare transition?

Healthcare transition is the process of moving from the pediatric to adult healthcare setting. This is a process, not a singular event, and it requires intentional planning and preparation. The goal of healthcare transition is to make sure that appropriate healthcare services continue into adulthood in order to maximize an individual's function, quality of life, and potential. Healthcare transition happens for everyone but can be especially challenging for people with special healthcare needs and their families.

## 2) At what age should healthcare transition planning begin?

The American Academy of Pediatrics recommends that individuals, families and healthcare teams start planning for transition during the early teen years (generally 12-14 years). While your child might not transfer care to adult healthcare providers for several years, the early teen years are a good time for your child to develop skills needed to independently manage as much of their care as they can. Start by teaching your child about his/her health conditions, medications, and medical care team. If appropriate, you can also allow your child to practice meeting independently with their doctor for a portion of their visits. For a list of other self-management skills, check out [GotTransition.org](http://GotTransition.org).

## 3) Who should be involved in the transition planning process?

Healthcare transition is a team sport that involves the individual, family, and healthcare team. Make a list of people who provide medical services for your child. This medical team may include a primary care provider, specialists, therapy providers,

nursing companies, medical equipment providers, and health insurance service coordinators. As your child enters the teen years, start asking each healthcare team member what changes to expect in your child's services as they enter into adulthood.

## 4) At what age do most people move on from their children's hospital team?

Most people transfer care to adult providers between age 18-21, but this is highly dependent on the children's hospital, the medical provider, insurance coverage, and availability of adult specialists. Therefore, it is important to ask each healthcare team member how long they will continue to provide services for your child. Some may continue to provide care into adulthood. This is especially true if a particular medical service/specialty is needed in adulthood but adult providers are not available.

## 5) My child's/My medical history is very complex. How should I get organized for healthcare transition?

A child with medical complexity may have a lengthy medical history that goes back many years. Often, parents have a binder that includes their child's detailed medical history as well as a succinct medical summary (usually 1-3 pages) for the adult healthcare provider to review. You want to provide your adult providers with something they will actually read! If appropriate, you can work on creating a medical summary with your child, as this can be an opportunity for your child to learn about his/her medical history. Review your medical summary with your child's pediatrician and specialist doctors regularly. They can help

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you update it and make sure you include only the relevant details. When your child is ready to transfer care to adult providers, you can send them this medical summary to review prior to your child's first appointment.

What to include in a medical summary:

- Medical diagnoses (examples: Nager syndrome, craniosynostosis, autism, intellectual disability, constipation, g-tube dependence, ADHD, etc): for each diagnosis, include what treatments your child receives for that diagnosis (such as medications, therapies, specific nutrition if applicable) and the name of the doctor that manages the diagnosis
- Surgical history: for each surgery list the date (as best as can remember) and location
- Allergies: to medications and foods
- Medications: up to date list of medications/supplements/vitamins (including dose and frequency)
- Medical Equipment/Supplies: list equipment/supplies as well as the supply company and the doctor that prescribes the equipment
- Support services: list of therapies, home nursing and/or provider services, insurance and waiver case managers
- Communication: Briefly describe how your child communicates (for example: verbal, assistive devices, picture board). You can also include a sentence that highlights his/her strengths!

For sample medical summaries, go to [GotTransition.org](http://GotTransition.org) or [medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx](http://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx).

## 6) How do I find adult healthcare providers that are suitable for my child's needs?

Putting together an adult healthcare team requires a multi-step approach. First talk to each member of your child's current pediatric medical team (including doctors and support services such as therapy, nursing, and equipment companies) to see how long they will be able to continue to care for your child. You may not need an adult specialist for every pediatric specialist your child sees. An adult primary care doctor can often manage aspects

of your child's care that may have previously been managed by specialists (for example- hypertension, asthma, allergies). Discuss with your child's pediatric specialists whether your child will need an adult specialist in the same field.

Once you know what services your child needs from an adult medical team, there are multiple ways to find adult healthcare providers.

- Ask your pediatric doctors who they recommend for adult care.
- Get involved with local groups (with similar diagnoses) and ask other families who they recommend for adult care.
- Ask your insurance service coordinators to find adult providers in network with your plan. Keep in mind that your child's adult medical team members need to be in network with your child's insurance, which may change as they age.

Finally, if you will need multiple adult doctors, it may be helpful to transition one doctor at a time. It's ok if transferring care to your new adult medical team happens over the course of a few years.

