

cca^e-network



e-newsletter of children's craniofacial association

2021: ISSUE 1

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Meet the Arnolds

by Jennifer Arnold

My name is Jennifer Arnold, and I live in Northern California with my husband Earl and our four kids, Henry, Lilly, Byron, and Chance. I was born with Otopalatodigital syndrome (OPD.) It's a rare genetic condition that affects less than 1 in 100,000 people. It's so rare that I had no idea there was even a name for it until Lilly was born in 2006 and diagnosed by the genetics team at UC Davis Children's Hospital.

OPD affects the ears, the hands, soft palate of the mouth, and the fingers and toes. It affects each person

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letter from the executive director



"We can do hard things"

There were a few phrases I really clung to last year. One was "We can do hard things." If you know me, you got that phrase a lot. I first heard this motto while taking the free trial classes on the Peloton app. Instantly, I was hooked (yes, on the phrase and the workouts). I resonated with the phrase so much that I used it in staff meetings, ordered about 200 stickers with the phrase on it, bought a t-shirt, said it to myself every time I found myself in an anxiety spiral, and cried-chanted it while doing **see we can, page 6** burpees.

Arnolds , from the cover continued

differently, and a common feature of OPD is a craniofacial condition called **Pierre Robin sequence**- a very small mandible (lower jaw). A small mandible can compromise breathing and often requires jaw surgery to correct. OPD also varies from person to person and is considered a "spectrum" disorder as some people have very mild cases and some are severely affected.

I have the unusual experience of having a craniofacial condition and also raising children with the same condition. I consider it a huge blessing. It's made me a better mother and allowed me to grow in ways that I never thought possible.

When I was born in 1972, my mom was forty-one years old. Back then, it was rare for women to have babies past the age of forty, and many of the issues I was born with were attributed to her age. Because of my small jaw and cleft palate, I had trouble feeding and could only handle an ounce or so of formula every hour. The doctors told my parents that I would probably not survive long, and if I did I would have all sorts of medical and developmental issues. One of them gently suggested that maybe I would be better off in an institution. My mom wasn't having any of that and firmly told them that she was taking me home, even if my future was uncertain.

I grew up in a small town on the outskirts of Boston, MA, and had a pretty "free-range" childhood.



My parents never assumed that due to my condition I would not be able to do anything. I think that was a blessing in disguise. Since they never had an official diagnosis, they didn't have any reason to believe I had any limitations. The only things I remember not being able to do were playing the violin and doing chin-ups in P.E class because I'm missing some bones in my wrists and can't fully rotate them. I was bummed about not being able to play the violin. The exercises in P.E class? Not so much!

I had a close circle of friends, most of whom I'm still in touch with today. I was aware that I looked different from other kids, but it was never really an issue until I reached my teenage years. Going through that awkward, hormonal phase is hard enough, but it makes you feel even more self-conscious when you have a noticeable difference. By this time, I knew that I had some sort of syndrome, although it would

be several years before they could pinpoint exactly what I had.

When I was fifteen, I had a jaw surgery called a bilateral sagittal split osteotomy, and although it boosted my self confidence, it was a pretty traumatic experience. My jaws were wired shut for a month, and I lived on a liquid diet even after the wires came out until I gained some strength in my jaw. It also took forever for the swelling to go down and the numbness in my face to go away, which meant I drooled- a lot. It's definitely not something a fifteen-year-old wants to have going on!

I went on to college and eventually a graduate program in Family Counseling, after which I took a leap of faith and moved across the country for a fresh start. A couple of years later, I met **Earl**, and before we were married, we decided to see a genetic counselor "just in case." I felt like I was back in high school biology class as the geneticist drew up some Punnett squares and took a lengthy medical history from both of us. We learned that I had a 50/50 chance of passing whatever condition I had onto our future children.

We were married in 2003, and in August of 2004, our first son, **Henry**, was born. Two years later, I was pregnant again and learned at a routine ultrasound appointment that we were having a little girl, and she most likely had the

Arnolds, from the cover continued

same condition that I did. Her jaw was noticeably small, and the bones in her forearms measured short. Even though I had mentally prepared myself for this ever since our genetic counseling session, it still hit me like a ton of bricks, and I had a good cry in the genetic counselor's office. We knew it was a possibility, but no one is ever really prepared for that type of news.



Lilly was born at the end of September 2006 and was immediately whisked away to the Neonatal ICU because of breathing issues. Her lower jaw was so small that her tongue was obstructing her airway. They were able to stabilize her, and I got to hold her for a little bit before she was airlifted to **UC Davis**- two and a half hours away from where we live.

Lilly had her first jaw distraction surgery when she was five days old, which was terrifying. The thought of my tiny, brand new baby being put through such an

invasive surgery was overwhelming, and I kept running through everything that could go wrong over and over in my head. I was also just five days post-partum and hormonal as hell, so that didn't help matters.

It was a much different type of surgery than mine, although the goal was the same- to bring the lower jaw forward so her airway wouldn't be compromised. While my surgery involved breaking my jaw and moving it forward in one done deal, hers involved turning pins in the surgically placed distractors in her jaw. For several weeks, we turned the pins each day until her jaw was in the correct position. It was during that time that I first heard the words "Otopalatodigital syndrome." While most parents might dread getting a diagnosis like this for their child, I was relieved because now I had an actual name for our condition.

Lilly ended up staying in the NICU for three months. In addition to her cleft palate, she had severe reflux, which resulted in significant feeding issues. She couldn't take a bottle and breathe



properly at the same time, and she would end up vomiting up whatever she managed to get down. Because of this, she wasn't gaining weight. She eventually had a G-tube placed and was able to come home a few days before Christmas. Our little apartment looked like a mini-hospital suite with all of her medical equipment and supplies. It was a huge adjustment, but after a few months, we settled into a routine, and the tube feedings, beeping machines, and the endless doctor and therapy appointments became our norm.

In 2009 we welcomed **Byron** into our family, and two years after that, I became pregnant with **Chance**. Since we now had an official OPD diagnosis, Chance was diagnosed during my 20-week ultrasound, as his jaw and arms were also measuring small. I chose to have a scheduled C-section at **UCDavis** since it was pretty much a given that he would spend some time in their NICU after birth. It wasn't until after he was born that we realized his condition was much more severe than Lilly's.

His lower jaw was so small that he wasn't a good candidate for distraction surgery right away, so he had a tracheostomy tube placed at two days old. When he was four days old, he went into acute respiratory failure. He was retaining carbon dioxide, and no one knew why. He was placed on an **Extracorporeal membrane oxygenation (ECMO)** machine in the hopes that it would allow his



lungs to rest and heal. We were given a grim prognosis and no guarantees that he would survive. Being the fighter he is, he was able to come off ECMO a week later, but he spent a total of four months in the NICU after contracting a staph infection in his lungs and having multiple feeding issues. He also came home with a feeding tube, a diagnosis of chronic lung disease, and just like Lilly—a room full of medical equipment and supplies. The first few years of his life, he spent at least two weeks a year in the pediatric intensive care unit with pneumonia or RSV, and much of that time was spent on a ventilator. As he became more mobile, his health became more stable, and we've been fortunate these last few years with less frequent respiratory illnesses and hospitalizations.

He had his first jaw distraction when he was a year old, and he and Lilly both had their second jaw surgery on the same day in 2015. The surgeons spent over 12 hours in the operating room doing back-to-back surgeries on our kids. That was their last major surgery. I've lost count of the smaller procedures they've had, such as ear tube placement, dental procedures, and bronchial scopes. They've both had cleft palate repairs, and Lilly has had surgery to separate two fingers that were fused on one hand. Lilly still has her feeding tube, but Chance had his removed just before turning three and now eats more than his two older brothers combined.

Bullying is definitely an issue when you have a facial difference, and I've experienced my fair share through the years. Now that I have two kids with significant facial differences, I'm getting to experience bullying behavior from

a parent's perspective, and I can tell you it is a million times harder than

experiencing it first hand. Luckily the intentionally rude comments have been few and far between. We generally get more stares than anything else. I've found that most people are genuinely curious. I'm always open to questions -- even the blunt ones, and it's been my experience with younger kids that once you answer their questions, they'll be satisfied and move on.

Another thing that people with craniofacial conditions have to contend with is the presumption of competence.



Arnolds, from the cover continued

Unfortunately, there is still the assumption that looking different somehow affects your intelligence and ability. I've been talked down to and patronized more times than I care to remember. To me, that's just about as insulting as the rude comments or stares. When explaining our condition to other people, especially kids, I strive to show more similarities than differences. Chance is active, loves playing video games like Mario and Minecraft, and would eat candy for breakfast, lunch, and dinner if we allowed him. Lilly loves pop music, all things pink and glittery, and her favorite food is the strawberry shakes from In-n-Out.

I would never have imagined several years ago that I would be so outspoken. I had a significant speech impediment when I was young, and I was also painfully shy. Not just the "quiet" type of shy. I was the "hide behind my mother's legs when



people tried to talk to me" type of shy. My speech improved after years of speech therapy, but I've always felt more comfortable expressing myself through writing. I love to write so much that I turned it into a career. I write for a regional parenting magazine and recently started my own copywriting business. I also came out of my shell socially as I grew older, and after Lilly and Chance were born, I found my voice as an advocate for them. I've surprised myself when the "mama bear" claws have come out a few times. Hell hath no fury like a mom of a medically fragile child who is fighting for her kid's fundamental needs and rights.

When I was growing up, I didn't know anyone else with a facial difference. When I was older and officially diagnosed with OPD, I wondered if I'd ever find anyone with the same diagnosis. I spent a good chunk of time after Lilly was born searching the internet for answers, but because OPD is so rare, they were few and far



between. It took several years, but thanks to the power of the internet and social media, I not only found several people with OPD, but I also discovered the **Children's Craniofacial Association (CCA.)** Having a community of people that understand you in a way that no one else can is priceless.

