ccae-network

e-newsletter of children's craniofacial association

2020: ISSUE 1

inside

forbes family's story

by The Forbes Family

Dear Mom, I've been meaning to write you a letter ever since I celebrated my fiftieth birthday last year. A lot has happened in my life and its been an amazing journey. I wanted to take a moment to share it with you. Needless to say, without you and Dad none of this would have been possible.

When you brought me into this world in 1969, I checked in at number seven out of ten in a Irish, Catholic Family. No doubt when you first laid eyes on me you must have been surprised and concerned for my health. Not sure how soon after the diagnosis of Treacher Collins syndrome became official, but the classic symptoms were there on display: lack of cheek bones, receding jaw,

calendar of events

APRIL 5th-10th
Virtual

CCA'S SOCIAL MEDIA FUN WEEK
Check out Facebook, Instagram, and Twitter

MAY 5th
National

#GIVINGTUESDAYNOW
Additional info coming soon!

CONTACT: candler@ccakids.com
NorthTexasGivingDay.org

AUGUST 1st
National

ART CONTEST DEADLINE
CONTACT: kmoten@ccakids.com

SEPTEMBER
National

CRANIOFACIAL ACCEPTANCE MONTH
Plan your picnic! | Zoom Now

SEPTEMBER 21st
Southlake, TX

6th ANNUAL PAR PREMIER GOLF TOURNAMENT | Benefiting Children's Craniofacial Association
CONTACT: candler@ccakids.com

SEPTEMBER 26th
Carrolton, TX

DALLAS CAM PICNIC
CONTACT: areeves@ccakids.com

empowering and giving hope to individuals and families affected by facial difference and in my case, lack of outer ears on both sides. I remember in particular you telling me later that I did not cry when first born and that you were concerned that I may have been deaf. Though once a hearing aid was put on, I became alert and cried due to the noise around me. Also, in the very early days of life there were times when sleeping that I would stop breathing. You would stay awake to make sure these episodes did not last long. Must have been exhausting! Eventually this would pass as well through growth and surgeries.

For me personally, the surgeries of the early years are all a big blur. I remember having my left sided ear canal built. The surgery was painful, and even more of a pain was having to wear an inner earpiece while sleeping at night. This allowed me to quit wearing the bone conducted hearing aid (which at the time looked like head phones) and use a normal hearing aid that was fitted to my prosthetic ear.

By the way Mom, I remember when you would use double sided tape to place the prosthetic ears on my head. After applying them, I would drive you crazy by taking them off in our playroom and trying to hide them from you. Always placing them in the driver and passenger seats of my yellow Tonka truck. You will be happy to know, that I got used to the prosthetic ears and go through about one pair every couple of years. I still use double sided medical tape to apply them. To this day, I wear a fitted regular hearing aid on the left side and a BAHA aid on the right. Since adding the BAHA, my hearing has never been better.

Before we knew it, I was off to follow my siblings to start Kindergarten at a Catholic grade school. It was the perfect environment for me. The teachers there were wonderful and I was able to make many friends. For the first few years, since I had a difficulty articulating words, I would get speech help from one of the moms in class. This time is filled with great memories with family and friends sprinkled in with occasional surgeries that were done over the summer months. You would have me take part in the school band (drums) and sports (basketball and soccer). During this time, I didn't see myself as any different than any other kid.

When high school started, I attended an all-boys, college preparatory school in Saint Paul, Minnesota (St Thomas Academy). These years were difficult on a numbers of levels. First, entering the insecurities of the teenage years with a deformed face was not the most ideal situation. But I was blessed with making tremendous friendships which I am still blessed to have to this day. You were always so supportive of the friendships my siblings and I forged during this period. I remember our kitchen always being "open" for late night chats and snacks. Even if you were fast asleep, you would always come down and partake in the festivities. To this day, my friends still remark and appreciate all the sacrifices you made.

I do want to mention to you that there were a number of ups and downs during this period. Several things that were spoken to me during this time really changed my outlook. The first was at a pre-op physical for an eye surgery. Our family pediatrician noticed that I was nervous and probably a bit depressed about the surgery that was to take place. He paused for a moment during the exam and looking me straight in the eyes said, “You know Richard, its only physical.” Mom, those simple words just struck me. They took so much guilt, weight, pressure off of me. For the first time, I was able to separate what was happening to me physically with who I was as person.

The second, came from a high school tennis instructor. For years, I took lessons from an amazing instructor who not only taught us to play great tennis, but also how to handle ourselves on and off the court. When we would make a great shot or totally flu bone, he would come over and ask us how we feel. The answer was to neither be too high or too low. He would tell us to play with an even keel. These lessons of being able to control my emotions in times of stress proved invaluable. The most successful players demonstrate an even keel, keeping focus on the prize, and not getting too up and down in the process. It was really helpful for me later in life when having additional surgeries. Staying focused on my goals was most important.

College brings about a sense of liberation for most leaving home for the first time. I was no different. Needless to say for me it was the best of times and worst of times. I remember calling you and telling you I had been accepted to Pharmacy School at Creighton University. We were both so excited! The future was looking so bright. Then discovering your battle with cancer. As Pharmacy classes started in the fall of 1999, our family was devastated by your passing away. At fifty-six years of age, you were way too young to go. At twenty years of age, I was too young to say goodbye. Honestly, it took me several years to regain my footing and start taking responsibility for myself. Hard lessons for any young person to endure. It was at graduation from Pharmacy School, that I made the decision to do a residency program in Pittsburgh, PA. It allowed me to be totally out on my own away from family. Self perseverance is a great teacher.

Now Mom, you're probably wondering what happened in the years since those college days. Well, like Forrest Gump, I got into running. A lot of running! In fact, I ended up finishing a number of marathons around the world, including, the Great Wall Marathon in 2004! After several moves around the country, I eventually settled back in Omaha. My Pharmacy career eventually led me to my current place of employment at Children's Hospital in Omaha. It was all well until I had a set back from a surgery to put implants in my cheek area that lacked them. The left sided one felt great and natural.

The right sided one never felt healed. About three weeks post-op, on the day of 9/11, I woke up to see news of the twin towers on fire. After watching for several minutes, I walked past a mirror and noticed a stream of blood down the right

forbes, from the cover continued

side of my face. Infection had settled in and the implant needed to be removed. I was in surgery two days later and after being in the hospital for several more days, was discharged to home on six weeks of IV antibiotics. It was at that time, I decided it would be my last surgery.

A few short years later, I met the love of my life: A woman who loves me for who I am as a person and sees past my physical appearance. Mom, she is not the typical girl next door. In fact, she is originally from Malaysia! In the eleven years we've been married, life has gotten even more exciting for us as we have adopted two precious, beautiful girls from China. Trying to keep up with them at fifty years of age helps keep me young. We are so blessed to have them.

Mom, before I say goodbye for now, I want you to know that this last year, as a family we attended the Children's Craniofacial Association (CCA) Retreat in Scottsdale, AZ. It was our first time, but the organization's 29th Annual Retreat. I was so impressed with everything they did. But I have to say that we met and witnessed so many mothers at the Retreat that reminded me of you. Such loving, courageous people who sacrifice everything for their children. On behalf of those of us who needed special mothers, thank you from the bottom of our hearts. We appreciate and love you.