## 7) What legal changes may affect my child's healthcare?

The "age of the majority" is the age at which a minor child becomes an adult. In most states this occurs at age 18 but can be as old as 21 in a few states. As an adult, your child will have the rights and responsibility to make their own decisions, including those regarding medical care. Some young adults can make decisions independently, while others will need varying degrees of support to make decisions. If you think your child will need help making decisions as an adult, discuss this with your pediatric primary care provider before your child turns 18. Recommended options for decision-making support may include guardianship, supported decision-making, power of attorney, or advanced directives. For more information about decision-making support, check out [TheArc.Org](http://TheArc.Org) and [supporteddecisionmaking.org/](http://supporteddecisionmaking.org/).

## 8) How does the transition process affect my child's insurance coverage and other benefits?

Insurance can be complicated and continue to change as your child ages. If your child receives supplemental security income (SSI) and Medicaid services as a minor, be aware that the rules and requirements for adults to receive SSI are different. Therefore, your child's medical condition will be reassessed at age 18 to ensure he/she meets adult disability criteria (which differs from pediatric disability criteria). This review usually occurs in the one-year period beginning on your child's 18th birthday. If your child was not eligible for SSI before age 18 because your household income exceeded the limit, your child may be eligible for SSI at age 18 as only his/her income will be considered. For more information about SSI benefits, go to [ssa.gov/benefits/ssi/](https://ssa.gov/benefits/ssi/).

Medicaid benefits often change at age 21. Before your child turns 21, ask your Medicaid service coordinator what changes to expect. This may include less coverage of therapies, nursing hours, and certain adaptive aids/equipment. If you utilize nursing services, document everything your nursing team does in order to demonstrate continued need for nursing services as your child ages. Before your child's Medicaid program changes at age 21, also verify that the members of your child's adult medical team are in network with your child's future insurance.

Many states have Medicaid waivers that cover equipment and services not covered by Medicaid insurance. In some states, waivers have long waiting lists, so get your child on a waiting list as soon as possible. For more information, go to: [medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html](https://medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html).

Young adults covered by a parent's private health insurance plan can stay on the plan until at least age 26. Depending on your child's abilities and medical complexity, he/she may be eligible to continue on your private health insurance plan past the age of 26 as an "adult disabled

dependent." Contact your employer's human resources department and insurance company well before your child's 26th birthday to discuss this option. Documentation from a physician is often required.

Special needs trusts may also be appropriate for some families. Go to [specialneedsalliance.org](https://specialneedsalliance.org) for more information, including listing of attorneys that specialize in special needs planning.

## 9) In addition to changes in healthcare, what other life transitions should I prepare for?

Transitioning out of high school is a challenging time for all young people and particularly those with special healthcare needs. As young adults age out of school, they may experience loss of their daily routine, socialization with peers, and in-school support services such as therapies. Thankfully, many people with special healthcare needs may continue in high school related programs until age 22. One to two years before completing high school programming, work with your child and school staff to develop a plan for your child after he/she completes school. This may include further schooling, employment, volunteering, social programming, dayhabs, and/or recreational therapy. If your child is interested in post-secondary education, resources are available at [aucd.org/template/page.cfm?id=509](https://aucd.org/template/page.cfm?id=509). Most states have vocational training options for people with disabilities (more information at [askearn.org/state-vocational-rehabilitation-agencies/](https://askearn.org/state-vocational-rehabilitation-agencies/)). Other resources for post-graduation opportunities may include your child's Medicaid/waiver service coordinator or other families with children of similar diagnoses. Having a regular activity and sense of purpose is important for all people and should not end after your child ages out of high school.

During adolescence, your child may also start experiencing changes or ask questions regarding sexual development, special relationships, and/or body image. It is important for all parents to discuss these issues with their children, including



individuals with special healthcare needs. Check out [ncil.org/sex-ed-for-individuals-with-idd/](https://www.ncil.org/sex-ed-for-individuals-with-idd/) for video-based sexual education resources designed for individuals with intellectual and/or developmental disabilities.

Some young adults may also explore different living options to allow for greater independence, such as a more private space in their current home, a group home, or living independently with provider services or other support services. Talk to other parents for ideas on what may be appropriate for your child. National and local resources on independent living can also be found at [ncil.org](https://www.ncil.org).

Lastly, if your child needs significant caregiving support throughout adulthood, it is important to start conversations with family members and/or your insurance/waiver service coordinator about who will continue to support and care for your child in the event that you are no longer able. These conversations are challenging but important to have before the need arises.