Lilly and Chance have many challenges, some of which are related to OPD and some of which are not. Lilly is diagnosed with an intellectual disability, autism, and is mostly non-verbal. Chance, on the other hand, is very verbal. He has some developmental delays and still has his trach due to sleep apnea. He'll most likely have it until he can tolerate a CPAP machine or his sleep apnea improves. Despite all these challenges, they continue to amaze us every day and have taught me more already than I could ever hope to teach them. 🧡



We can, from the cover continued

Shortly thereafter, I learned that this mantra can be traced back to the book **Untamed**, by **Glennon Doyle**. I knew I liked her from the “we can do hard things,” moment, but there’s one other precept that might have struck an even-deeper chord with me. It was her sentence,

There's no such thing as other people's children.

Oof. I had to read it several times, and then just sit there a moment in awe of that concept.

You see, I know I am guilty. And you probably are too... it’s little things like the side-eye we shoot kids running wild through the store. The ones we can change the channel on when the sad commercial comes on. And it’s the big things... like knowing that currently, there are about 400,000 kids in foster care in the U.S.

We ignore those kids – and their parents – because we have our “own” families. We can’t bring meals to hungry kids down the street, because our kids (or nephews, or grandkids, or friends’ kids) take priority in our lives. I get it. We see our kids, we love our families, and they are in proximity to us, so it’s natural that “charity begins at home.”

But what I’m saying is we can’t stop there, just taking care of those with whom we share a bloodline. We have to be willing

to see that Doyle says, “What if we used our [...] love less like a laser, burning holes into the children assigned to us, and more like the sun, making sure all kids are warm?”

We can all do some analysis on the energy and resources we spend on the people in our life. Are we focusing too much attention and borderline obsessing about something good or bad in our immediate circle? Perhaps some of that energy can be redirected to see the needs of children out there who are struggling.

The pandemic has brought many inequities to light. It is time that we, both at CCA and as individuals, realize that we can’t just take care of “our kids.” All kids are our kids.

At CCA, that means refocusing on the families who get less attention. Those who perhaps don’t self-select into large groups or events, like Retreat.

It means being more intentional about providing emotional support opportunities for everyone, not just families who can travel. Now more than ever, we can reach people where they are with virtual programming.

It means that our #ChooseKind program is all the more relevant. We are not just serving the craniofacial community, we are starting a revolution of self-acceptance, diversity-awareness, and inclusivity, in students across the country.

Being and choosing kind is a nice phrase, but it’s also a radical concept. If we really want to put kindness in action, we need to periodically ensure that kindness is delivered where it is most needed, not just those who are the easiest. Sometimes, to be sure, your best friend needs a listening ear. But sometimes, we need to listen to the voices of people beyond us, different than us, and really honor the requests they make, and those pleas that go unspoken.

It is hard to wrap this note up with a poetic bow, but because we can do the hard things, we can take care of all children. There is no “other” in an inclusive, kind world. We are all in this together, and together we rise.

Thank you,

Erica Klauber

Erica (Mossholder) Klauber
CCA’s Executive Director

#WE
CAN DO
HARD
THINGS



enjoy interacting with fun people a lot like me.

I've taught my family more than a few life lessons. Perhaps most importantly, no matter what life has thrown at me, I always find the time to smile. If you'd like to connect or hear what I'm up to, you can find me at on [Facebook](#) and [Instagram](#).

Thank you, CCA, for allowing me to say "hello!" 🐶

my name is **Hadley Rose** and I'll be turning 5 later this year. I was born with **Pfeiffer syndrome** and have since been diagnosed with cerebral palsy. I like playing with my brothers as they crack me up, enjoy silly sounds and music, and love dressing my cutest on a daily basis. My faithful golden doodle, **Bo**, is usually at my side and while he may make "doggie chew toys" out of my brothers, he's always sweet to me. I am fortunate to have grandparents that live

very close by and spend as much time as I can with my BFF Grammy who pushes me around in my carriage and loves me without limits.

My parents feel fortunate for the community fostered by CCA. To have access to families that listen, share, and empathize is a tremendous comfort when navigating something both unexpected and challenging.

As for me, I like CCA because I



ccakid



ccasupersibs

meet oliver

greetings! My name is **Oliver** and I hope you'll find me intriguing. I'm eleven years of age and hail from the great state of Florida. My interests include using my microscope (I own some fascinating slides), etymology, and playing video games. I am an active Boy Scout in Troop 225, and I enjoy helping people.

My sister **Hadley** has **Pfeiffer syndrome**, and I'm grateful for how welcoming CCA is. When she was born, I knew nothing about craniofacial disorders, but over time, I've learned quite a bit. I enjoy reading books to Hadley, as well as helping with more strenuous things like lifting and carrying things for her. For certain, I love and care for her deeply, and would not know what to do without her. In the future, I plan to raise more awareness for kids like Hadley, and I look forward to pursuing the Boy Scout Disability Awareness Merit Badge.

Sincerely,
Oliver Lund



meet micah

hi, my name is **Micah** and I am 9 years old and in the third grade. Some of my hobbies include swimming, art, and drama. I live in Orlando, FL. My mom likes to call me a gentle giant. I always try to make everyone



laugh. I am active in the cub scouts and my favorite event is the pinewood derby.

What is it like to have a sister like Hadley?

Hadley is special because she's sweet, playful, and unique. I

help Hadley by carrying her equipment, playing with her, and picking out her outfits and bows. I call her "girl girl" or "princess" and she smiles at me. Sometimes, I read books to Hadley or bring her toys. I can't wait for the pandemic to be over so that we can go to CCA retreats again. Our first one was Scottsdale, AZ and it was a lot of fun. 🌈



2021 Retreat Cancellation

dear Children's Craniofacial Association community,

We have made the difficult decision, once again, that it will be impossible for us to hold the Children's Craniofacial Association's Annual Family Retreat and Educational Symposium scheduled at the Hyatt Regency Minneapolis from June 23-27, 2021.

We did not make this decision lightly. CCA, like the rest of the world, hoped a COVID-19 vaccine would return our lives to some semblance of normalcy by June 2021. However, it is now quite clear to us that this is not a realistic timeline, and consequently, the Board of Directors has decided unanimously that we are unable to safely host the in-person retreat.

We regret having to make this decision and have deliberated options for months. With this said, please do not lose hope! We have in the works a bigger and better Virtual Family Retreat for our families. For 2021, we will shorten the number of days and length of sessions to prioritize small-group discussions and breakouts. We will include lots of new fun, too, like breakfast with Zoo animals, plus retain our favorites like, CCA's Got Talent and a Dinner/Dance, with enhanced audio-visual capabilities.

All of the planning is just at the beginning stages. Stay tuned for a full schedule of events and registration, but save the date for June 25-27, 2021! Finally, we are enthused about sending "welcome boxes" to each family that registers. The box will contain special goodies to make it feel like we're together.

It's not what we hoped for, but we promise to make this a special weekend. Remember, YOUR presence and participation will make it a remarkable, memorable weekend for our CCA Family. Sincerely,

Erica Klauber

Erica (Mossholder) Klauber

CCA's Executive Director

2nd Virtual Retreat

GROUP
MEET UPS WITH
FAMILIES
ACROSS THE
GLOBE

VIRTUAL ZOO

TALENT
SHOW



FAMILY
FUN



Save
the
date

JUNE 25TH-27TH
2021

APRIL
1ST

Registration
Opens

JUNE
1ST-20TH

Retreat
Boxes
Arrive

JUNE
25TH-27TH

Virtual
Retreat



meet vanessa

The traffic was tedious. Several doctors entered the patient room for observation. Shy, hidden behind the curtain, afraid to speak, filled with anxiety, stood a young girl. A group of doctors, students and residents; ranging from audiologist to speech therapist to psychologists entered the exam room for my yearly follow-up. My diagnosis is **hemifacial microsomia**.

University of California Los Angeles healthcare system provided and continues to provide exceptional care! For this I am forever grateful. This is the day I became determined to pursue a career in mental health.

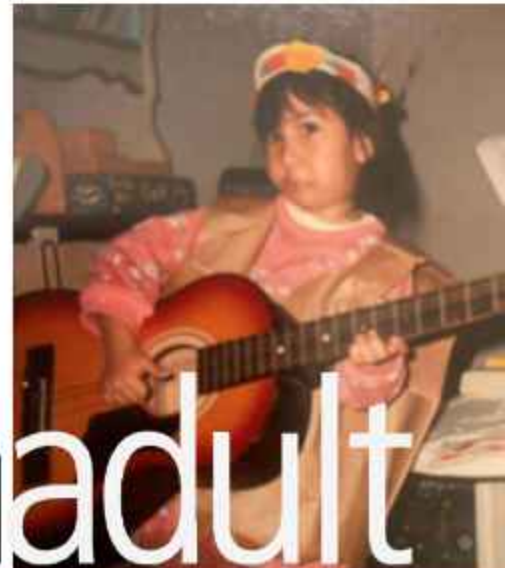
My name is **Vanessa Acero, PsyDC, M.S., APCC**. I was born

and raised in Southern California by two loving parents. I am the oldest of three children. I have two younger siblings. My family always allocated time for game nights, vacations and quality time. Some of my fondest memories as a child include waiting for my dad to come home from work to play hide and seek, beach days with my mom and stories at bedtime.

My journey hasn't always been easy. Loving myself every step along the way hasn't been easy. I've had two rib bones graphed into my jaw (first graph was rejected), several fat injections for face symmetry, bone stretching of the jaw and more. My fears overwhelmed me. I know what it's like to feel physical pain post-op. To experience emotional pain, and pre-surgery worries consumed my mind; "why me?"

At the age of 7, I recall having a retainer (that kept my mouth wired shut) for weeks in order to retain the new bone structure. My diet consisted of liquids, pudding and soft blended foods. I recall looking forward to being "Post-Op": my attire consisted of a hooded sweatshirt, scarf and sunglasses. Roaming the shops in Westwood, CA and drinking a Boba tea felt so comforting.