God Bless,

Richard

Children's Craniofacial Association's 3rd

ART CONTEST

THEME: Self-Kind

How do you choose to be kind to yourself

DEADLINE: AUGUST 1, 2020

PRIZES: Kindle Fire, Hydroflasks, & more

For additional info and to enter visit:
tinyurl.com/ccaart3

we are committed to safety, health, & well-being

RE: COVID-19

To our CCA Family: In the midst of these trying, uncertain, and frankly scary times, we intend to still serve as your support network. We are setting up webinars and video calls, so we can stay in contact and help manage the increased stress, anxiety, and isolation some of us are feeling. Truly – we EXIST to combat these very conditions, and we will be here to fulfill those duties – perhaps in an even more innovative way during the COVID-19 pandemic. Please stay tuned to email and FB for chances to virtually connect.

start with self for mental health: resiliency tips for mind, body, and soul

by Kara Jackman

How are we doing? I mean really doing. This is a surreal time, but as I have been reminded by many in our community, we have made it through tough times before. Thus, we truly are uniquely prepared for this time in our nation's history, battling the COVID-19 pandemic.

I am sure you are wondering, how do we manage this seismic change to our lives. I've read much about how to handle everything from working from home to home schooling. All of which is well and good, but true work must begin within one's self: mind, body, and soul. But what does that look like? Here are some suggestions.

CALMING THE MIND

I originally titled this section "Clearing the Mind," but quickly realized that is an unrealistic expectation even under normal circumstances. Our mental health is everything. We must be able to calm the racing thoughts and tough emotions, so that we can execute all the tasks that make up each day. Where do you begin? A friend suggested on Sunday morning that I begin my day with meditation, journaling, or prayer. I must say I did all three and it really helped. I also wrote a "to do" list. All of it took less than 10 minutes. It really organized and clarified my priorities. I was more productive and self-assured, too. For meditation, or mindfulness practices, please check out the Calm app, Fitbit's 90-day FREE premium membership, or check out the offerings on Youtube by searching for "guided meditations." I would suggest ending your day in much the same way, too. There is something so vital about these transition points, out of and into, restorative sleep.

MOVE!

The other important element for boosting our mental resolve is through physical movement. I will not be so bold as to say the dreaded "E" word, exercise, because I hate to lose a captive audience. That said, committing to some physical movement that works best for your body is vital. Go for a walk, preferably outside, with your family, while honoring the six-foot distance that we must maintain for social distancing. Yoga, or just simple stretching can help, too. Tai Chi and other martial art forms can be soothing, too. Here's a couple videos from youtube to get you started.

resiliency tips ...continued from start with self for mental health

With the gym closed, I have turned to the streets to run. I am by no means fast, but I make it fun, listening to music that I love, taking pictures of the interesting things I come across on the road. What will you do?

LOVE THE SKIN YOU'RE IN

If the thought of physical activity freaks you out, don't worry. There are other ways to stimulate your physical body to bring about the positive mental health you need during these trying times. Take care of your skin. It is the largest organ of your body. Watch this six minute video about how dry brushing and applying body lotion or oil can calm your stress response. You can perform dry brushing on yourself, your children, and even your pet. Additionally, dry brushing can be helpful for those of us that have sensory processing issues. And if not for all those reasons, who doesn't love to pamper themselves?

HUG YOURSELF

Go ahead, it's not weird. We need human touch, to heal, feel settled in our physical being. But we are told not to touch others, so we can't do this one, right? No! You can hug yourself, which in this study was shown to reduce physical pain. In fact, you could probably do this with others while maintaining the mandated six-foot distance. There is also a move called a hookup, used by some teachers and occupational therapists for individuals with Attention Deficit and Hyper Activity disorder. Learn more about it in this article.

This is how you can perform a hookup. Sit, stand, or lay down. Cross your legs. Stick your arms straight out, then cross your wrists one over the other, and face your palms together. Then interlace fingers and swoop your arms down and into your body, hinging at the elbows. Your hands will land just below your chin. Now breathe deeply, from the abdomen, in through the nose, and out through the mouth. During a time when we really cannot hug others, I find these so very calming. Focus on loving-kindness in your mind while you do the breathe and body work. You will find yourself more grounded in the here and now. I hope you take these suggestions to heart. Please consider implementing some or all of them in your daily lives, while experiencing these extremely stressful times.

MORE RESOURCES FOR FAMILIES AND INDIVIDUALS

While geared toward kids and education, I found this link to provide very helpful advice on stress reduction, nutrition, and caring for our bodies.

https://www.actionforhealthykids.org/resources-for-schools-and-families-during-covid-19-coronavirus/

yoga fundraiser for cca kids

Practice yoga with your family in the comfort of your home and support a good cause! Each online class is $10. For every class purchased $1 will be donated to CCA.

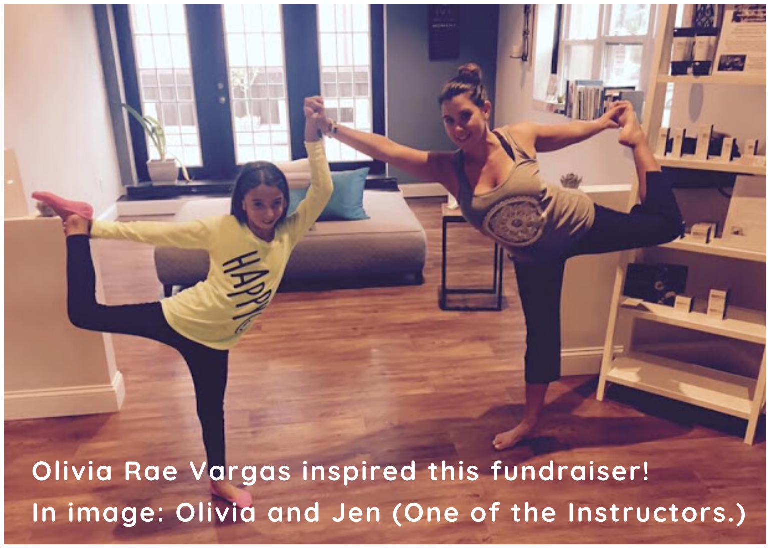
To register: TulayogaNJ.com

View Class Schedule: Click the drop down that says classes
- Click on Aberdeen Schedule

You will see the class listed in MINDBODY as:
> Tula Yoga at Home
> Tula Barre at Home .

We have a combination of Yoga classes for all levels as well as Barre Fitness and Dance Classes.

Click the sign up now button and proceed to create a account and enter your information. When checking out choose : **CCA Kids Drop in**



Olivia Rae Vargas inspired this fundraiser!
In image: Olivia and Jen (One of the Instructors.)

You must be registered by 9am the day of the class. We will email you the link to our YouTube page by 9:30am that day. You can do the class ANYTIME that is convenient for you from your phone, laptop or on your TV!!

The link will be active for 24 hours.