## 10) What resources are available to help me navigate the transition process?

The healthcare transition process can be overwhelming and daunting, but you don't need to go through it alone! Many local and national resources are available to guide you and your child through this process.

### Local resources:

- Talk to a social worker at your children's hospital or clinic.
- If your child has Medicaid or a Medicaid waiver, ask your assigned service coordinator for help. They can be particularly helpful in looking for in-network adult service providers. Many managed Medicaid plans also provide specialized transition service coordination.
- Get involved with local organizations for families of children with disabilities or chronic illness. Many local organizations provide transition guidance, workshops, and/or mentorship with other families who have gone through the transition process.

### National resources:

- Got Transition ([gottransition.org](https://www.gottransition.org)) – this is a federal funded national resource center on healthcare transition. Resources are available for youth/young adults, parents/caregivers, and healthcare providers.
- American Academy of Pediatrics' National Resource Center for Patient/Family-Centered Medical Home ([medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx](https://www.medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx)) – this resource is designed for children and youth with special health care needs and includes a section on "Transition to Adult Care."
- The Arc ([thearc.org](https://www.thearc.org)) – The Arc is the largest national community-based organization advocating for and with people with intellectual and developmental disabilities. Resources related to healthcare transition and a listing of local Arc organizations can be found on The Arc website.

### Final thoughts

Transitions are hard. The thought of leaving your child's pediatric healthcare team may be scary and anxiety provoking. However, this season can be a time to reflect on how your child has grown, developed, and perhaps overcome medical odds. It can also be a time to look ahead to new opportunities and achievements for your child. As you jump (or gingerly step) into this transition process, remember to take it one step at a time, and know that a little planning now can make a way for a brighter future ahead. In the words of President John F. Kennedy, "Change is the law of life. And those who look only to the past or present are certain to miss the future."



by Kara Jackman

## meet david

*“Adapt...persevere:  
because you are  
limitless.”*

**D**avid Garcia, newly-minted doctor of chemistry from Brown University, is here to remind you that anything and everything is possible. He believes he holds the “blueprint of success for people with disabilities.”

He challenges us and asks, “What is your excuse?”

David was born with Moebius syndrome, partial upper limbs, and no feet.



He is the oldest of five born into a first-generation, Colombian immigrant family, living in New Jersey. In his own words, nothing has ever held him back. In May 2020, he successfully defended his Ph.D. thesis in chemistry. Next up, he is training for the 2024 Paralympics.

Life became easier for David once he accepted his body. There were moments of doubt, and plenty of questions from others like “what is wrong with your feet and hands?” David says, he “remembers the moment when the universe presented me with two options: to be consumed with self-pity or the second, to face my reality, accept my disability with all its challenges and refuse to be defeated.” Through the encouragement of lived experiences and a loving family he continues to persevere, to take every moment of adversity as an opportunity to grow.

At age five, while surrounded by the bright lights and sharp tools in the operating room, enduring surgeries to improve the function of his eyes, mouth, and left hand, David realized that his “life was extraordinary” and he “had to be brave in the face of adversity.”

He says, “Those surgeries, without



a doubt, made me stronger and provided me with the courage to accept my reality.”

As a child and teen, David says, “Every single step was a struggle. From the moment I could walk with my little prosthetics every step was a fight, a fight I learned to embrace.” He also struggled to accept his appearance. One day while putting on his prosthetics, he told himself “in order to play fútbol, run, and have fun, I would have to put on my prosthetics everyday for the rest of my life.” While David has never looked back, each day was a struggle he had to overcome, mentally and physically.

As early as elementary school and middle school David refused to be treated differently and rejected help from



well-intentioned occupational and physical therapists. David says, “I taught myself to write with two hands, play fútbol with prosthetics, and perform in a band with soul.” During a trip to the beach as a child, he fondly remembers his mother telling him, “Davidcito, take off your prosthetics, enjoy your life, and jump into the water! Who cares if people stare at you?’ Ultimately, she was right... “No one cares... but at that age it was difficult for me to share the same vision,” he recounts.

Now he can look back and realize these were seminal moments in his life. He muses, “I still feel insecure about my disability. Today, the difference is that I have learned to express self-love and embrace all my imperfections unapologetically. I have learned through self-reflection that my limb difference is not a weakness, but rather a shield that has given me the strength to forge my own path. I have learned that I am limitless.”

Today, David trains four to five times a week for one and half to two hours varying his workouts, alternating among the many muscle groups throughout the body with special attention to

chest, biceps, triceps, shoulders, and abdominals. He begins with a lengthy warm up that includes stretching, 50 pushups, 10 pull ups, and 5 to 10 minutes of cardio. He concludes with more cardio and stretching after focusing on that day’s strength training.