Throughout my educational endeavors, I attended a public school system. It wasn't hard to notice that I "looked" different than my peers. Being raised in a small town had many benefits, including small class sizes and hometown comforts. Beginning in Pre-K at the age of 3 until midway into high school, I struggled with selective mutism. This posed many challenges navigating through presentations, asking questions, and building atypical relationships. I had friends. However, feeling alone and isolated was always an ongoing struggle. Feeling validated and accepted and wanting to speak out loud felt so distant.



ccaaadult

vanessa, from the cca adult



Going into high school I underwent a depressive episode. I struggled to get out of bed and rarely found joy in daily activities. It became challenging to find direction and hope. My parents helped me find support to overcome my depression. With lots of work and dedication, I found my center self.

After high school, I completed my undergraduate studies with a **B.A. in Psychology**, holding on to the goal of helping in the mental health community. College

was fun. I made friends, worried less to little about what people thought of me and became active in campus organizations. After my under-graduate studies, I took some time to focus on my personal growth. I focused on self-love, fitness, and explored my personal passions. I then resumed my academic journey focusing on grad school and doctoral studies.

During my free time I enjoy going to the beach, trying new restaurants and spending time in nature. I work at an outpatient mental health clinic providing trauma-based psychotherapies and clinical assessments. My mission is to help others and give back globally.

*Today I live my dreams.
My dream job.
My amazing support
system.
Ownership & self-love.*

Lastly,
Our differences shape who we are. Embrace individuality.

Healing isn't always linear.
Never give up.

Warmly,
Vanessa Acero



Camp Cosmos | ConnectMed & CCA

by Annie Reeves

On December 11th and 12th, CCA and ConnectMed teamed up for a weekend of Camp Cosmos fun!

The weekend kicked off Friday night with CCA providing a virtual screening of "Wonder", starring **Jacob Tremblay**, **Julia Roberts**, and **Owen Wilson**! Everyone grabbed their movie snacks, blankets, tissues and a comfy spot to gather and watch this heart warming movie.

Saturday was a full day of fun which started with a Career Roundtable presented by CCA. We had four amazing women discussing education, work and careers. Each of these ladies come from different work backgrounds so it was quite inspiring to hear their stories. Thank you to **Lia Burton**, **Casey Deakins**, **Bianca Moon** and **Erin**



Richmond for sharing and for all of your wonderful suggestions and feedback.

Following the Roundtable discussion, **ConnectMed** kicked off their **Holidays with Camp Cosmos**. They had lots of fun activities lined up for the families such as a team trivia game which was run by **Trivia Hub**, a scavenger hunt, theater games led by **Robert Wagner**, a special reading of "Mandy Monkey and the Mirror" which is a book about self-confidence and inner beauty, written by **Amanda Rose Jacobik**, arts & crafts and more!



Peter Dankelson and his Mom, **Dede Dankelson** were guest speakers. Peter shared some of his journey with the families and wow'ed us with his guitar playing skills! After this epic jam session, the parents gathered for group discussions with **Dr. Azmaira Maker, Ph.D** and **Cashel Gaffey, MSW**.

It was wonderful seeing so many familiar faces and meeting new families as well! We were truly honored to be a part of ConnectMed's Holiday event and would like to thank **Rita Albert**, **Cashel Gaffey**, **Valeria Restrepo**, **Dr. Azmaira Maker**, **Dr. Amanda Gosman** and everyone involved in planning this wonderful event.

We look forward to working together on future events!



tributes to robin williamson



PEOPLE COME INTO OUR LIVES FILLED WITH ALL THE COLORS OF THE RAINBOW. THEIR GREATEST GIFT IS SHARING THEIR COLOR AND LIGHT WITH OTHERS, MAKING OTHERS STRONGER, HAPPIER, AND MORE VIBRANT.

ROBIN WILLIAMSON WAS ONE OF THOSE COLOR-FILLED PEOPLE. GIVE HER PAPER, PENCIL, A COMPUTER, OR FABRIC AND SHE COULD TURN IT INTO A MASTERPIECE.



ROBIN WAS A DEDICATED LEADER FOR CCA. SHE SERVED ON THE BOARD OF DIRECTORS FOR OVER TWO DECADES, SERVED IN EVERY ROLE AS AN OFFICER, CREATED OUR ENTIRE DESIGN PORTFOLIO, INCLUDING THE CCA LOGO AND ALL OF OUR PRINT MATERIALS, OUR SYNDROME BOOKLETS, EDUCATIONAL OVERVIEWS, AND CCA NETWORK NEWSLETTERS. ROBIN PASSED AWAY FROM METASTATIC BREAST CANCER ON DECEMBER 23, 2020. WE HAVE GATHERED

SOME TRIBUTES FROM THOSE THAT WORKED CLOSEST WITH ROBIN AND TRULY APPRECIATED AND BENEFITTED FROM THE LOVING WORK SHE SHARED WITH US AND OUR CCA COMMUNITY.



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page 31

c c a artist

by Kara Jackman

meet joshua

"I cannot change myself, but I can change something about this."

Rembrandt, Caravaggio, and Lucian Michael Freud lit the way for artist, **Joshua Gale**, to a better more fulfilling life. Sand, a humble surgical tray, and his fingers turned these positive influences into action.

Well, maybe it wasn't all that poetic.

Josh was born with **hemifacial microsomia** in 1984. He had early surgeries to repair his cleft lip and palate, along the right side of his lip and oral cavity. At five years old, he had a jaw surgery which took bone from his fifth rib on the right side to fortify the jaw. His mouth was wired shut for many weeks after to allow the jaw to set. It was during this hospital stay that he yearned for something to tune his attention to the present moment. This is when he began his lifelong career as an artist.

"As a kid, drawing is something fun. It allowed me to focus on the here and now, and be in the moment and forget about the pain." On a surgical tray, filled

with sand, sitting on a bedside table in the hospital was where he made the first of many masterpieces. He sought peace, but found his calling.

Josh reflects back on that moment now and says about this first creation, "I cannot change myself, but I can change something about this," meaning the sand on the tray in front of him. "Through play, you are able to come to grips with things in your mind and in your present reality. Drawing and painting was an escape; it was a way to understand the moment, and process the feelings I was experiencing: so much turmoil, fear, anxiety."

This artist has natural talent. At nine years old, Josh began playing around with pastels and charcoal. His early work features sketches of images, photos, or items in his room. To this day, he has a skull on his desk to draw and sketch. As a teenager, his classmates realized his talent, and asked him to draw everything from superheroes to supermodels. His friends would pay him for his work. Pastels were his favorite medium because, as he says, "you can use your fingers to blend them. I loved the tactile feeling." Only a few years later, after being paid for his work, did he consider going to school for art, and making a living at it.

Not all of Josh's time was spent in pursuit of the visual arts. Thanks to his father, a carpenter, he also enjoyed the



outdoors: riding around on various vehicles down country roads, hunting, fishing, and exploring the wilds of Western Massachusetts. These positive encounters with art and nature influenced Josh, providing him with a counter balance to the scary, institutional world of the hospital. He reflects, "My days were spent outside playing, doing fun things, and that was always sandwiched with the hospital world and big buildings."

In school, the classroom environment was difficult for him, too,





as he fought hard to overcome dyslexia, a learning difference, that jumbles words and makes it tough to read and write. In grade school, "After recess, we had these blank books where you were supposed to write. I would just draw. **There is so much about ourselves that we cannot change. Yet, we do have control over what we put on that blank page. That was a huge lesson in creating for me.**"

The teachers did not appreciate Josh's perspective, so he went to a small, vocational school called Franklin County Technical School, where he was able to split his time between vocational education and receiving assistance with reading and writing. Teachers there were very aware of his intellect. One special teacher, Ms. Judy Cummings, got through to Josh, putting a university education on the table. "I had an amazing teacher at Franklin County Tech, Ms. Cummings. I was in the special resource room, where Ms. Cummings was the teacher. I had a tough time laying out ideas on paper, but when I was able to dictate something it came out excellent, so much so that I was accused of plagiarism. This teacher championed me. 'This kid

is brilliant, talented,' she said. Ms.Cummings and my Aunt Anita, were the ones that encouraged me to go to college. They really helped me out."

Josh reminiscences about his peer interactions at Franklin County Tech, by sharing this, "In my early teens, 13 and 14 years old, I still got picked on sporadically. However, I developed enough sensibility to be funny, a comedian, and to be positive on the outside, even if I didn't feel positive on the inside."



After middle and high school years of what Josh describes as "great pockets of happiness where I felt like I was doing the right things, moving in the right direction," he graduated high school at 19 years old. He then applied and was accepted to a Western Massachusetts community college where he took art, psychology, and wellness

classes. At community college, he painted with oils for the first time. This medium really pushed him out of his comfort zone. "I wish I could be happy painting cows and landscapes, but I always seemed to want to go to the darkest parts of myself. I guess so all of the pain and suffering I experienced will have not been for nothing."

The hope was that his two years at community college would help prepare him for a four-year degree program at Mass College of Art and Design, but unfortunately, it did not go as planned. Classically trained, and naturally talented, Josh's style did not jive well with his fellow students at MassArt. His short time at MassArt was very dark, and riddled with drug addiction, but triumphantly, he kicked the habit just blocks from the school that proved a poor fit for him.

He says this formalized education was not a good match





for him. "When I went to school to learn how to do this [art], you learn about the concepts of light, volume, scale, and how it all works. Going to school demystifies the magic of art, and it can be sad. After my time in Boston, art lost its wonder."

Newly released from the chains of addiction and after a brief stint living south of Boston, Josh looked to New York City for his next academic adventure. His dear friend, Tyler Vouros, brought him to visit the New York Academy of Art where he found a home, friends, and a following. Without Tyler's artistic intervention, Josh says, "I don't think I would have done half the things I've done."