SUNDAY April 5th	Get Crafty!	Share a picture of yourself with a project you are currently working on. Don't have one? Check out our Art Contest!
MONDAY April 6th	Whatcha Readin'	Share a picture of yourself with a book. Add in a favorite quote from it!
TUESDAY April 7th	TikTok Tuesday	Post a video of you doing or teaching someone a TikTok dance or whatever else.
WEDNESDAY April 8th	Lets Get Movin'	Show us how you are staying active. Oh, you're not? Well lets change that...starting today!
THURSDAY April 9th	Family Time	Show us how you and your family are having fun! Or a picture of you chatting on the phone with them.
FRIDAY April 10th	CCA Spirit Day	Show us your CCA sprit by dressing in CCA gear OR reposting/sharing one of our previous postings.
SATURDAY April 11th	My Pet & I	Celebrate National Pet Day by taking a picture with your furry or not so furry pal. Don't have a pet? Get creative!

CCA'S Social Media Fun Week

Join the fun by posting or storying a photo for each day! (April 5th-11th)

TAG US and use the HASHTAG: #CCAFunWeek so that we can share.

Also make sure to tag your friends to join in on the fun!

@ccakids
@ccakidstweet
/ccakids

meet meadow hendry

Meadow is a spunky outgoing Kindergartener. She loves to entertain others and is a great storyteller. She always keeps us laughing. She enjoys making up her own songs, singing and dancing. You will always find Meadow surrounded by books and she is the top reader in her class. Right now her favorite book and movie is “A Bug’s Life.” You will usually find Meadow wearing either a bumblebee or lady bug costume.

Meadow loves being outside and exploring all things of nature

She is curious about everything and can find the best sticks. All the flowers smell amazing and she will never leave a dandelion puff without blowing every last seed into the sky.

She has a wonderful imagination that transports us into other worlds and helps us to explore fairy lands in enchanted forests. The swimming pool is Meadow’s happy place. She can spend hours diving her head under the water and practicing swimming strokes. It’s always amazing to see how long she can stay under.

We were able to go to the CCA Retreat this year and she couldn’t get enough of the pool!

Meeting new friends at the pool and playing in the sand were definitely her favorite activities.

Meadow has had several surgeries to open up her skull and separate her fingers. Although she had a serious infection from her last cranial surgery, and had to go back countless times for clean outs. Then she ended up having infected bone removed and a skin graft placed. She was a trooper through it all.

Meadow is a magical little five-year-old that loves pink, princesses, and all things Christmas. She brings light and love to all those around her, and she can get away with anything because she’s just so darn cute! We couldn’t be more proud that she is a part of our family.

ccakid

cca athlete

meet nova cox

Nova Cox steadied herself, took a deep breath in, and swiftly brought both arms down to break two wooden boards with her forearms. She used her Taekwondo skills and mental toughness to break them both representing **Team Avalanche** at the **2020 United States Breaking Association Massachusetts State Championships**. The event featured top-tier, black-belt athletes from across the Northeast -- teens, children, and adaptive athletes -- all set to compete against the common enemy: wood and stone. All performed in various skills competitions displaying feats of strength, fighting to perform at their personal best. At the center of it all was Nova. She moved grown men, women, and children to come together in the spirit of sport and generosity, to donate money in her honor to her favorite nonprofit, Children's Craniofacial Association. Overall, $6,000 was raised by this tight-knit community!

Ken Goodrich, Nova's martial arts teacher, mentor, and friend, met her only a year and a half ago. He knew there was something special about Nova. She took part in an adaptive Taekwondo class at the **Center for Martial Arts and Fitness in Chicopee, MA**. During one of the first classes, Ken pulled Nova's mother, **Liz Cox**, aside, and asked if she would be willing to bring Nova to a few more classes during the week. Nova took to the sport "naturally," Liz said. She put in additional time with Ken, working on a number of Taekwondo defensive moves, known as forms, and slowly advanced to breaking boards. The forms are various postures and movements that the athlete creates with their hands, arms, and legs. Nova's mom Liz points out, "the forms may look very graceful, but they are actually defensive moves. You need to be determined in mind and body," as you move through the sequences.

Ten-year old Nova says she practices taekwondo "because I really like it, and want to push my limits to become the best I can."

When asked why she chose martial arts, she says she "just liked the idea of it, and having the opportunity to try the adaptive classes helped, too. ”Reflecting on her recent Le Fort III surgery, Nova says that taekwondo, helped her manage her feelings in a far more constructive way. She says, "the mental strength and control I gained though martial arts helped with controlling my frustration and other strong emotions around the surgery and recovery." She enjoys the breaking because you have to be super "focused" and "need to be pumped" in order to make strong, solid contact with the board to break it.

nova , continued from cca athlete

Taekwondo originated in Korea. People began practicing in the mid-twentieth century, blending traditional, Chinese martial arts like karate with indigenous Korean traditions, like Taekkyon, Subak and Gwonbeop (Wikipedia). Spectators will see more high-leg kicks and jumping than found in other martial art practices. Ultimately, the sport is a form of self-defense, enhancing self-confidence and self-discipline in its enthusiasts.

In much the same way, the Massachusetts martial arts community will never be the same without Nova. Thanks to her indomitable spirit, she encouraged people from across New England to give so generously. The men's black belt competitors were extremely touched by her story, resilience, and spirit. After competing and winning in his weight division, **Mike Thomas,** still emotional after breaking ten patio slabs of concrete and stacks of wood, said of Nova, "I've never met anybody who has an indomitable spirit like hers. All my motivation for this stuff [breaking] comes from her. This stuff seems simple. I told her all week it wasn't about me today, it was about her. And that is why I have the success that I do, because of people like her looking out for me."

The martial arts community in many ways mirrors the level of devotion that we see in the CCA community. Everyone looks out for one another, cheers one another on, and celebrates each victory no matter how small or large. It takes a lot of heart and strength of mind to willingly strike a piece of wood with your bare hand or foot. Similarly, it takes a lot of strength to live with facial differences, but both are possible with a loving community of like-minded individuals behind you.

meet eduardo verastegui

Hi everybody! My name is **Eduardo Verastegui**, and the first thing I would like you to know about me, is that if somebody would've told me a few years ago that many of my biggest dreams would become a vivid reality, I would have not believed them, but today, I'm here to tell you otherwise. Everything you've ever dreamed can become as big of a reality as the intensity with which you desire it! Just hear me out! I'm currently a 19-year-old teen born with Goldenhar syndrome, a congenital condition that took effect in me through the lack of full development of several craniofacial features of mine, as well as presenting microtia, and ptosis. But what is a physical condition to ever define who we really are, right? I'm also an online content creator, freelance videographer and photographer, and paraprofessional in Communication and PR at Pasadena ISD based in Houston, Texas.