For those interested in starting or continuing an exercise routine, David encourages that you define your goal by asking yourself “What am I looking to achieve? Then, once that is decided, you develop a fitness and nutritional plan that works for your body. The most important thing is to stick with your plan and see it through till you meet your goal.”

Commitment to the cause is vital in this adaptive athlete’s opinion. A big piece of motivation may come from your past, remembering what you went through and overcame as a child. David says he was “empowered

by my past successes, I never give up and [I] stay true to my vision. I remember the challenges I overcame, learning how to write with a pencil, learning how to shoot a basketball, learning how to ride a bike.” All of these successes were possible because he chose to adapt and persevere.

As you can see, in order to excel and work out at an elite level, a bulletproof mindset is required. David’s focus on how to adapt and stay committed to meet his physical fitness goals also helped his mind become more nimble, too. Choosing to lift weights, play rugby, and just move is a powerful outlet for feelings of insecurity and powerlessness.

“Exercising was always the key to keeping my stress and anxiety levels low. In fact, the less I exercised the more disordered my life was, and the






## david, continued from cca athlete

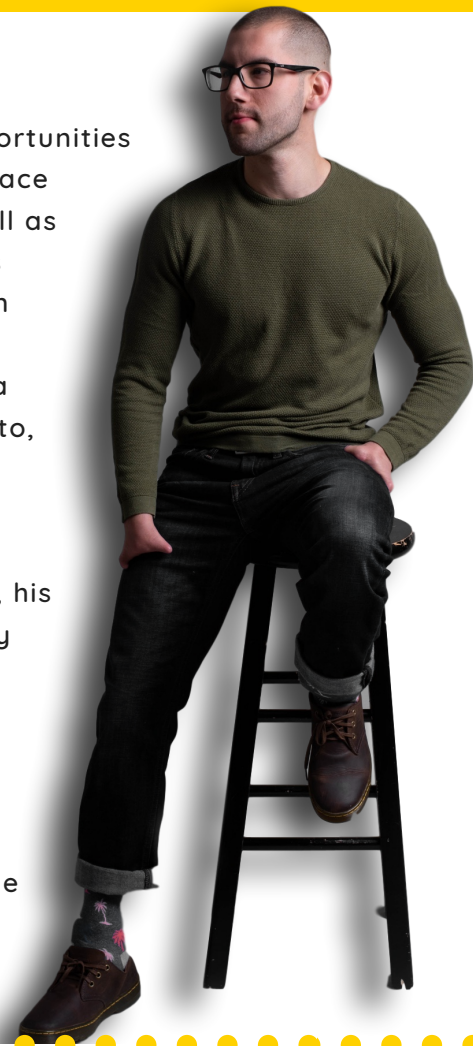
more anxious I felt. So overall, exercise is crucial for maintaining my mind at equilibrium.”

His next challenge will be training for the 2024 Paralympic Games as a wheelchair rugby player. He was recruited by his home country of Colombia to participate and compete for an Olympic medal. David says he looks “forward to representing Colombia in the Paralympics and in the International World Cup tournaments during the next 4 years.” In between workouts, and rugby practice, David is pursuing motivational speaking and modeling in order to share his story with a broader audience. David also supports Positive Exposure, a New York-based nonprofit founded by award-winning photographer Rick Guidotti, that

“is committed to creating opportunities to empower, support and embrace our disability community as well as all individuals and communities at risk of stigma, discrimination and exclusion.” As a member of the action committee, he is a living ambassador of their motto, “Change how you see, see how you change.” 

Read more about David Garcia, his journey to acceptance, and why he wants to share his Moebius syndrome story with us on the blog at: [tinyurl.com/y9yqxly6](https://tinyurl.com/y9yqxly6)

Find David on:  
Facebook, Instagram, & Youtube  
at @davidgarcialimitless.



## LIBRA GROUP

### group workshop series

Libra Group’s September workshop series begins this September!

Mark your calendars for every Wednesday in September from 4-5pm EDT starting September 9th.

These Wednesday afternoon workshops will help you optimize your life.

#### Topics include:

- interview skills
- public speaking
- personal budgeting
- and more

Sign up here, spots are filling up fast.

<https://buff.ly/2OLA4YY>

## libra group 2021 internships

Our friends at the Libra Group are offering a unique, *once-in-a-lifetime internship experience during Summer 2021*. They are specifically recruiting from the CCA community, based on a personal connection and deep admiration of our families.