"The people at the Academy were honest about what they did and created. I treated everyone the same, from the janitor to my classmates and teachers. I definitely had more in common with the janitor, though. Many called me the mayor of the

school." With his capacity to bring people together, he launched many art shows. Josh remembers, "I put together my own art show, down the road from the Barclays Center in Brooklyn. I received no help from the school, did it all on my own. I would just talk to people in a bar and make plans to do stuff." Creating art shows and bringing people together in the New York's art world is no easy feat. Josh

says, "Nobody wants to actually work together. No one cares about you and your artwork. The only people that care are other artists. I was influential in getting people to care and bringing them together."

Josh had a prolific period when in Manhattan. He painted stunning portraits of himself, friends, and girlfriends. All of his works sold and many are held



Joshua, continued from cca artist

in private collections. "Nothing is good enough for me. I always feel like I can make it better. I spent a lot of time destroying what I created. And I don't have images of pieces I sold."

Though it did not meet the creators' standards, enthusiasts and friends like actor, **Kevin Corrigan**, and New York art collector and philanthropist, **Josh Rechnitz**, would disagree, as both of these gentlemen own paintings by Joshua Gale.

After graduating from **New York Academy of Art**, Josh began teaching at **Franklin Pierce University in New Hampshire**. He had great empathy and rapport with his students because of the difficulties he faced with dyslexia as a boy and adolescent. He found new and better ways to teach students because of the experiences he had in school. Now after being a student and a teacher Josh says, "I am starting to rethink how I approach drawing and painting. While drawing, you're observing and interpreting something outside of you through your own eye. You are working through the object with pencil, or a paintbrush. It makes the artist exist in the here and now, grounding you in reality. Art focuses you back to the present, and invites the viewer to look inwards at themselves."

Josh feels that art making is the best therapy for himself, children, and adults. He says, "There is a kid that lives inside all of us and depending on what happened to that kid, in my case incredible

amounts of trauma, there is much to process. Therapy will never touch as deeply as a kid with a bunch of paper and pencils with an art teacher in the room to tell them how the tools before them are used. In the act of drawing and painting, it may be years before you truly understand what is going with your inner child, but over time the perception of the art you create will bring increased awareness." This is the process of better understanding one's self.

Through examples, Josh brought clarity to this notion, he showed me two pieces he created when he was 15 years old. He held them up and said, "Clearly, I was working through some stuff." One was a self portrait and another was of Michael Myers from the Halloween film series. Twenty years ago he was just creating something, today he sees that 15-year-old Josh was in a lot of pain.

"The inner child, the subconscious is always there. **Through drawing, I found meaning in the chaos. Drawing and painting is just one way to untangle that chaos.**"

For aspiring artists, Josh dispenses the following advice, "Gather paper, different colored pencils, charcoal, pastels, and even paints. Try not to think about all the color you are wasting and whatever may be making you anxious. Draw from life, or have an object, or image in front of you to recreate. For instance, on my table I have a model of a skull to draw." Another thing to note is the physical



joshua, continued from cca artist

experience of drawing and painting. Recently, Josh painted the walls of his home and remarked that just the "act of painting is very soothing with many components to that one motion." Break down the components of your pencil marks, and brushstrokes, and you may just find inner peace like the talented Mr. Gale. 🎨

See examples of Josh Gale's artwork on Instagram at [@joshuajgale](https://www.instagram.com/joshuajgale).



11th Annual Gingertown

by Christine Andler

The 11th Annual Gingertown raised nearly **\$10,500**, in a year where we couldn't comprehend at times how we could even pull off a version of this event! Thanks to **RJ Reissig** and the dedicated **Design and Construction Team at NorthPark**, who helped us reinvent this important fundraising event without hesitation. They never said "sorry, we can't help this year", instead, they helped us figure out a way to make an impact, we hope to maintain the momentum of this amazing partnership for years to come.

The reimagined event was a social distancing safe online sweepstakes, which ran for two weeks, with the opportunity to win thousands of dollars in prizes. Thanks to donations from **NorthPark** retailers and some friends of CCA. An extra special thank you to **Massimiliano Tosi**, from the newly opened **Eataly Dallas at NorthPark** for creating most of the amazing packages available for the sweepstakes. They

were truly priceless experiences!

Historical Gingertown Participants, CCA families and the DFW Community purchased tickets for the opportunity to

win one of the many luxury packages and prizes. "The Gold Standard" was graciously donated by NorthPark Center and individual team members of the NorthPark Design and Construction team to create **\$1,500 in NorthPark Gold**, which never expires and can be used at any of NorthPark Center's 200 best-in-class boutiques and restaurants. The "Eataly Grand Prize" valued at over **\$1,200** was a full immersion into the new Eataly Dallas at NorthPark Center store through a private tour, dinner and merchandise to take home.

A show stopping, one-of-a-kind, 26.8-carat Honey Citrine necklace was donated by one



of CCA's loyal friends, **Denny Bradley**. Other prizes included: Dinner for Four at **Terra by Eataly**, Dinner for Four at **Eataly's La Pizze e La Pasta Restaurant**, Two VIP Virtual Santa Visits to "e-meet" the famous **NorthPark Santa**, a one-hour photography session by CCA friend, **Smith Reissig**, from **Everything Smitten**, Vertuo Next **Nespresso** machine, "Behind the Scenes" at Eataly Dallas at NorthPark Center tour, and two special gift boxes from Eataly Dallas at NorthPark.

Thank you and "Grazie" to all those who helped to make Gingertown 11 a huge success in a year of so much uncertainty. We are optimistic for an amazing build in December 2021 as we celebrate the 12th year of this amazing event! 🎉

what siblings would like parents and service providers to know

Emily Holl, Director • Sibling Support Project
A Kindering Program, Bellevue, WA

In the United States, there are over 4.5 million people who have special health, developmental, and mental health concerns. Most of these people have typically developing brothers and sisters. Brothers and sisters are too important to ignore, if for only these reasons:

- These brothers and sisters will be in the lives of family members with special needs longer than anyone. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.
- Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.

Despite the important and life-long roles they will play in the lives of their siblings who have special needs, even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters, often left in the literal and figurative waiting rooms of service delivery systems, deserve better. True “family-centered” care and services will arrive when siblings are actively included in agencies’ functional definition of “family.”

The Sibling Support Project facilitated a discussion on SibNet, its online group for adult siblings of people with disabilities, regarding the considerations that siblings want from parents, other family members, and service providers. Below is a discussion of themes discussed by SibNet members and recommendations from the Sibling Support Project:

1. **The Right to One’s Own Life.** Throughout their lives, brothers and sisters may play many different roles in the lives of their siblings who have special needs. Regardless of the contributions they may make, the basic right of siblings to their own lives must always be remembered. Parents and service providers should not make assumptions about responsibilities typically developing siblings may assume without a frank and open discussion. “Nothing about us without us”—a phrase popular with self-advocates who have disabilities—applies to siblings as well. Self-determination, after all, is for everyone—including brothers and sisters.
2. **Acknowledging Siblings’ Concerns.** Like parents, brothers and sisters will experience a wide array of often-ambivalent emotions regarding the impact of their siblings’ special needs. These feelings should be both expected and acknowledged by parents and other family members and service providers. Because most siblings will have the longest-lasting relationship with the family member who has a disability, these concerns will change over time. Parents and providers would be wise to learn more about siblings’ life-long and ever-changing concerns.
3. **Expectations for Typically Developing Siblings.** Families need to set high expectations for all their children. However, some typically developing brothers and sisters react to their siblings’ disability by setting unrealistically high expectations for themselves—and some feel they must somehow compensate for their siblings’ special needs. Parents can help their typically developing children by conveying clear expectations and unconditional support.

© 2020 children’s craniofacial association

4. **Expect Typical Behavior From Typically Developing Siblings.** Although difficult for parents to watch, teasing, name-calling, arguing and other forms of conflict are common among most brothers and sisters — even when one has special needs. While parents may be appalled at siblings' harshness toward one another, much of this conflict can be a beneficial part of normal social development. A child with Down syndrome who grows up with siblings with whom he sometimes fights will likely be better prepared to face life in the community as an adult than a child with Down syndrome who grows up as an only child. Regardless of how adaptive or developmentally appropriate it might be, typical sibling conflict is more likely to result in feelings of guilt when one sibling has special health or developmental needs. When conflict arises, the message sent to many brothers and sisters is, "Leave your sibling alone. You are bigger, you are stronger, you should know better. It is your job to compromise." Typically developing siblings deserve a life where they, like other children, sometimes misbehave, get angry, and fight with their siblings.
5. **Expectations for the Family Member with Special Needs.** When families have high expectations for their children who have special needs, everyone will benefit. As adults, typically developing brothers and sisters will likely play important roles in the lives of their siblings who have disabilities. Parents can help siblings now by helping their children who have special needs acquire skills that will allow them to be as independent as possible as adults. To the extent possible, parents should have the same expectations for the child with special needs regarding chores and personal responsibility as they do for their typically developing children. Not only will similar expectations foster independence, it will also minimize the resentment expressed by siblings when there are two sets of rules—one for them, and another for their sibs who have special needs.
6. **The Right to a Safe Environment.** Some siblings live with brothers and sisters who have challenging behaviors. Other siblings assume responsibilities for themselves and their siblings that go beyond

their age level and place all parties in vulnerable situations. Siblings deserve to have their own personal safety given as much importance as the family member who has special needs.