I immigrated to the United States about six years ago along with my family, and from that point, I began an ongoing journey of acquiring English as my second language while sharing the experience with hundreds of thousands of viewers on YouTube. Has it been an easy ride? Most definitely not! I still remember crying every single day for the first week I spent in the US. While I was fully aware of the great opportunities that immigrating to this country would bring into my life, I just missed my family dearly. I faced a tremendous fear of the unknown. How long would it take for me to learn English? Will I make any friends? Will I be able to perform well academically? All of those were questions that would not leave my mind during my first year in the US as I started to adapt to a different culture, school system, and lifestyle. Fast forward two years, I discovered I had a huge passion for sharing my stories, thoughts, and ideas with people in hopes to spread a positive message, so I began to document the human experience of a Mexican immigrant adopting a new lifestyle in the United States, and by doing so, I started growing an audience on YouTube.

As many newcomers arrived at my channel, a recurrent question began to make presence, "What happened to your face?".

Eduardo's family at the Renissance.

eduardo, continued from the cca adult

I obviously wasn't surprised about this, and happily created a five-minute video explaining what it entails to be born with Goldenhar syndrome. Oh boy… Little did I know this would be life changing! The video instantly took off and exponentially outnumbered the amount of views, engagement, reach, and interaction of all my other videos combined! Wrapping an unbelievable 5,000,000+ views as of today, this video allowed for my channel to gain a lot of traction and positive feedback. As this was happening, I was able to reach one of my biggest goals, surpassing 100,000 subscribers on YouTube. I could only dream about achieving this milestone a few nights prior to this event. I just could not believe it…


Eduardo filming an interview.

What's even better, I discovered something that would change my perspective of life forever. Having a physical condition that makes someone different and unique, should be regarded as a powerful tool to evoke motivation, inspiration, and hope to those who truly need it. Reading comments from people saying how much my story motivated them to chase their dreams no matter their challenges, opened my eyes to the impact we can all have by sharing our stories of courage and perseverance in life as we battle every challenge that comes our way. There is one ability that absolutely every person has, and it is to demonstrate to the world that the pursuit of happiness and personal success is a choice, and no barrier is to ever prevent us from achieving them.


Graduation Day.

Fast forward to only one year ago, as I began to feel more confident about my ability to communicate in English, a new array of experiences started to make presence in my life. Not only did I get to graduate high school, but I also decided to turn one of my biggest hobbies in to a profession. Photography & videography had always been an interest of mine that I devoted countless hours to while in high school. As I was just about to start college at the University of Houston pursuing a bachelor's in Digital Media, I simultaneously started offering freelance photo/video services and put my heart and soul into the project in hopes to get some professional experience. To my surprise, my fear of not getting many clients quickly faded away as I began to grow the business little by little through word of mouth. That, once again, proved that even when I thought being different would make people less likely to hire me, turned out to be the complete opposite. People seemed to enjoy the films and photos I was delivering and did not care a single bit about anything else I'd worry about, which instilled great confidence in me to keep going. That is how another dream in my bucket list became a reality!

eduardo, continued from the cca adult

Followed by this, I was able to land a paraprofessional position in Communication and Public Relations at Pasadena ISD. This had not only been a goal of mine for a long time, but it also allowed for amazing networking opportunities that led me to share my story on several media and news outlets in Houston such as ABC13 and KPRC2. This paved the way to a new hobby of mine that truly makes my heart full. Being able to attend private and public events to speak to students and adults about the importance of breaking the barriers imposed by any physical condition is a true blessing, and I will always encourage anybody who has a condition that makes them unique, to give it a shot. People will love to hear those stories and they will spark great motivation in them.

I would like to end this article with the following note, each one of our stories is different, and we all face challenges and pursue happiness and success in distinct ways, but the beauty about the Children's Craniofacial Association is we can all come together to make lifelong friends, share our stories, and connect in a way that is very unique and special. I'm very excited to begin my involvement in this organization and look forward to making a ton of new friends and hearing the amazing and inspirational stories of everybody involved!

Eduardo with a huge fan.


Eduardo's dad's side of the family.


Eduardo's mom side of the family.


Student Hero Award.


Edyardo's work buddy.

ccasupersibs

meet aspen

My name is **Aspen Hendry Branin**. I am 19 and the oldest of us 3 sassy sisters. I recently got married to my high school sweetheart, **Jaeden**. **Meadow** was my flower girl! I enjoy hiking and camping as often as possible during the summer, and have a goal to visit every National Park. I work as a secretary in an elementary school, and I love my job. I've gotten to see how the book "Wonder" has been recently incorporated into classrooms and the impact that it's making on kids. It's important to teach children as early as possible, that everyone is different, and we need to be respectful and accepting of everyone, no matter the differences they have.

Differences are what make us unique.

There is a 14 year age gap between my sweet sister Meadow, and me. When she was born she was immediately placed in the NICU for several weeks. Because Sage and I were minors, we weren't allowed to enter the NICU.

Only being allowed to see pictures of her was extremely difficult, especially knowing she was just in the next room and we couldn't go in.

We knew before Meadow was born we knew that she had Apert syndrome, but as a 14-year-old I wasn't quite sure what it meant. Except that she would be different. Watching Meadow go through 10+ surgeries in the first couple years of her life was challenging, but she was always happy. She learned to grab things, and crawl with casts all the way up her tiny little arms. The things that she is able to do every day amazes me. It's hard not living in the same home as her, and not being able to see her everyday. She brings an indescribable amount of joy with her everywhere she goes and lights up every room she walks into. I am truly blessed to have her as my sister.

meet sage

My name is Sage Hendry. I'm 17 years old and a senior at Orem high school. I spent most of my high school career on the varsity swim team and spent this year as their captain. I have always loved swimming but recently discovered the only thing better than swimming for your team is swimming with your sisters. My younger sister, Meadow, was born when I was almost 12. She is a great swimmer and we love to play in the water. We also like to dance and watch Princess and the Frog together.

Over the past five years my life has been enriched by her presence. I am so glad such a happy little girl was brought into our lives and I can't imagine it any other way. I'll be going off to college soon but intend on coming back home at least once a month to spend time with my favorite little girl and the rest of my family. Meadow is a high-spirited and tough young lady and I can't wait to see the person she becomes.

Insurance? We’ve Got You Covered

by Kara Jackman

INTRODUCTION

I recently watched a webinar that helped demystify how to interact with your medical insurance company. Like me, many people are wary of asking (some would call it “fighting”) for what they need and want from their insurer because they are convinced they will say “No” to their requests. **Being knowledgeable about your policy, strategic in your approach, and persistent in your interactions** will make you successful in receiving the treatment you need and feel is best for you. Working with your insurance company is the key.

But how? Here are some tips.

THE STAKEHOLDERS AND HOW TO APPROACH THEM

There are many people, organizations, and institutions that stand between you and what could be a life-altering medical treatment. Who are the stakeholders and how do you leverage their power to get what you need?

YOUR INSURANCE COMPANY -

There are many places to start in the battle for insurance coverage, but the most obvious place is with your own insurance policy. Get a copy of your policy documents and read them. Be aware that you may find a difference between your policy and what is covered. The policy documents provided to you both by your employer and by the insurance company will tell you what services are covered at what level by both stakeholders. Important: If you do not understand the policy, this is the stage to call the insurance company and simply ask them to explain it to you, without giving details of your situation. Read the map before you hit the road.