The Libra Internship Program is a **paid opportunity** for undergraduate students to intern with the Libra Group and its global businesses. Internship roles are available in:

- **social responsibility**
- **finance**
- **engineering**
- **human resources**
- **accounting**
- **hotel operations**
- **and more**

Register for Libra’s upcoming info session:

**Thursday, Sept. 10th**

**5:30-6:15pm EDT**

<https://buff.ly/31jzUxw>



# donor in the spotlight

by Kara Jackman

Schools may not be in session over the summer, but the work for all school systems continues behind the scenes. **Mary Ann Jackman**, mother of CCA staffer, **Kara Jackman**, is one of the people that makes schools kind, welcoming spaces for diverse students in cities across the Commonwealth of Massachusetts. After 11 years of service as a regional director for the **Department of Elementary and Secondary Education Statewide System of Support [SSoS]**, she brought her service to a close on June 30th. In her honor and in lieu of a gift, her colleagues donated \$400 to CCA after hearing about the good work that we do for kids across the country. On top of that \$400, Mary Ann and her soul mate and husband **Patrick Jackman**, contributed an additional \$200 towards their daughter's birthday club fundraiser. This \$600 will bring about a positive impact for our families, providing life-changing medical care for kids in need, building family network connections, and educational materials for students of all ages.

Mary Ann Jackman is a tireless advocate for children in urban, diverse municipalities from Chelsea, Framingham, Randolph, Taunton, and Lowell. She began her educational career at schools in Dorchester, Jamaica Plain, and Roxbury.



She taught at various grade levels, plus put her certifications in math and computer technology to good use in the **Boston Public Schools**. Mary Ann was the first to bring computers into Boston classrooms. Later, she would move into administrative positions, working as an assistant principal, principal (of two schools no less), and ultimately superintendent in a small town closer to the family home, so she could better care for her family. She retired as superintendent in 2006, but her passion for education remained intact. Mary Ann knew there was more work to do. It was then, after two years working at an Apple retail store, that she returned to work in education with the **Department of Elementary and Secondary Education**. There she teamed with colleagues and partnered with schools/districts to work together to better understand and support the needs of the diverse and changing student populations, toward the goal of improving outcomes for all.

Surrounded by dedicated colleagues and school/district leaders, school improvement plans were developed, implemented, and progress monitored; student opportunities and achievement grew and improved.

Mary Ann leaves a positive impression on all people with whom she works. She exemplifies all the principles in our #ChooseKind initiative, especially for black, indigenous, and students of color. Many of the team members were touched by her work ethic and eagerly took the opportunity to donate in her honor. Thanks to Mary Ann's leadership, all of them live out Margaret Mead's message. "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has."

CCA is grateful that this group of thoughtful, committed citizens has helped to improve the lives of families in the facial difference world, too. Thank you to the **Massachusetts Department of Elementary and Secondary Education Statewide System of Support Coastal Region**. We salute you, your work, and the countless opportunities you gave to a young girl from Dorchester that just wanted to help children reach their aspirational educational goals.



Three cheers for you, Mary Ann!  
What a career, Mary Ann Jackman,  
what a career!



# letter from born a hero

**D**ear Colleagues,

Born a Hero is a 501 (c)(3) non-profit organization that focuses on accelerating innovation and research to improve the quality of life for patients with FGFR Syndromes. We will be hosting the inaugural FGFR Syndrome-Collaborative Research Network Virtual Conference. The goal of the Conference is to bring basic, translational, and clinical researchers together to launch an impactful initiative. The Conference is based on Dr. David Fajgenbaum's Castleman Disease Research Network approach, which he used to cure his own rare disease. Dr. Fajgenbaum will be the Keynote Lecturer.

Professionals from multiple disciplines will come together and discuss how to advance treatment approaches. We hope to generate a strategic plan to improve research, treatment, care, and resources for individuals with FGFR Syndromes. Born a Hero is eager to invite you to attend this event. Your attendance would be very appreciated.

The Conference will be held on Friday, October 9th. included is the SAVE THE DATE flyer and the Agenda, with more details about the event.