7. **Opportunities to Meet Peers.** For most parents, the thought of "going it alone," raising a child with special needs without the benefit of knowing another parent in a similar situation would be unthinkable. Yet, this routinely happens to brothers and sisters. Sibshops, online groups such as SibNet, Sib20, and SibTeen, and similar efforts offer siblings the common-sense support and validation that parents get from Parent-to-Parent programs and similar programs. Brothers and sisters—like parents—like to know that they are not alone with their unique joys and concerns.
8. **Opportunities to Obtain Information.** Throughout their lives, brothers and sisters have an ever-changing need for information about their sibling's disability, and its treatment and implications. Parents and service providers have an obligation to proactively provide siblings with helpful information. Any agency that represents a specific disability or illness and prepares materials for parents and other adults should prepare materials for siblings and young readers as well.
9. **Siblings' Concerns about the Future.** Early in life, many brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Ways parents can reassure their typically developing children are to make plans for the future of their children with special needs, involve and listen to their typically developing children as they make these plans, consider backup plans, and know that siblings' attitudes toward the extent of their involvement as adults may change over time. When brothers and sisters are "brought into the loop," and given the message early that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. For their own good and for the good of their siblings who have disabilities, brothers and sisters should be afforded the right to their own lives. This includes having a say in whether and how they will be

involved in the lives of their siblings who have disabilities as adults, and the level, type, and duration of involvement.

10. **Including Both Sons and Daughters.** Just as daughters are usually the family members who care for aging parents, adult sisters are usually the family members who look after the family member with special needs when parents no longer can. Serious exploration of sharing responsibilities among siblings—including brothers—should be considered.
11. **Communication.** While good communication between parents and children is always important, it is especially important in families where there is a child who has special needs. An evening course in active listening can help improve communication among all family members, and books, such as *How to Talk So Kids Will Listen and Listen So Kids Will Talk* and *Siblings Without Rivalry* (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.
12. **One-on-One time with Parents.** Children need to know from their parents' deeds and words that their parents care about them as individuals. When parents carve time out of a busy schedule to grab a bite at a local burger joint or window shop at the mall with their typically developing children, it conveys a message that parents "are there" for them as well and provides an excellent opportunity to talk about a wide range of topics.
13. **Celebrate Every Child's Achievements and Milestones.** Over the years, we've met siblings whose parents did not attend their high school graduation—even when their children were valedictorians—because the parents were unable to leave their child with special needs. We've also met siblings whose wedding plans were dictated by the needs of their sibling who had a disability. One child's special needs should not overshadow another's achievements and milestones. Families who seek respite resources, strive for flexibility, and seek creative solutions can help assure that the accomplishments of all family members are celebrated.
14. **Parents' Perspective is More Important than the Actual Disability.** Parents would be wise to remember that the parents' interpretation of their child's disability will be a greater influence on the adaptation of their typically developing sibling than the actual disability itself. When parents seek support, information, and respite for themselves, they model resilience and healthy attitudes and behaviors for their typically developing children.
15. **Include Siblings in the Definition of "Family."** Many educational, health care, and social service agencies profess a desire to offer family-centered services but continue to overlook the family members who will have the longest-lasting relationship with the person who has the special needs—the sisters and brothers. When brothers and sisters receive the considerations and services they deserve, agencies can claim to offer "family-centered"—instead of "parent-centered"—services.
16. **Actively Reach Out to Brothers and Sisters.** Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, IEP, IFSP, and transition planning meetings, and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make positive contributions to the child's team.
17. **Learn More About Life as a Sibling.** Anyone interested in families ought to be interested in siblings and their concerns. Parents and providers can learn more about "life as a sib" by facilitating a Sibshop, hosting a sibling panel, or reading books by and about brothers and sisters. Guidelines for conducting a sibling panel are available from the Sibling Support Project and in the Sibshop curriculum. Visit the Sibling Support Project's [website](#) for a bibliography of sibling-related books.
18. **Create Local Programs Specifically for Brothers and Sisters.** If your community has a Parent-to-Parent Program or similar parent support effort, a fair question to ask is: why isn't there a similar effort for the brothers and sisters? Like their parents, brothers and sisters benefit from talking

with others who “get it.” Sibshops and other programs for preschool, school age, teen, and adult siblings are growing in number. The Sibling Support Project, which maintains a database of over 450 Sibshops and other sibling programs, provides training and technical assistance on how to create local programs for siblings.

19. Include Brothers and Sisters on Advisory Boards and in Policies Regarding Families.

Reserving board seats for siblings will give the board a unique, important perspective and reflect the agency's concern for the well being of brothers and sisters. Developing policies based on the important roles played by brothers and sisters will help assure that their concerns and contributions are a part of the agency's commitment to families.

- 20. Fund Services for Brothers and Sisters.** No classmate in an inclusive classroom will have a greater impact on the social development of a child with a disability than brothers and sisters will. They will be their siblings' life-long “typically developing role models.” As noted earlier, brothers and sisters will likely be in the lives of their siblings longer than anyone—longer than their parents and certainly longer than any service provider. For most brothers and sisters, their future and the future of their siblings with special needs are inexorably entwined. Despite this, there is little funding to support projects that will help brothers and sisters get the information, skills and support they will need throughout their lives. Governmental agencies would be wise to invest in the family members who will take a personal interest in the well being of people with disabilities and advocate for them when their parents no longer can. As one sister wrote: “We will become caregivers for our siblings when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us.”

About the Sibling Support Project

The Sibling Support Project, believing that disabilities, illness, and mental health issues affect the lives of all family members, seeks to increase the peer support and information opportunities for brothers and sisters of people with special needs—and to increase parents' and providers' understanding of sibling issues.

Our mission is accomplished by training local service providers on how to create Sibshops (lively community-based for school-age brothers and sisters); hosting workshops, online groups, and websites for young and adult siblings; and increasing parents' and providers' awareness of siblings' unique, life-long, and ever-changing concerns through workshops, websites, and written materials.

Based in Seattle since 1990, the Sibling Support Project is a national effort dedicated to the interests of over six million brothers and sisters of people with special health, mental health and developmental needs.

For more information about Sibshops, sibling issues, and our workshops, online groups and publications, contact:

Emily Holl

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donor in the spotlight

CCA would like to send a huge **THANK YOU** to CCA Teen: **Kelsi Spurlin**!

Kelsi and her family breed French Bulldogs. She captures their adorable expressions through her passion for photography. Kelsi was born with **Pfeiffer syndrome** and decided to turn her love of French Bulldogs and photography into a fundraiser for CCA! She created a 2021 calendar showcasing all of her amazing work and the proceeds went to CCA! She raised \$500 for CCA! Thank you so much for your generous donation and passion for giving back! We would also like to thank Kelsi's parents, **Chris and Wendy Spurlin, Fenton Printing** (for printing the calendars), and everyone who ordered a calendar!

Thank you,

Annie Reeves

CCA's Program Director



About the Photographer:

Hello,

My name is **Kelsi Spurlin**. I was born November 11, 2004 in the beautiful state of Michigan. I was born with a rare syndrome called **Pfeiffer syndrome**, which affects about 1 in 100,000 babies. Not only did I have Pfeiffer syndrome, but I was born with a congenital heart defect, too. I had a half a heart. My aortic valve was under-developed and I had a leaky valve. They call my heart condition **Hypoplastic Left Heart syndrome**, which affects about 1 in 4,334 babies. The Genetics Specialist have sent in my DNA to find other people that have the same Gene mutations as me, but to date they have not found anyone with this condition. I am the first. My first 2 months of life were spent on life support in hopes that I would receive the Gift of Life (a new heart). On January 19th, 2005, I received the Gift of Life from a beautiful family and that is why I

am here today. So now my life has begun with never-ending trips to doctors, specialists and hospitals. I have had 38 surgeries so far. Some of them consist of craniofacial surgeries, heart surgeries, kidney surgeries, lung surgery, tonsil and adenoids, etc. I am so thankful for all the love and support from my family, friends and God.

I started a passion for photography when I was 9 years old with one of my Dads' old point-and-shoot cameras.



kelsi, continued from donor in the spotlight

My parents saw how much fun I had with it so they bought me my own point-and-shoot Sony camera and as I got better my dad let me use his big Nikon camera (which I thought I was so cool) My parents surprised me with my very own Nikon D3400 for my birthday. Since then I acquired another Nikon D610, lenses, backdrops, photo booth and props. Some of these items I received as amazing gifts. For the others, I saved money and bought on my own.

I am a person of few words (I was diagnosed with Selective Mutism, which makes it very difficult for me.) I love to share my photography so people can see and feel what I do through my photos. I really enjoy taking photos of animals, nature, macro, landscape, still life, food, newborn, weather,

and architectural. With the sales of these calendars, I was able to donate \$500 of the proceeds to CCA.

I hope you enjoy my French Bulldog Calendar and thank you for your support.

-Kelsi Spurlin



healing hobbies

by Kara Jackman

Forget about the sourdough starter and the puzzles! We can do better than that when it comes to new-found hobbies. COVID-19 has forced us all into our homes and boy, does it get boring! Through this article, I hope to reveal a few hidden wonders that may be hiding in plain sight around your home.

Preserve Family Photos, Slides, and Videos

First on the list is preserving your family's photographic memories. You know you have them. Boxes and boxes of photos, slides, and maybe even VHS or reel-to-reel tapes. Wouldn't you love to share these with the world, or at least, the rest of your family? Well you can. Grab some muscle, a few flexible people to get into the attic crawl space, and start by pulling out all the

boxes of pictures. Then, take a deep breath! Allow this process to be enjoyable, not over-whelming. It can be cathartic to take a walk down memory lane ... but make sure it's a leisurely stroll, not a virtual 5K!

Take out the photos, look them over slowly. Really use your senses to experience the colors, people, and format. If you have family around, ask them to identify anyone you don't know. Be prepared... this could turn into a gab fest with your relatives. Perhaps you even want to record some of your conversations as voice memos on your phone. This can enrich the history you are preserving.

Now you must decide to group the photos by year or occasion. Then, once organized, scan them or send them out for scanning by a professional digitization service. (Pssst, HotTip: There are often

[Groupons for such services.](#))

If you have slides, purchase a slide digitizer like this one from [Kodak](#) for \$150 to create digital images of your slides. Slides are really neat, but hard to view unless you scan them.

Finally, plan a time to gather the family around to share those awkward teenage years with your teenage kids. This can be done via Zoom or you can save this for a special night when you are able to gather safely in person.

This is a labor of love, for which (most of) your family will be truly grateful. Beware! They will dub you the family historian, but that comes with major brownie points.