STATE STATUE ENFORCERS -

Also, you need to know the state statutes around insurance coverage and what your workplace is willing to cover, too. The state statutes govern what the insurance coverage may or may not cover. Place calls into the appropriate state government officials to discover more. You could learn something that could strengthen your case for care. More information about state statutes for craniofacial and cleft conditions can be found at http://cleftresources.com/health-insurance/.

Eric Brown, father and insurance advocate for his son born with a bilateral cleft lip and palate, says, “In 15 states, laws have been passed that require insurance companies to cover additional services that aren’t usually included in a basic policy.” Know your rights!

EMPLOYER -

If you are insured through your employer, they may have a say as to what the insurance company will cover. Read your human resources website dedicated to health insurance benefits and **talk to the benefits representative** in your human resources department, if you have questions about specific kinds of care that may not be covered on the website. The benefits professional in your human resources department is an expert on the plans your company offers. Bring them chocolate, a photo and note from your child, come in calm and collaborative, make them an ally, and leverage their knowledge. Explain your situation briefly, but be personable. They need to see your case as one they are motivated to help.

PHYSICIAN AND MEDICAL DEPARTMENT ADMINISTRATIVE STAFF -

A strong partnership with your physician and the department’s administrative staff are essential to success. Be open and forthcoming with your doctor. You need a good, positive relationship to ensure requests for medical treatment submitted to your insurance company are successful. You, the doctor, and the administrative staff member know the patient's needs best. The same approach works best here too: start by being calm and collaborative. Ask for help and tell them that you need them on your team.

WHAT CAN I DO TO MAKE AN ASSERTIVE ASK?

Persistent and consistent conversations on the phone and in person with your insurance company, state statute enforcers, your employer, and physicians are critical. But how should you approach asking for what you need? Initially, you will be checking to see if something is covered. If the insurance company is unsure, or you feel the need to support your ask with evidence, **request a letter of medical necessity from your doctor**. These letters, which you will write with guidance from your medical provider, should contain proper medical terminology, medical and/or billing codes, and an explanation of the doctor's notes to make the case to your insurance company for treatment.

WORDS MATTER

Words have massive impact, and using the right ones could force the insurer's hand in granting coverage. Never use words like "cosmetic", "experimental," or "unproven" to describe the surgery, medication, or intervention required to help you or your child thrive. Do use words like "medically necessary," "improved function," and "standard of care." In order to give your letter more impact, Eric Brown, encourages you to get a copy of the medical provider's notes. An especially helpful time to ask for these notes is during medical appointments and team visits. The notes are a roadmap to treatment, and can be easily copied and mailed to you from the doctor's office upon your request. Brown warns, "If they don't send a copy of the notes, ask for the patient file." Brown suggests that these notes "must state 'medically necessary' and be very descriptive. Nine times out of ten, the insurance company will have 'expert doctors' look over the case and make the determination if the treatment is necessary."

DO YOUR RESEARCH AND GET FUNCTIONAL

To add even more pop, patients and their families are encouraged to do their own medical research in online databases like Medline or JSTOR to strengthen your argument and increase the likelihood that the insurance company will provide coverage. Positive research studies that prove a treatment improved a condition could improve the chances of receiving coverage. You can also take the steps to request a functional assessment from a third-party, objective physician. You can learn more about functional assessments at: https://www.impactmedinc.com/company.html. The physician, physical therapist, dentist, or other medical provider conducting the assessment should provide documented evidence, in the form of a letter, about how the patient's medical condition has a negative impact on activities of daily life. Documenting difficulties with things like sleeping, eating, breathing, walking, caretaking, working, hobbies, education - be specific - could force the insurer to cover a medical intervention.

POSSIBLE PITFALLS

Be aware: not all medical professionals are great at communicating with patients or insurance companies. You can assist them throughout this process as the most knowledgeable person about your or your child's condition.


Eric Brown and family at CCA's mini retreat in FL.

continued... Insurance? We've got you covered

For instance, the non-profit advocate organization, Patients Rising, notes that medical professionals affiliated with HMOs may be combative with doctors and vice versa. Doctors that are part of HMOs get penalized for referring patients out to additional specialists, forcing you to potentially pay out of pocket for just a consultation. Be aware of that by working with the doctor and their administrative staff to obtain the proper, prior authorizations you may need before moving forward to see a specialist. Specialists and second opinions can be life-changing, not only in your fight for improved quality of life, but also in the insurance coverage game.

THAT DIDN'T WORK, NOW WHAT?

Appealing the Insurance Company's Decision So, let's say a week or a month goes by, and the insurance company denies your request for coverage. No fear, you still have further recourse. You can appeal their decision. Many people feel appeals are not worth the time and effort, but often times they are. Patients Rising, states that appeals are won 39% - 59% of the time when appealing directly with the insurer. The appeals process is somewhat similar to the one for establishing medical necessity, however, the forms, and people reviewing the patient's case will be different. You are entitled to a peer-to-peer review, an internal review, and an external review, all of which will be done by different people in different ways. Please go to the insurance company's website and carefully read the appeal process instructions. The appeals process will be different for each insurer. **If you miss one thing, you could be out of luck.**

Finally, be sure to document any communications you have with your insurer, doctors, and other stakeholders during the appeal process. Write down people's full names, position title, dates, the phone number you called, and what was discussed. We suggest a specific notebook or journal dedicated specifically for this purpose. Take it to appointments with you, jot down the notes when you're on the phone, and keep additional copies of receipts and letters here, too. Being organized is another essential key to success.

Each insurance company has on-staff experts that read these appeals and make decisions about what should be covered. It may take 30-60 days for the insurance company to deliberate your case, and respond with its approval or denial. Be patient and remain hopeful. From our conversations with Eric Brown, we learn attitude is everything. Do not treat anyone like an enemy - rather envision yourself as a persuader, convincing them that your case is one that is right, fair, logical, and medically necessary. Channel your emotions into persistence and thoroughness, trying hard to avoid desperation and anger.

To learn more about getting your treatments covered, watch a recording of the Patient's Rising webinar that inspired this article. Remind yourself that you do have a lot of power, but you have to have the wherewithal to channel it for you or your child's best interest.

CCA Webstore

Have you checked out our new webstore materials?

NewBalance Logo Jacket

Holographic Sticker

ChooseKind keychain

& a throwback Polo!

ccakids.org/shop

spaghetti dinner

Madisyn Bower inspired **Seneca Valley High School student, Maddie Karchut**, to host a spaghetti dinner to benefit CCA. This was not just any spaghetti dinner, though. No, Maddie and the surrounding northwestern Pennsylvania community came together to raise over $7,000!

The event featured a sumptuous meal feeding 200 people with 6 families in attendance affected by craniofacial conditions. Many hours were put into contacting local business, and 80 of them came through with something to give towards the 45 raffle baskets that were on display around the room. Other sponsors found ways to make the day special for all who attended. Twenty five volunteers coordinated the activities for the 200 supporters, ensuring everything ran smoothly.