Our speakers include:

- **David Ornitz,**  
Alumni Endowed Professor



- of Developmental Biology at Washington University
- **Moosa Mohammadi,**  
Professor of Biochemistry and Molecular Pharmacology at New York University
- **Amy Merrill-Brugger,**  
Assistant Professor of Biomedical Sciences, Biochemistry and Molecular Biology at University of Southern California
- **Ethilyn Wang Jabs,**  
Mount Sinai Professor of Developmental Genetics at Icahn School of Medicine
- **Andrew Wilkie,**  
Nuffield Professor of Pathology at Oxford University
- **Jeffrey Fearon,**  
Director of The Craniofacial Center at Children's Medical Center Dallas
- **John Dahl,**  
Pediatric Otolaryngologist at Seattle Children's Hospital and Assistant Professor in the Department of Otolaryngology-Head and Neck Surgery at the University of Washington

- **Kelly Evans, MD**  
Attending physician at Seattle Children's Hospital and an Assistant Professor in the Department of Pediatrics at the University of Washington School of Medicine.

To register or if you have any questions, please don't hesitate to email me at [carolina@bornahero.org](mailto:carolina@bornahero.org).

Thank you so much,

**Carolina Sommer**  
CEO/Founder, Born a Hero,  
Research Foundation





# FGFR Syndromes- Collaborative Research Network Virtual Conference

SAVE THE DATE  
**FRIDAY,**  
**OCTOBER 9**  
FREE to attend

**Start time @ 8:00am PT - End time @ 4:00pm PT**

To register and for more information, contact Carolina Sommer at [carolina@bornahero.org](mailto:carolina@bornahero.org)

Please include the following information:

Subject: FGFR- Virtual Conference

Body: Name, Job Title and Job Description

**PLEASE SHARE AND HELP US SPREAD THE WORD**

**The mission of the FGFR Syndromes - Collaborative Research Network (FSCRN) Virtual Conference is to bring together basic, translational, and clinical researchers as well as patients and families to launch an innovative and impactful initiative to develop management and treatment for the complex and multi-system FGFR syndromes, including but not limited to Apert, Crouzon, Pfeiffer, and Muenke syndromes. Professionals from multiple disciplines will come together, share, and discuss how research can advance treatment approaches. International collaborative discussions will generate a strategic plan to improve research, treatment, care, and resources for individuals with FGFR syndromes.**

The meeting will include presentations by families, clinicians, and researchers as well as breakout sessions to address the following questions:

- What research questions are most important to answer?
- What studies are most important to conduct to answer these key research questions
- What will be the impact of these studies in improving patient outcome?
- What resources are needed to perform these key studies?
- What collaborative groups of researchers are needed to perform these studies?
- How feasible will it be to conduct these studies (e.g. logistically or technically).
- What is the order in which the research studies should be undertaken?

## SPONSORS



Research Institute

# REGENERON



HOSTED BY

Born a Hero, Research Foundation

# 3 cheers

for volunteers!

by Khadija Moten

interns

For the second year in a row CCA was approved to have a sponsored intern for the summer. The previously known Dallas Mayor's Intern Fellows Program expanded this year and was rebranded as Dallas Works, Mayor's Summer Youth Employment Program.

The program provides Dallas teens opportunity in various career paths through a paid-summer opportunity. This year we were so fortunate to have Georgia Leakey as our summer intern sponsored by Bank of America.

Even though current times definitely have put a damper in normal day-to-day activities. We are so glad to have been able to continue our partnership with this amazing program and have Georgia onsite in the office for a few days while practicing social distancing and CDC protocol.

Georgia helped us immensely

over the short 6 weeks by playing a huge role in CCA's #ChooseKind Initiative, Outreach activities, and even assisting in some CCA Development. She assisted us in projects to widen our reach and spread awareness through creating marketing material for social media, contacting educators across Austin, TX, and surrounding cities, reaching out to libraries and child care centers across the nation and offering our free curriculum and inviting them to check out CCA's 3rd Annual Art Contest. Additionally, she assisted us with proclamation requests and creating an updated feedback survey for educators to improve future programming.

Thank you, Georgia, for your hard work and dedication. We were truly sad to see you go so soon. All the best in your future endeavors! 🌈



by Georgia Leakey

My experience working at CCA has been so enlightening. Craniofacial differences were not something I was familiar with up to this point in my life. It disappoints me that my schools never taught me about craniofacial differences. However, it makes me so glad that CCA is taking steps to change that for current and future children. The 2020 Virtual Retreat that CCA hosted earlier this summer was especially impactful for me. I got to see kids from all around the globe that have craniofacial differences enjoying some fun activities together. Parents and siblings were able to talk about their experiences, give advice, and learn from each other. And doctors explained how craniofacial differences actually look skeletally and about common procedures that many of the families go through. All of these things have opened my eyes to more experiences than I've previously been familiar with. I am excited that I know these things now so that I can be a better, kinder, and more compassionate person in the future. I am really honored that I had the opportunity to help CCA with their amazing mission during such a challenging and important time of COVID. Thank you all!