What makes this a healing hobby?

Looking back on the past can really give you something positive to focus on, even if it is laughing at your relatives in those crazy outfits. The art of organization



healing hobbies, continued

helps give you a sense of control over something during a time when everything seems so uncertain. Creating order out of chaos in this small way will make you feel as if you accomplished something positive. Sharing the photos with extended family will conjure up old, happy stories. And, finally, it's a way to "time" travel for those of us that miss seeing different parts of the world.

Making a Body Scrub

We all love a good shower, but it might be time to mix it up with something new and different in the tub. Yes, even you, big guy! We know the fellas enjoy using a dollop of that pearly body wash on a poofy sponge. We see you! So instead of baking another batch of cookies, or the dreaded bread again, try this calorie-free recipe for a body scrub made from all natural ingredients brought to us from our friends at [Boston University's Howard Thurman Center](#). Then, try the recipe for this body oil for after you shed that dead, winter skin.



PEPPERMINT BODY SCRUB

Effects and benefits:

Peppermint may release tension and increase circulation, which can help soothe congestion, headaches, and stiff muscles

What you'll need:

- Mixing bowl
- Spoon
- Jar or container with airtight lid

Ingredients:

- 1.5 cups sugar
- 0.5 cup sea salt
- 1.5 cups almond oil (or [carrier oil](#) of your preference)
- 20 drops peppermint essential oil

Recipe:

- Mix all ingredients in bowl
- Continue to fold sugar into oil until fully incorporated

Note:

Essential oils should never be applied directly to skin. Always dilute with [carrier oil](#) of your choice. Before applying essential oils, please [patch test](#) to ensure no allergic reactions.

SWEET ORANGE COCONUT OIL

This mix is a mood-lifting alternative to lotions and cremes. In addition to sealing in moisture, coconut oil provides a layer of protection against UV rays, relieves common skin irritations, and has antioxidant properties. The sweet orange included in this recipe may reduce feelings of anxiety and depression, inflammation, and physical pains.

What you'll need:

- Microwave safe jar/container
- Spoon

Ingredients:

- 1 cup coconut oil (melted)
- 0.5 cup jojoba oil (optional)
- 20 drops sweet orange essential oil

Recipe:

- Microwave coconut oil for 10 seconds to melt down
- Combine all ingredients and store in airtight container

Note:

Coconut oil will solidify at room temperature.

WHAT MAKES THIS A HEALING HOBBY?

Body Scrubs combined with the scent of your favorite essential oils help to calm the nervous system, rid the body of toxins, and increase circulation. For those allergic to essential oils, [dry brushing](#) accomplishes the same goals. Children and adults that are hyperactive, and or hyper-sensitive will enjoy how calming this can be. In addition, both will calm anxiety and reduce depression that you may be feeling while our lives are disrupted by the coronavirus. Plus, it is just fun to make things from scratch!

Reading and Writing Poems

I've had a huge volume of all of the works ever written by my favorite poet, Robert Lowell, in my book collection since 2003. The book got cracked open from time to time over the last 18 years to turn to favorites, but I never had the time to read the whole book cover to cover. Enter the pandemic.

Poems are blessedly short, but they require a lot of concentration, or mindfulness. Watch how the words unfold on the page. Look for alliteration (when two words begin with the same letter) or rhyming couplets (when lines rhyme.) I know, I know, "It's hard, confusing, or sounds like a bore." But give it a try!

There are all kinds of poetry: poems in the shape of drawings; poems about sports, monuments and love. Poems can be short and inspirational

like the work of 20-something author, **Rupi Kaur**, who's latest collection, "[Home Body](#)" really resonates with our community around acceptance of one's body and past traumas. If you cannot figure out what you like, go for an anthology to see what your mind gravitates towards.

Finally, try your hand at your own masterpiece. Even if it starts with "Roses are Red, Violets are blue," it may end in some simple brilliance.

Refocusing your attention on one thing, the poem in this case, will keep your mind from spinning out like a teenage

driver on black ice. Poetry is a stepping stone to mindfulness meditation. Reading poetry allows you to focus your mind on one singular word, sentence, or stanza. It is not overwhelming like reading a novel, or nonfiction book, because the margins of the paper offer up open space, a true oasis from our chaotic homes.

Mindfulness meditation is one of the most accessible forms of meditation because it only requires you think about what is right in front of you. If you don't love words, that is ok. You can count things in your space, or start with song lyrics you know, to get your head more centered. Mindfulness of the present moment is the destination. How

you get there is your own journey. I love words so poems work for me... I'd love to hear what works for you!

There are so many ways to find healing in these challenging, turbulent times. Explore other activities that may bring about the same benefits offered up in this article. I hope this gives you some new hobbies with which to experiment. If you have ideas to share, post them on your social media timelines with the hashtag #CCAHealingHobbies. We can't wait to see your creative hobbies that heal.



For the Home



Shop at:
<https://www.barnesandnoble.com/deals/actions/670-chicks4chickadees>



All orders will ship mid-September



Thank you to CCA Mom, Courtney Schmidt, from California for doing this.

CLICK HERE



WE NEED EACH OTHER



CLICK HERE



Remembering a true giant of craniofacial surgery: Kenneth Salyer, M.D., 1936-2020

By Paul Snyder

Used with permission from [The American Society of Plastic Surgeons](#)

Plastic surgeons around the world are mourning the loss of a giant in craniofacial surgery, **Kenneth Salyer, M.D.**, who passed away December 28, 2020 at age 84. In addition to organizing the **World Craniofacial Foundation**, Dr. Salyer was founder of the **International Craniofacial Institute** and the **Cleft Lip and Palate Treatment Center** in Dallas.

"Dr. Salyer was one of the original fathers of craniofacial surgery," says ASPS President Joseph Losee, M.D.. "His contributions to the specialty were immense."

Born in Kansas City in 1936, Dr. Salyer received his medical degree from the **University of Kansas School of Medicine** in 1962 and performed a general surgery residency at **Parkland Memorial Hospital** in Dallas. He completed a surgical Fellowship at the **University of Texas Southwestern (UTSW) School of Medicine** and began his plastic surgery residency at the **University of Kansas School of Medicine**.

In 1969, Dr. Salyer became UTSW Medical School's first chief of the division of plastic surgery. He entered private practice in 1979 and established the **International Craniofacial**

Institute in Dallas in 1986. To date, the institute has served more than 17,000 patients from more than 75 countries. He also organized the **World Craniofacial Foundation** in 1989 to help provide life-changing surgery to children who had craniofacial deformities.

Linton Whitaker, M.D., who co-founded the **International Craniofacial Club** (which would become the **International Society of Craniofacial Surgery**) with Dr. Salyer, recalled first meeting his colleague in 1972 when the two were invited to France to observe the work of **Paul Tessier**, the pioneer of modern craniofacial surgery. "We struck up a relationship and had the idea of forming an international club that, to start, only had six members," Dr. Whitaker notes. That group of luminaries included Dr. Whitaker, Dr. Salyer, **Ian Jackson, M.D.**, **Daniel Marchac, M.D.**, **Fernando Ortiz-Monasterio, M.D.**, and **Ian Munro, M.D.** "We communicated and exchanged ideas through the first several years. We were finding our way through what we were doing as we were doing it. We'd talk to each other over the phone, share pictures and discuss various matters when we got together. Each of us also started our own training programs, and that really led to the widespread practice of craniofacial surgery."

David Genecov, M.D., who now



serves as the director of the **International Craniofacial Institute**, says working closely with Dr. Salyer provided invaluable insight and guidance into the world of craniofacial surgery. "Dr. Salyer was part of a generation of surgeons that was unique – they did things that we will never really be able to contemplate in terms of guts, vision and sheer imagination," Dr. Genecov says. "Ken's imagination and creativity were truly amazing in the O.R. He could think of doing things that were unique and very specific that not only made a difference functionally, but went beyond repairing anomalies to create a result that was also aesthetically beautiful."

Throughout his career, Dr. Salyer remained an active researcher – his work predicated on the driving belief that plastic surgeons must use their natural talents to change their lives and the lives of those around them. Even after he retired from clinical practice, Dr. Salyer devoted himself to mission work through the **World Craniofacial Foundation**. He focused on

dr. salyer, continued

the topic of helping change the lives of others when he delivered the Maliniac Lecture at Plastic Surgery The Meeting 2013 in San Diego.

He recalled being a resident on neurosurgery call at Parkland Hospital in Dallas on Nov. 22, 1963, when President John F. Kennedy was assassinated. At one point, Dr. Salyer found himself alone with Jacqueline Kennedy, and later reflected that the loss of his hero was a seminal event in his pursuit of serving others.