After all was said and done, the leftover food and supplies were donated to **Light of Life Rescue Mission**, a homeless shelter, in nearby Pittsburgh. A fine way to pay forward the spirit of kindness, good karma, and great fundraising from a super successful event. Thank you Maddie Karchut, we are confident that you will make all your dreams come true in the bright and bold future that lies before you after high school graduation.

Congratulations on running a successful fundraising event that will bring medical care to kids in need, provide social networking for families feeling alone, and provide opportunities for learning about empathy and kindness in classrooms around the country.

financial assistance testimonial

by Donise Cinnamon

William and his twin brother, **Scott** were born in Oklahoma City, OK on a very icy day in January of 2001.

I knew from the beginning that William was born differently, but it took me awhile to convince the doctors. Once a genetic study was performed, we learned that William has **Jackson-Weiss syndrome** and later developed hydrocephalus.

His first two craniofacial surgeries were performed in Oklahoma City, but unfortunately, both the neurosurgeon and plastic surgeon went into private practice and no longer performed the type of surgeries William would need. His plastic surgeon then referred us to **Dr. David Genecov** in Dallas and our long journeys began. It takes us anywhere from 6 to 8 hours to travel from our small northwest Oklahoma town to northeast Dallas. When we first began these journeys, we were introduced to **World Craniofacial Foundation at Medical City.**

Two years ago, after being reorganized I was informed that WCF was actually set up to help people outside the USA to gain medical assistance and it was then that I was introduced to CCA. I had received newsletters from CCA in the past, but had never contacted them to help us. I looked up their website and out the contact information. It wasn't long before **Annie Reeves** contacted me and told me what she would need to take before the financial assistance committee to ask for assistance. It turned out that this first time was going to have to be rushed a little as the meeting was only a few days off, however she soon notified me that they would help us with a certain amount which would go towards a hotel room and fuel expenses.

I was so relieved that they were willing to help as these trips are not cheap and we are on fixed incomes. CCA has helped us a couple of times since then and each time is greatly appreciated. It is so nice to know that there are organizations like CCA out there who are dedicated and able to help children like William obtain the medical help that they need. I pray that God continues to bless CCA with the ability to continue to help all those that they can. Thank you, CCA and Annie for all that you do, you are truly a blessing.

normal - magda & nathaniel interview

by Kara Jackman

At CCA we encourage our families and kids to share their stories. **Magda and Nathaniel Newman** took this suggestion to the next level, publishing two books with Houghton Mifflin. Both books share the same title, “Normal.”

Nathaniel’s book, “Normal: One Kid’s Extraordinary Journey,” which features his mother’s words, too, focuses on what it means to grow up with a facial difference. While Magda’s book, “Normal: A Mother and Her Beautiful Son,” shares the parent perspective. Both inspire readers to embrace their normal.

We interviewed Nathaniel and Magda about their stories, narrative choices, and the reason for putting pen to paper in this bold way.

Why did you decide to combine both of your words in the young readers' version? (e.g. do you feel it is important for kids to sometimes understand their parents?)

MAGDA: In the young readers edition we thought it was important to show multiple perspectives. We wanted young readers to have a view into how caregiver parents worry about and dream of a normal life for them. We, of course, wanted kids and others reading the book to gain insight into the real-life challenges of children with facial differences.

How do the challenges you faced already prepare you for those to come in the future? What lessons learned do you take into your daily life?

MAGDA: We as a family have gained tremendous perspective. We understand more than most what is important in life. Little challenges don't worry us, and we don't worry about things we can't control. While we don’t wait for bad things to happen, with Nathaniel in particular, we always know that future challenges will pop up from time to time. For me having survived multiple cancers has left me with resilience and a belief that no matter what happens in the future there really is no challenge we can't overcome. Every day our family approaches each day as a gift we have been given and we work hard to cherish every moment. We appreciate little things, like our dogs, more now than ever before.

Nathaniel, you have a great sense of humor about your medical challenges… Does that come naturally? Or did you work for it? What advice do you have to find humor for other people who live with a disability, chronic condition, or facial difference?

NATHANIEL: To be honest it must come naturally because I really don't think about it too much. I just feel better when I am laughing and joking around. It keeps me from thinking about the negative, or the challenges I face. The only advice I have is: be you. If you find something funny then laugh! Don’t worry if others think it’s dumb, or not cool. I just watched a video about how to talk like a Minion from the “Despicable Me” movie. I cracked up, while others might find it silly or stupid. I don’t care; it made me laugh all day.

Magda, How has your life changed since opening up and telling your stories?

To be honest, life has not

changed much at all. Since day one we knew we wanted Nathaniel to change the world. That meant sharing our story every chance we could. Very early in Nathaniel's life we did public events, TV shows, videos for charities and other public facing events that we hoped would make life easier for children and families struggling with facial differences and other health challenges. This telling of our stories really just seems like the logical next step. We love that **WONDER** taught people to be kind, but thought the world needed to know and understand more about families like ours. We want to move folks from Kindness to Inclusion and make sure everyone embraces their NORMAL!

Would you encourage other people to share their story with the world? Why? What should they know first?

MAGDA: We have been blessed and have always found the positive in even the darkest times. We really only encourage others to tell their story if they can do it from a place of positivity and love. The world does not need to hear downer, sad, or depressing tales. There are plenty of those already. While we have had our own dark and scary times, we really wanted to focus on the positive and the up lifting. People should know that telling your story is not without challenges or trauma. Reliving all the things that you may have thought were in your past is not always easy. It was a very emotional and at times tear-jerking effort. If you do feel like telling your tale, people should know that it will often unearth deep emotions that you may not have even been aware of.

Thank you, Magda and Nathaniel for this interview! Both books are available for purchase through Amazon (adult), Amazon (young readers) and wherever books are sold. Follow the Newman's on their book tour and stay tuned for dates.

3cheers for volunteers!

by Sharon Allbright

CCA has been a part of my life since 1991, when our craniofacial surgeon, **Stephen Beals**, informed us about CCA. This was before the World Wide Web and social media! So, we attended our first Retreat in 1993 when it was held in Phoenix, AZ. CCA has been there for us through the good times and the bad. **Robbie** and **Jonathan**, my sons, enjoyed attending the retreats because they could reconnect with their friends and I have made lifelong friends.

The support Jonathan and I received after Robbie's death in 1992, was greatly appreciated. **Char Smith** and **Jill Patterson** told me we would always be part of the CCA family. I took that to heart, and this year I will be attending my 23rd Retreat.

Volunteering and giving back is something I enjoy. Each year, I like to purchase and send items for the Retreat welcome bags and the care packages because it reminds me of Christmas morning, waking up to see what was left in my stocking. I have been able to help with the Retreats when held in **Arizona** by having items sent to my house for storage or when asked to find leads for entertainment. I appreciate all that CCA does for the families and I am just repaying them for all they have done for my family.

And we appreciate you Sharon!

thank you rare tamu & delta zeta

texas A&M University's students of RARE and sorority Delta Zeta teamed up to collect supplies for CCA care packages.