# manny ventura goes the distance

by Kara Jackman

*"if I wanna be free,  
I gotta be me!"*

**W**as the battle cry uttered by Manny Ventura on July 1st when he began a month-long quest to "Save A Smile," running a 5K every day in July. Manny Ventura, New England-based motivational speaker, took no days off in July to raise money and awareness for five non-profits including CCA Kids, MyFace, SmileTrain, American Craniofacial Cleft-Palate Association, and Global Smile to help kids born like him with



a facial difference.

Manny was born in Providence, RI, to an immigrant mother. His cleft lip and palate were a surprise to his parents. He had five surgeries to repair his cleft, including a bone graft at age 12, using bone from his hip that was placed to repair his hard palate. During his 28 years, Manny attended college at Bentley University, worked in commercial real estate, and flipped houses, too. Now, his goal is to be a motivational speaker.

In total, Manny raised \$12,070 on his GoFundMe page. All of the donations will be dispersed among the five nonprofits. Every day during his early morning runs, Manny went live on both Facebook and Instagram. Some days people from the benefiting nonprofits joined him. Erica Mossholder, Executive Director of CCA, and avid runner, ran with Manny on July 14th, and Kara Jackman, Marketing and Communications Coordinator, helped him close out the very last run of the month!

Representatives from MyFace and ACPA also made appearances throughout the month.

In addition to the unwavering support from these nonprofits, Manny harnessed the power of

local businesses, spotlighting one each day with a fresh t-shirt sporting their logo. He also told his story on local TV and radio stations, garnering even more attention on his fundraising efforts. By the end of the month, Runner's World magazine covered his amazing, month-long feat with an article titled, ["This Man Went From Never Running to a 5K Every Day in July for Charity."](#)

Then, shortly afterwards Manny was invited to speak at a conference at the CNN Headquarters after garnering so much attention for his July campaign. He delivered his story and inspired the attendees of the "Instant Marketing Miracle for Doctors, Experts, and Entrepreneurs," in Atlanta, GA. Manny, we know you'll go far and we're so happy that we get to be a part of your journey.

CCA is very grateful to you, Manny Ventura! Thank you for your hard work and dedication to our kids; kids like you thriving with facial differences. Anything is possible if you put your mind to it. Your intense effort during the month of July really impressed, inspired, and touched us. 🙏

**Thank you for sharing your story and your strength to motivate others to do the same.**

# ccaadult



## meet ella davies

**H**i everyone my name is Ella Davies. You may remember me as I was introduced to the CCA family last year. Firstly, I live in England. I was looking forward to meeting you all at the Annual Retreat in Austin, which would have been the first stop on my American Dream road trip. Unfortunately, COVID-19 put a stop to everyone's plans for 2020.

I am 29 years old and was born with Craniofrontonasal Dysplasia which is characterized by body - especially facial - asymmetry, midline defects, skeletal abnormalities, and dermatological abnormalities. Due to my condition, I have had 3 operations in total. The first two occurred when I was one

year old. Then, I had another at age 5. Both operations were to allow for normal development. The third operation was the hardest one, as I had a choice as to whether I wanted to do it. At age 18, the thought of another operation was a little daunting due to being older and understanding the procedure. Also, I understood the risks that come along with having major surgery. I decided to have the operation done. My reason for my choice to have it done at the time seemed incredibly vain, as the operation was cosmetic rather than function or out of medical need. After having the operation, I noticed a massive boost in my self-confidence and knew I had made the right decision.

Having a visible difference has not

stopped me from having a "normal" life. I don't want to say I have gone through my life without staring, pointing, and the odd comments because it happens every day. However, I don't let anyone get me down. I just smile and carry on with what I am doing. If I did not then I would not have graduated university, worked at a summer camp in New York, been employed since I was 15 and travelled to some of the most beautiful places in the world.

I have a fantastic family and group of friends who stick by me and support me in whatever I want to do. Also, I've learned over time that negative people only win by making you think you're alone. Well, I certainly know that I am not alone thanks to my family and new-found CCA friends.