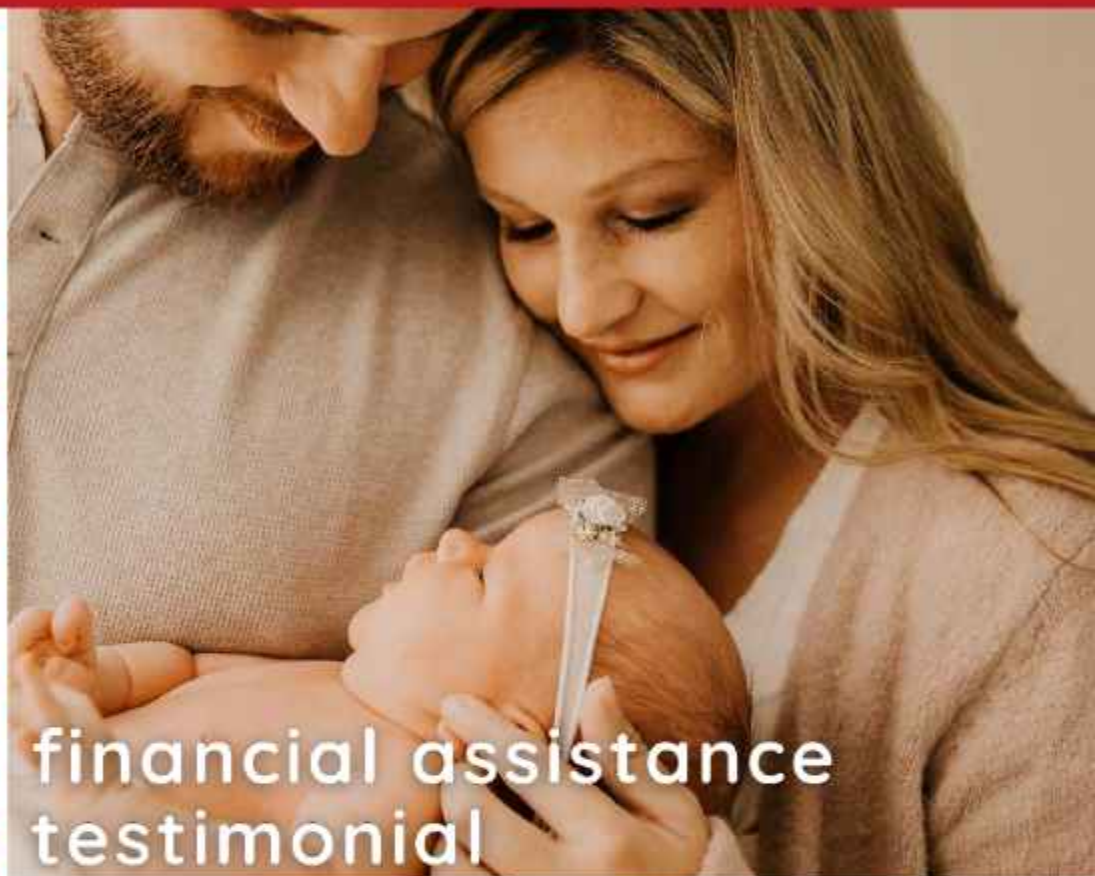
"In the aftermath of the president's death, I had a new understanding that life was both fragile and precious," he told the audience. "I grew increasingly determined to create a professional life that mattered - one in which I could be of service to mankind."

Legacy Giving



Simply put, planned giving enables you to make a meaningful gift to CCA that reflects your beliefs and values while leaving a unique legacy to memorialize those values and beliefs by supporting CCA Kids during your lifetime and beyond.

To learn more about how to leave your mark on the world through supporting CCA Kids and Families, visit: ccakids.org/legacy-planned-giving/ or email Christine at candler@ccakids.com



financial assistance testimonial

by Laura Chaffin

What a blessing CCA has been to our family! Shortly after our Collins was born, she was diagnosed with Saggital Craniosynostosis. We learned that she would require surgery to remove part of her skull that had prematurely fused together, followed by 9 months of helmet therapy with adjustments every two weeks. My husband and I wholeheartedly believe the Lord led us to the most wonderful surgical and orthotics team who

are located several hundred miles from our home. We have and will continue to make that drive many times throughout this journey, and CCA has provided assistance for travel expenses for every appointment and hospital stay!! We are forever grateful to this organization for the help and support they have provided our family during this time!

-Sidney, Laura Leigh, & Collins Chaffin



thank you to our 2021 facebook fundraisers:

names are listed in alphabetical order by the fundraiser campaign owner

1. Chelsea Buyalous
2. Donna Marie Roberts
3. Francis Menard
4. Haley Holubec
5. Jeanie Ross
6. Jennifer Dockter
7. Jill Laufbaum
8. Joel Brusk
9. Katie Hartke
10. Kellie Lloyd
11. Kyle Hoelting
12. Lisa Bowers-Alters
13. Maddie Cameron
14. Megan Mejia
15. Melissa McQueen Benfer
16. Nicole Cheri Clifford
17. Paige Michelle Edwards
18. Robb
19. Tanya Tiger
20. Tenny James Philip
21. Torey Harrah
22. Victoria Green

Thank you

create your own facebook funder

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

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

IT'S THAT EASY!

upcoming events

MARCH 24th

Online: Zoom Workshop



PTSD FROM THE MEDICAL TRAUMA PERSPECTIVE

Conducted by Dr. Monheim-Janss, PhD.

Clinical psychologist in the Cleft and Craniofacial Center at Barrow Neurological Institute

CONTACT:

Annie Reeves, areeves@ccakids.com

JUNE 4th-5th

SEATTLE RARE DISEASE FAIR

The Fair and Summit aim to educate, engage, and inspire our community about the importance of rare disease research

CONTACT:

Carolina Sommer | Born A Hero:
carolina@bornahero.org

JUNE 25th-27th

Online: Zoom Workshop

CCA'S VIRTUAL ANNUAL RETREAT AND EDUCATIONAL SYMPOSIUM

More info to come (See pg. 9)

SEPTEMBER

[Craniofacial Acceptance Month](#)

[North Texas Giving Day](#)

SEPTEMBER 8th-9th

California

MORGAN MECK 10TH ANNUAL GOLF CLASSIC INVITATIONAL

CONTACT:

Christine Andler, candler@ccakids.com

OCTOBER 10th

Timarion Country Club Golf Course | Southlake, TX

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

CONTACT:

Christine Andler, candler@ccakids.com

tributes to robin williamson

... continued from pg.13

Jana Peace, CCA Volunteer and Robin's Dearest Friend:



I first met Robin when I started working for CCA as the Program Director and Robin did the production and design for the Network, our newsletter. I would stop by her house and bring her pictures of families we were highlighting and she would show me layouts. It was never dull when you stopped by her house! She had a sweet dog named, Charlie, and a rare grey bird that shouted from upstairs to let you know he heard your every word. Robin usually had three projects going at one time and I was in awe of her big computer and her skills to maneuver and edit things on a page faster than any human I had ever seen work a keyboard.

Fast forward many years, and Robin and I began working together again under a much different set of circumstances. Robin had just been diagnosed with a very aggressive form of breast cancer and let's just say, she got 100% on the breast cancer test, because sadly, her diagnosis checked every box. She was an overachiever like

usual, but you really don't want to be in this situation. So began the journey.

Robin was ready for the fight of her life, true to her determination and perseverance that I'd seen for many years already. Robin's schedule included long days of doctor appointments, chemotherapy, breast surgery consultations, cosmetic surgeon visits, and radiation treatments. This diagnosis felt like another full time job. Robin displayed her winning spirit with a smile at every visit and confidence each time we set out. Everyday, on her phone, she had an alarm set for 2PM. The name of the alarm was "I trust you Jesus."

She spent her treatment days "on the job" actually working on her computer and she went to quilt shows and quilting retreats on the weekends. The diagnosis did not change her. No, she changed her outcome of the diagnosis and beat breast cancer, with her smile and her faith. But Robin had no break or time to rest from her chemotherapy, as nearly immediately thereafter, she was diagnosed with scleroderma. This presented an unknown prognosis to both her and her doctors, but she took it all in stride. Her routine was not new now; it was just tweaked. Her

oncologist remained true and faithful to help her get the best protocol for treatment and it was decided that she would stick with chemo to fight this disease, too. You see, there is no cure for scleroderma.

Robin's left hand slowly became locked in a clenched position with many sores and constant pain, but she kept on fighting. Her skin on other parts of her body tightened, too, as the disease tightened its grip on her. She learned every trick in the book to adapt her body to perform daily tasks, work, and hobbies, too.

Robin just kept adjusting. Her alarm still went off every day, "I trust you Jesus," to remind us both.

Robin was so strong and amazingly, she became more determined as time went on. The doctors soon realized that she would live life on her terms and would keep going.

Once again, Robin was hit with more bad news. The cancer was back. Another punch to the gut.

This hit hard, as Robin had seemingly just found her way around all the obstacles.



tributes to robin williamson

Jana Peace, continued...

Maybe, it is hard for you to imagine, but to say that she got no break is an understatement. Even her doctors marveled at her courage, commenting that facing back-to-back life-threatening illnesses is unfathomable to most of us. Still, Robin just digested the news and got back in the ring. She knew it was not going to be easy. She was going to have to live with the fact that she would fight hard and there would be no finish line, short of a miracle. Yet, a miracle indeed Robin showed us again.

After the diagnosis of cancer returning in multiple areas of her body, including her spine, she began falling and lost stability to even stand and walk. The doctors offered a Hail Mary surgery. One she had to go into not knowing if she would even walk again.

I don't have to tell you Robin wasn't having any of that "never again" nonsense. Robin faced every new diagnosis by saying, "Let me get my bitching out then I'll get over it." Her motto was never "Why me?" It was "Try me." She always thought of her experience as a chance to teach others.

So, she decided she was going to adjust and learn to walk. Dr. Kerr, her oncologist, was up to bat for her again. Never did this man leave her side. Her strength and courage bolstered

his and he approved the operation to let Robin stay in the fight.

Well Robin showed them all, and she indeed walked again. She worked harder than anyone could have imagined and impressed all the staff.

She never complained; she just kept her focus. She left the hospital in a wheelchair, but was walking. She counted every step and every step counted. The nurses cheered her every lap and clapped when she walked into their offices. After a brief stay in rehab, she was released home right before the pandemic.

Robin was no ordinary patient. She was no ordinary person. She didn't want to be ordinary. She would think that was boring. Robin was creative, talented, determined, courageous, stubborn, beautiful, strong, gentle, humble, and kind. If anything, Robin encouraged us to go the extra mile, to stretch ourselves, and never settle for ordinary. Be colorful, be unique, be something that will inspire people to learn and grow.

Robin would say, *"Smile, it won't always be easy but it will be worth it."* Robin won. She won the fight, and she ran the race without ever getting a break. She did it smiling and full of gratitude.