Together they collected an assortment of fun and practical supplies to be sent to children and adults at the time of their surgery. The items included but were not limited to: coloring books, stuffed animals, card games, lip balm, face masks, personal care items, and more! We are so grateful to you all!

Thank you! To request a care package for your surgery, visit our website at **ccakids.org**.

To donate or hold a fundraiser in honor of CCA, email us at **contactCCA@ccakids.com**.

lentil's update

by Lindsay Condefer

Here goes that CCA "Dog" Mama again! Like any of us Mamas- I want to Be Heard and won't stop until I am!

Some people may think we are just annoying and persistent... but I think persistence to the point of success is a blessing!

I always count my blessings in finding CCA... My boy - although he has "fur and four legs" - is still my baby. I've had countless sleepless nights- stress over surgeries- and the moments where I was so tired I couldn't imagine another second.. but I did it. That's all of us - that are a part of CCA - we who team up together and make peace in our lives.. and one of the reasons I'm so thankful for our community.

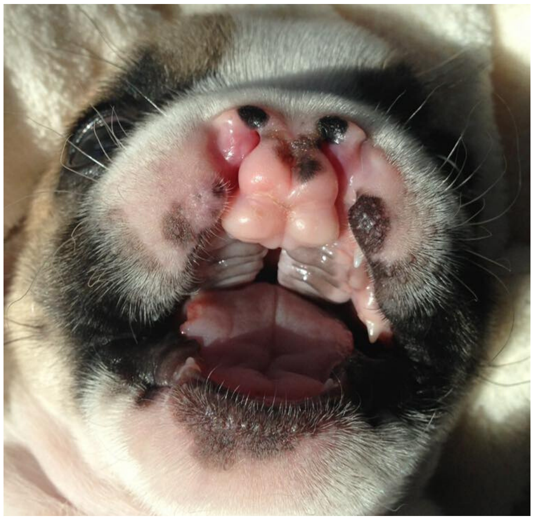
None of us "plan" to be a part of CCAKids... we are chosen to be here. We are the lucky ones. To have this support. We are never given more than we could handle - so we are strong- and we are the advocates that will change the world.. .because our kids are special.

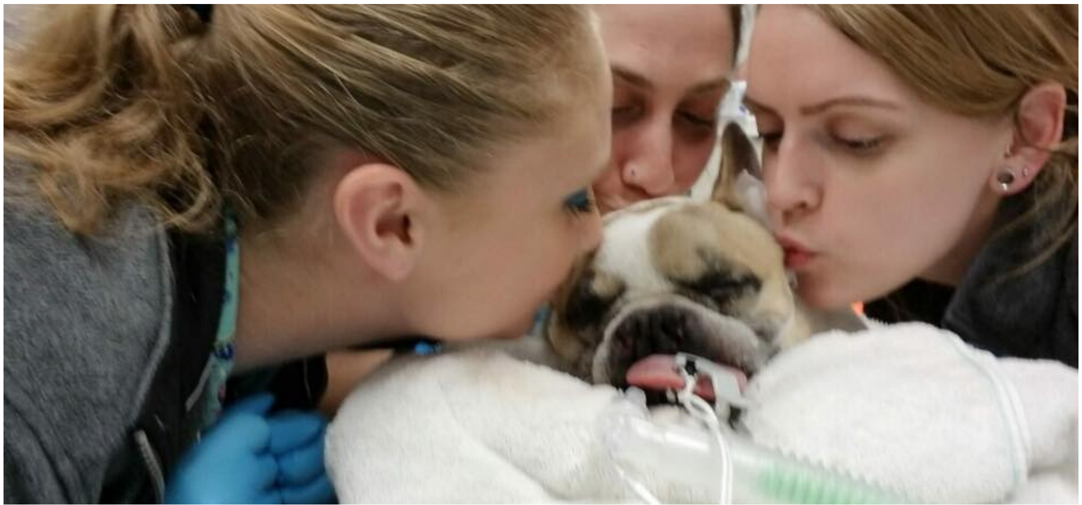
My life led me to Lentil. A tiny puppy who couldn't survive on his own. He needed me... and I stepped up. Not for anything other than trying to save a life. I never could have never imagined where our path would take us.. I have a special needs dog rescue. I saved lives that I knew were important- placed hundreds of animals in their perfect home - but no one cared what I did until a chubby face with a heart shaped nose went viral online.

I'm a Mama, and don't want (or deserve) a pat on the back. I just do what we all do here! Love, embrace, stand tall, and give back any way we are able. If you follow our story, Lentil has recently put me through a whirlwind (and of course right before his birthday)! Hopefully my feelings/thoughts can be summed up in his "GoFundMe" which benefitted CCA and also our own medical bills along with what will be "our new normal."

From our fundraising appeal:
Lentil's 7th Birthday is coming up and we are staying confident that it will be our Best. Birthday. Yet! It's taken me a bit to try to compile thoughts - and I'm not even sure I can formulate all I want to say even now, but here we go.

I want to start out by saying "Thank you" to all of you for all of the support and love that you have been sending. I know he feels it and I surely do too. I know they are small words, but please know there is so much meaning behind them. Each year we raise money for CCA Kids, an organization that we hold





so close to our hearts. So this year, even though we have mountains to climb - we are doing the same - because nothing will stand in the way of our kids!

The first $5000 of our Birthday wish will go to CCA Kids - we want to help them in their efforts to support the children and families we just love so much. Everything over the last couple days is a blur. It feels like I'm living in a bubble....now to try to sum up info for you without writing a novel.... I always knew that Lentil's back was an issue, but all one can do is hope for the best and celebrate each day as it comes (and goes).

We have so much to do- we can't let "worry" stop us.

The universe just decided that January 9, 2020 was our day. I woke up about 6AM and Lentil was sitting up- in a puddle of saliva- looking at me panting and paralyzed in his hind end. At that point I knew it was "our turn" - I've watched so many animals and their amazing Moms and Dads go through it.

Now it was just time for us to do the same. I picked him up, as he was screaming in pain and pouring urine down the front of me, and the words that's I've said so many times to him...Here.We.Go. We were in the car headed on our 20-minute drive to Mount Laurel Animal Hospital, as I'm calling his "Aunt Taylor" in Emergency to fill her in. If anyone has had to come through ER there...you've probably met Taylor, the beautiful blonde, who's loud and bubbly, and BEST yet...she knows her stuff! (So does everyone there, but I'll just say poor Taylor got the "lucky" wake up call that day we were coming).

Lentil is not a good patient...he likes the world to be exactly his way and will not tolerate anyone (including myself) telling him what to do. He tells us. And when he doesn't feel well, he makes sure to punish everyone around him. Honestly though, I think that's the blessing in disguise with that boy. Taylor was able to place a catheter and by that time **Dr. Cohen** was coming into the Hospital. Upon exam, Lentil had no deep pain sensation in his hind end. Dr. Cohen spoke to me as his coworker there, but most importantly talked to me as Lentil's Mom, the way he treats every patient and their family that comes to him. I appreciated that so much.