## ella, continued from the cca adult

Which brings me on to the campaigning work I do for a visible difference charity here in England called **Changing Faces**. Changing Faces raises awareness and challenges discrimination that people with a visible difference face. I help the organization by sharing my positive story to let others know that having a disfigurement does not define you, nor the way you want to live. With Changing Faces, I have also had some great experiences. If I had not become a campaigner for equality for those with facial difference, I never would have had these experiences. For instance, I was on the National TV news. And even got a politician to admit they were wrong, which doesn't happen often! Since being a campaigner for Changing Faces, my confidence has grown immensely. I am consistently overwhelmed by the public's response to my story. I didn't think that anyone would be interested, but boy was I wrong! I burst with pride every time I represent Changing Faces. I know if I can have a positive impact on just one person then my job is done.

When growing up, I never had anyone who looked like me. I want every child who has a visible difference to know that they can have a good life that includes having friends and landing your dream job. Your visible difference doesn't define you, nor should it restrict your opportunities. I appreciate that



Giving a speech for Changing Faces

growing up in today's modern world is different than it was back in the 1990s. We didn't have social media. Remember whether you are on Facebook, Instagram, TikTok, don't ever be afraid to show the world who you are. Proudly say "This is me" often enough that people who matter will care and celebrate you, and the people who hate, don't matter.

One of my biggest passions is sports. I have been sporty ever since I can remember. I love futbol (soccer) and my favorite team is **Everton**. I will often go to futbol games on my own. I love watching all the big sporting events like the Olympics, including the winter games. I love running as well; I took up running in 2017 and have not looked back. I completed 3 half marathons so far, and fingers crossed, I will be running the Amsterdam half marathon in October. Running has also been a way for me to indirectly raise awareness of visible differences. I also have a voice in the running community, which has welcomed me with open arms. I'm

seen as "Ella the runner," rather than Ella the girl who looks different. Running levels the playing field for everyone. I've met so many amazing people through my love of running. We all inspire and motivate one another. In the year to come, I aim to make the step up to a full marathon and take part in the London marathon in 2021.

I hope in the not-too-distant future to combine traveling with running. Especially when I visit the US next year. In 2021, I will finally get to do my road trip, which will be something ticked off the bucket list. It will be a great way to celebrate my 30th birthday, too. I will be traveling with my mascot, Edgar, the excitable dragon. We plan to visit the following places Houston, Dallas, Memphis, Atlanta, and finishing off in Miami. I am hoping to complete 2 USA Park Runs, one in Houston and one in Atlanta.

"Meeting some famous faces in the running world - Especially Joshua Stevens, a Ultra runner from Colorado who has given me support through my running and Campaigning journey from a 5 minute conversation we had at the National running show in January 2020"



ella, continued from the cca adult

All in all, I try not to take life too seriously. I love watching and singing along to Disney films. I am a huge Harry Potter and Star Wars fan. I also enjoy cooking and can't wait to try some of the various cuisines that the U.S has to offer.

I love positive quotes, so let me leave you with this one from the movie Rocky:

" Let me tell you something you already know. The world ain't all sunshine and rainbows. It's a very mean and nasty place, it will beat you to your knees and keep you there permanently if you let it. You, me, or nobody is gonna hit as hard as life. But it ain't about how hard you hit. It's about how hard you can get hit and keep moving forward; how much you can take and keep moving forward. That's how winning is done! "

From that I hope you understand that you should not let the negative people make you feel like you're alone, because you are not. There are lots of us with facial differences out here that have all been where you are. Look at where we are today!

Don't let anyone stop you from reaching for your dreams. Having a visible difference is just one small part of the person who you are.

Keep all of this in mind until we meet in person. Hopefully, I will get the chance to meet you at a retreat in the near future.



# financial assistance testimonial

by Ashley Wall

My son, Colt, was diagnosed with Saggital Craniosynostosis two weeks after birth. He underwent an endoscopic strip craniectomy in Houston with 6 months of helmet therapy. This was unsuccessful and his head became elongated and developed a vertex bulge soon after finishing his helmet. I knew that something wasn't right and kept pushing to find answers. We had an eye exam that revealed he had fluid build-up in both eyes which was also an indication of intracranial pressure. During this time, my husband was laid off due to the oilfield crashing and Covid-19. We lost our health insurance and benefits. The stress seemed to pile on top of us especially finding out our cranio baby needed another operation. Some other parents in the groups on Facebook recommended that I reach out to the Children's Craniofacial Association to see if they could help with lodging fees,



gas or some expenses that come along with the travel such as food. Annie was very responsive & very sweet to talk to throughout the whole process. They take so much stress off of your shoulders trying to book a hotel for you as well as reimburse you for some gas and food. Anything helps during this absolutely crazy time. I am so thankful for this association and all of their help. They are truly a blessing from up above. Thank you!