While her poor body went through a vicious war, she remained focused on staying strong. She won freedom and her legacy lives on in all of us. ❤️

Ronald Kerr, MD:

When you think of Robin, you think of her quick wit and bright smile. She was undaunted by two serious illnesses. Scleroderma crippled her hands, robbing her of the joy of quilting, but it could not take away her smile. She laughed and joked in the face of breast cancer. She fought spinal paralysis and learned to walk again after spinal surgery. Robin was truly amazing and we will miss her greatly. ❤️

Lisa Vernon, Friend and CCA Graphic Designer:

I met Robin and Bruce 30 years ago, before they were married. What began as a working relationship grew over the years into a true friendship. While each of us had our own creative graphic design businesses, we worked together on hundreds of projects over the years. We helped each other creatively, bouncing ideas back and forth, and the end results were inevitably better for the collaboration.

Robin would always tell me exactly what she thought about

tributes to robin williamson

Lisa Vernon, continued...

(without hesitation) --- and usually had a suggestion as to how to make them better. And if she didn't have a suggestion at the moment, she'd say,

"...I got nuthin!"

She was at once a teacher, mentor, sister, friend, cohort, and partner in creativity.

Robin got me involved with CCA doing design work. Her desire to give back was an inspiration to me to do the same, and I am grateful to her for showing me how good that felt. Another love of hers was the Plano Civic Chorus, with whom she sang for years, and got me involved with doing design work for them as well. We loved going to the concerts together and enjoyed getting a little "culture."

When I was going through a rough time in my life, she literally took me in and made me a part of her family, welcoming me into her home for awhile so that I could get back on my feet. She probably saved my life.

Robin was one of the most positive, hopeful, cheerful people I have ever known. Even when she lost her husband, and shortly thereafter was diagnosed with cancer, in the face of all of that, she found a way to power through. Her faith was strong; her sense of humor intact. I don't know how she kept such a positive attitude through all of that. What an

inspiration. Whenever I had an issue I was dealing with, she was the one I always wanted to talk to. She was insightful, caring, giving. Brutally honest sometimes -- but that was a plus. She would talk me through it, make me look at it honestly.

She would sometimes quote one of our favorite television shows:

Chin up. Put your shoulders back, walk proud, strut a little. Don't lick your wounds; celebrate them. The scars you bear are the signs of a competitor. You're in a lion fight, Stevens. Just because you didn't win doesn't mean you don't know how to roar.

-Grey's Anatomy

I will forever be grateful for having her in my life, a best friend. I will always miss her, but she will live on in my heart, and forever be a creative soulmate.

She was one of Gods' Angels on earth. Her name fit her: Robin. A beautiful, cheerful songbird, flying high in heaven now. ❤️



Tony Davis, DMD, CCA Board Member Alumni

I first met Robin in 1999 when I joined CCA, so many years ago. I recall that first meeting and was touched by her sincerity and her smile. As the years passed, Robin and I became close friends. She was the same every time I saw her: warm, genuine, quick to laugh, and someone that you just wanted to be around.

Robin was a true friend who never judged, and I never once saw her angry. She was a hardworking and dedicated member of CCA and there were many times when we didn't have money to pay her, but she continued to provide her talents to our newsletter without hesitating.

What will I remember most about Robin Williamson?

Wow, it's easy to say "everything" but I would have to say it was her grace in the face of unimaginable struggles. Throughout Robin's illness, she always maintained her sense of humor. She never wavered and her texts and online postings always reminded me of all those years ago when she found humor in everything we did.

When Robin started getting too ill to continue her work, she found another way to express herself and literally sewed her imagination into works of art. She loved those quilts and I could feel the excitement in her messages

tributes to robin williamson

Tony Davis, continued...

when there was a quilting group get together. Having thought about all I will remember about Robin, I know there is one instance I will never forget. About 2 weeks before her final hospitalization, we were texting one day. I don't remember all the exchanges, but I could tell she was still smiling. After a few texts, I sent a message that said, "If I ever face what you are going through, I hope I can do it with half as much grace and humor as you have."

Her response:

"I hope you never have to, but if you do, I will be there to help you through it."

Robin, you ARE still here helping me through every day by teaching me that no matter how bad things seem you can always find a reason to smile.



Annie Reeves,
CCA Program Director:

Heaven has truly gained one of the most amazing, kind, hilarious, and strongest women I've ever known. Robin endured more than anyone I know and never complained! **Not once!** Her positive attitude blew me away. Her strength and faith were one of the many things I admired about this woman. She was a hard worker and a true blessing to CCA and everyone who knew her. I met Robin in 2003. At that time she was on the Board of Directors (BOD.) We instantly "clicked" and the two of us



Paula Guzzo,
CCA Board Member Alumni:

worked closely on many of our Programs & Services. She contributed so many wonderful ideas and we had such a great time working together! I loved working on the newsletter with her. We had quite a few laughs at some of my edit suggestions. I am known for overusing commas and she would always call me out about it. Robin also designed CCA's syndrome booklets, educational overviews, our retreat t-shirt designs, and website. She worked countless hours for little or no cost. She continued to do all of this after being diagnosed with not only breast cancer, but Scleroderma, which severely affected her hands. Most people would have given up, but not Robin! Her passion truly showed in her work and relationship with the CCA Staff, BOD, and our CCA Families.

Rubix, you are free of pain, now. You will be greatly missed. Thank you for being YOU! I love you and always will. ❤️

Robin, I'm at a loss for words to adequately describe my heart when I heard of your passing on Christmas Eve. When I was a newbie Children's Craniofacial Association Board Member, you'd spent years on the board and provided much guidance on the history of the board. When I was board chair and had a particularly difficult situation that came to a vote, you were the one who provided clarity to the situation. Your wit coupled with the ability to recognize what needed to be said in other situations provided the sage advice the board needed to move forward. As evidenced in this picture where you're giving Bunny Ears, you had FUN!! Your faith carried you through your many years of cancer.

You've won the ultimate reward. I'll see you later, my friend. ❤️

tributes to robin williamson

Erica Mossholder Klauber,
CCA Executive Director

She taught me how to curl my eyelashes, using a blowdryer on the lash curler. That is one of my first memories of Robin, when we were roomed together at my first CCA Board Retreat.

I quickly learned she was smart, sharp, direct, analytical AND wonderfully creative. To this day, I admire her ability to be completely direct and stand up for herself, but also to not take it (or give it) personally. She was relentlessly positive. And not in a syrupy, fake way. In a determined, settled, quiet, dignified way.

She knew herself and it inspired me to know myself. She owned her fight with cancer and scleroderma, but she was always quick to joke, always available to meet for lunch, ready to laugh, and endlessly at service. Her heart beat for projects, but that sharpness led her to do them right. No missing comma or uncapitalized letter was "okay." It needed to be corrected, because that professionalism serves the mission.

I loved Robin, and I will love her forever. She made an impact on my life that I will never forget.

Robin, thank you for a life beautifully, magnanimously lived. We miss you terribly, but so glad you get to celebrate Christmas in Heaven with the King Himself. ❤️



Rose Seitz, CCA Mom and Board Member Alumni

She was one of a kind. When I worked with her, I told her often that she was the only person I had ever personally met, who's BOTH sides of her brain worked equally, exceptionally. Anyone who knew her knows what I mean. To say she was a strong supporter of Children's Craniofacial Association would be an understatement. She worked tirelessly and always gave it 1,000%. She was a perfectionist and she gave CCA her best. She also had a wicked sense of humor

and thought it was funny when she posted this pic of us years ago, I still think she altered it since she was an exceptional graphic artist. She was a mother, a child of God with a strong faith and there is no doubt she celebrated Christmas in paradise. We are sad you are gone, but your time of suffering is gone and for that we are grateful. Rest easy friend. ❤️

The Nurses at the Texas Oncology Infusion Room

Robin was very special to us here in the infusion room at TXO. We all cared very much for her and always enjoyed spending time with her when she came in for her treatments. She always had such a positive, "can-do" attitude. No matter what life threw at her she was always smiling and ready to take on the next fight. She was an inspiration to all of us here. We all are going to deeply miss her. ❤️

Robin Williamson

When you think of Robin you think of her quick wit and bright smile. She was undaunted by two serious illnesses. Scleroderma crippled her hands, robbing her of the joy of quilting, but it could not take away her smile. She laughed and joked in the face of breast cancer. She fought spinal paralysis and learned to walk again after spinal surgery. Robin was truly amazing and we will miss her greatly.

→ Ronald Kerr M.D.

tributes to robin williamson

**Barbara Chen, RN,
Texas Oncology**

Robin was a fighter. She experienced several setbacks but came back up fighting. She laughed a lot! It was a pleasure to see her in our office. She will be missed. ❤️



**Morgan, Medical Assistant,
Texas Oncology**

Robin was very special to us here in the infusion room at TXO. We all cared very much for her and always enjoyed spending time with her when she came in for her treatments. She always had such a positive, Robin was a one-in-a-million type of patient! We could never tell if she was in pain or having a bad day, because she was always smiling and in a good mood. We had some fun times with her here at the clinic and she will be missed by all of us. ❤️

Memories of Robin Williamson

Robin was a fighter. She experienced several setbacks but came back up fighting. She laughed a lot. It was a pleasure to see her in our office. She will be missed. Barbara Chen, RN

*Robin was a one in a million type of patient! We could never tell if she was in pain or having a bad day, because she always smiling and in a good mood. We had some fun times with her here at the clinic and she will be missed by all of us.
- Morgan, MA*

It was always a delight to see Robin & Jana. They were a force to be reckoned with. Always cheerful, laughing & so sweet & friendly. Robin was a lovely lady. Her hurdles & obstacles never allowed her to be anything less than a beautiful spirit. I will miss her very much. Such a courageous woman. - Claire Robertson, RN



**Claire Robertson, RN,
Texas Oncology**

It was always a delight to see Robin and Jana. They were a force to be reckoned with. Always cheerful, laughing, and so sweet and friendly. Robin was a lovely lady. Her hurdles and obstacles never allowed her to be anything less than a beautiful spirit. I will miss her very much. Such a courageous woman. ❤️



Robin, Your Legacy Lives On!