We knew an MRI was necessary and we spoke at length about recovery. Recovery meant his chances of ever being "normal" again. **What's normal really?**

When we got the MRI results, his chances went further downhill, but when I saw Dr. Cohen and his team when they were off to surgery. I said to him "Are you confident you can help his pain?" He looked me straight in the eye and said he could. (Really he said he would try...but I know what he meant.)

I just needed to feel his confidence. That's all I cared about. A confident Dr. and Nursing Team. Lentil tolerated anesthesia like a champ; surgery went well and they felt as though they relieved a lot of decompression. He had/has a huge bruise at the base of spinal cord which set him back further, but again...We take things as they come.

The following day, Lentil was still recovering in ICU, and he was not a happy camper having his nurses and Drs. care for him...he wanted out. He had gotten himself so worked up being there (even though everyone was doing next to no handling), that he ended up having to be intubated to attempt to get him calm. While sedated, he still had shallow breathing...and couldn't get fully settled. I think it was around 2:30PM or so, but it could've been midnight for all know! I was talking with his ICU Dr. as one of his nurses ran in and said she needed her NOW. I've been in the veterinary field long enough to know what that means.

I peeked into ICU and saw (literally) everyone in the room surrounding him. That's when my brain shut off. I somehow walked into my Exotics ward and saw Mary at the computer with her back to me. I stood there as my life was running its circles through my head and then - and I think this is when I "accepted it" - said "He's gone."

Mary- being one of the most amazing nurses/friends a girl could ask for, whipped around, and ran to ICU. Somehow, I found Liz and Gianna- two other Exotics nurses that have been my rocks, and they stood with me in the hallway… literally giving me exactly what I needed at that moment - support. It feels like it was hours - but all of that happened in a about 2 minutes - and somehow my legs started to walk.

I bucked up as a Mama and went into ICU. Lentil was surrounded by the most loving and calm Team. Everyone in that room was working together. Nothing else mattered at that point except for the patient they had in front of them. And that goes for every patient in that hospital. You see "behind the scene" pictures of Lentil...but that's because I am there. But EVERY patient gets those kisses and that same love...it's what we do.

I walked into that room and saw Kim on top of him doing CPR. I remember him on his side and everyone around him working so hard. I called it - I told them to stop. I will take our boy to anywhere - but at that moment, I thought he was done. I accepted his fate. I told Kim to stop and I looked at him and said thank you...

She locked eyes with me, and I knew she didn't want to give up, but she accepted my wishes and stepped down and then the next thing I hear is someone scream that he was breathing!

That's when I walked out. My mind couldn't process it. And then I felt like such a crappy mom...I just gave up on him and he gave a slap in my face. I'll beat myself up over that forever...but it makes sense, because Lentil likes to beat me up! He isn't afraid to remind me when I'm a slacker. The staff at MLAH saved our boy. Every moment counted. From the front desk, each department, his clean blankets, EVERY single person that wears those scrubs in that building played an enormous part. THEY brought him back to us. Now it's our turn to see him through.

I'm rambling...but with reason! I know still can't find the words to express what happened. But here we are. I don't know what the future holds. I found our old blog...I needed a little reminder for myself....
mynameislentil.blogspot.com

I think we are going to do what we always did. Day by day.

I understand that there is judgment, but whatever anyone wants to say, please know that there's one thing…I made a pact to that boy and I'm sticking to it. No one knows what each day will bring, but we are here. We are trying. And it's not over just yet.

I'm a Mama. That's all I am. I'm so thankful for the support within our group. Lentil has taught me to be able to ask for help. I'm a strong woman, but sometimes I need support, too. Our CCA family is so special…we defy the odds we are kind to each other. And We. WILL. Change the World. Kindness is King, but our hearts together make it happen.

state breaking champs

Ken Goodrich, taekwondo instructor, friend, and mentor to CCA kid, **Nova Cox**, raised $6,000 in her honor for Children's Craniofacial Association as part of the **2020 Massachusetts State Breaking Championships.** Martial arts athletes from all levels and backgrounds, competed for personal records in breaking large stacks of wood and concrete slabs throughout the day-long event.

Ken is a third degree black belt in taekwondo...and fundraising. Previous tournaments featured a fundraising component supporting the American Cancer Society, Dana Farber Cancer Institute, Shriners Hospital, and Pets for Vets. While those efforts were successful, raising thousands of dollars, this fundraiser for CCA, Ken says, "was the biggest for me in over 10 years."

Ken uses Facebook to promote and raise money. He says, "it is the most effective way of getting the word out." He knows how to leverage his network twice a year to rally around a cause he is passionate about for tournaments and martial arts breaking events that he hosts.

All of these events are typically inspired by one special person. Nova inspired the fundraising for this year. She started adaptive taekwondo classes a year and a half ago at Ken's gym, the **Center for Martial Arts and Fitness in Chicopee, MA**. More recently she underwent a Le Forte III surgery to improve overall function of her head, face, and airway due to Pfeiffer syndrome. Her taekwondo practice allowed her to manage the anxiety, frustration and other strong emotions that came along the way with what was a rigorous recovery.

Ken says it was easy to support such a positive person, someone whom he feels has "indomitable spirit." "Nova is inspiring. Period. Her personality is the reason many people donated. Most people who have a personal connection with Nova, or my other fundraisers, tend to donate more."

And that is what we saw happen! Nova's taekwondo competitors, friends, and village really showed up and donated to make this a blockbuster of a fundraiser. Each competitor and spectator made a donation. Proof positive that participation in small amounts does pay off in the end. Ken said, "Everyone who attended the tournament helped to raise money. There was a $10 registration fee and all of those proceeds from the tournament were donated. Two sisters even came in from my after school program with $5 each from their piggy bank because they wanted to make a donation and help." One of the girls, Sophia Serrano, shared why she was moved to give, "Nova is my friend and I want to help her, and kids like her, as much as I can." Sophia works as a model, so she has a little income from that work. She also practices taekwondo, too. Her mother, Danielle, said, "while other kids would want to spend this money on toys, Sophia said, 'No I want to help someone.'

Every day at the Center for Martial Arts and Fitness, Ken hopes to "transform the lives of children today, while instilling a respect for their parents and peers, making them strong, productive leaders for tomorrow." With each tournament, he also shows the world how to make a positive impact by weaving philanthropy into his work, too. Thank you for your generosity of spirit and heart. The world needs more men like you!

thank you to our 2020 facebook fundraisers:

1. Melanie Roder Pipkins
2. Emily Rose Paulson
3. Katie Hartke
4. Meg Storie
5. Kelly Turbeville Lemmonds
6. Connie Williams
7. Lisa Bowers
8. Torey Harrah
9. Nancy Penelopy
10. Samantha Faulkenburg Corbett
11. Alayna Christine
12. Michelle Marcus
13. Joel Brusk
14. Amelia Sanborn
15. Sam Miller
16. Alayna Ventimiglia
17. Laura Weber Kemp
18. Amanda Mason
19. Katie Whicker
20. Brock Hale
21. Maddie Cameron
22. Lindsay Walters
23. Robb (no last name listed)

how can you join

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 Fundraiser or CCA Fundraiser, etc
- Enter - **tell your audience why you are raising for CCA** (We already have a template 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!