

ccaenetwork

newsletter of children's craniofacial association

2023: ISSUE 1

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CAMERA TO MAKE A
DONATION!



Left to Right: Rebecca (Mom), Oliver, Sophie May and Matt (Dad)

meet the joneses

by Rebecca Jones

It was summer of 2018 when I was pregnant with our second child, who we lovingly named Sophie May. We were so excited to add her to our little family! Our son, Oliver, was almost 2. This second pregnancy had been going so smoothly, and we were just blissfully happy. The 20 week anatomy scan revealed that everything looked perfect, but little Sophie would not let us see her face. My OB asked me to return a few weeks later just to double check. At 24 weeks pregnant, I went to that appointment alone. It was supposed to be just a quick sonogram, so I didn't want my husband to have to ask off work again to attend the appointment with me. The normally chatty sonographer had little to say, but I didn't make note of it until my OB entered the room and the words "bilateral cleft lip" left her mouth.

My husband, Matt, and I were married in March

see joneses, page 2

letter from the director of development



Looking forward and growing has been a constant theme for CCA since its inception in 1989. This holds true for all of us, personally and professionally, with the stride to look forward and grow. As I start to feel the weather change to crisp mornings and beautiful sunny days here in Texas; and as I see flowers start to bloom and the leaves reemerge on the trees... there is no truer sign that Spring is here! This time of year, always reenergizes me to grow and this note is a spotlight on the growth we are making as we embark on the heart of 2023's efforts already in motion.

Behind the scenes our staff never stops and is busy at

see letter from DOD
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joneses, continued from the cover

of 2015. We had met 5 years earlier, working at an ice rink together. Matt is a hockey goalie for a house league, and I grew up as a figure skater. After we married, Matt worked in project management, and I worked as a registered nurse. I always dreamed of being a mom with 2 children. We welcomed Oliver to the family in 2016. He was such an amazing kid, so smart and funny, and he brought so much joy into our lives! We were excited to keep our family growing. When we knew Sophie was on the way, our family rejoiced and anxiously awaited her arrival.



My OB's words after she said "bilateral cleft lip" were blurred in my memory. She referred me to an MFM doctor at Children's in Plano, but she was positive from what she saw on the ultrasound that Sophie was different. I frantically called my husband, and he met me at home where we just looked at each other, at a loss of what to do. The helplessness we felt. I cannot describe the pain of not knowing if your child would be okay. I didn't sleep at all that night, researching what exactly we were dealing with. I looked at photos, videos, and found a few groups on Facebook for parents of children born with clefts. I

2 Googled up doctors and surgeons



in the area who specialized in children's craniofacial conditions. Seeing words like "NICU" and "feeding tube" and "failure to thrive" haunted me. I researched what equipment we might need, what procedures she would need to have, and just wondered what our little girl might look like. As awful as it was, I worried what people would think of what she looked like. I knew our family would love her no matter what, but the world is so cruel and I was frightened of the obstacles she would no doubt encounter because she would look different. I felt shallow and vain to worry so much about my daughter's appearance, but the support groups I joined showed me that I was not alone in my feelings. And I knew in my heart that no matter what she looked like, she would be loved by us endlessly.



At the time, I was working as a nurse in the OR of a fertility clinic in Frisco, TX. I asked all the doctors I worked with about what they knew about children born with clefts. One anesthesiologist I was close with was friends with the MFM doctor I was referred to. She agreed to talk to us over the phone about what our options might look like. Soon after, we had an in-depth sonogram with her, where we finally saw the details of Sophie's face. Her sweet little lips clearly had a bilateral cleft and we were warned that most children with a bilateral cleft lip also have a cleft palate. But there was more. It wasn't clear if her brain was developing as it should. We were then referred to get a fetal MRI done at UT Southwestern. I was 28 weeks pregnant at this point.

Instead of leaving the MFM appointment with answers, we left with more questions and fear that had increased tenfold. Our daughter's sweet little face was no longer our biggest concern. Her brain. Her life. We didn't know if she would be okay, and the terror consumed us until the day of the MRI. Matt and I walked into the hospital, barely able to breathe. The MRI was done, and a doctor spoke with us immediately afterwards to discuss the results. They confirmed that Sophie would be born with a cleft lip and palate. We let out gasps and tears of relief when the doctor said, "her brain is normal." The weight of the world flew off our shoulders as Matt and I held each other, overwhelmed with the news that Sophie would be okay. We knew she would be okay!

We were then referred to

joneses, continued from pg 2

Dr. James Seaward, a plastic surgeon with Children's Health craniofacial team. We spent hours at the hospital, meeting the slew of doctors that would oversee Sophie's needs throughout the rest of her childhood. We began to plan for her first surgery, her lip repair, when she would be 3 months old. Her palate would be repaired at a later date within in her first year of life. Of course we were still nervous about what was to come, but at this point we were just ready to meet our daughter.

The rest of the pregnancy went smoothly and we welcomed our sweet Sophie May on September 10th, 2018 at 1:37 pm, measuring at 6 lbs 10 oz and 19.5 in. We felt the purest joy as we finally got to hold her in our arms! She was born with an incomplete bilateral cleft lip and cleft in her soft palate. Otherwise, she was perfectly healthy and never needed to go to the NICU. She was the most beautiful little girl we'd ever seen, and we were instantly in love! I could not stop looking at her sweet face. She was a living doll, my beautiful daughter.

When Oliver was born, one of our biggest challenges was breastfeeding. I wasn't very educated about it and neither of us was good at it. We switched to formula and thrived, but I swore that I would breastfeed my next baby. However, Sophie's lip changed our plans and I decided to pump for her. She required bottles that had seven, SEVEN pieces to them, but we were so thankful that we could feed her on our own. Exclusively



pumping with a 2-year-old and a newborn was quite the hurdle. Oliver was often jealous of "the baby water machine" as he scathingly called it. I valiantly pumped until Sophie was 6 weeks old, until I succumbed to postpartum depression and a condition called D-MER (dysphoric milk ejection reflex). The switch to formula was a welcome relief.

Before Sophie's first surgery, we were instructed to start taping her lip with medical tape to help encourage the muscles around her mouth to come closer together. The idea is to help those muscles acclimate to their position they would be in after the surgery and ease the process over time. She would need to have the tape on as much as possible, if not 24/7. To my surprise, rarely were we asked about her lip in public. I shamelessly posted our Sophie updates on social media and never once received any negative feedback. The fears I had worried over at the news of Sophie's cleft melted away and seemed so foolish. How could I have spent so much energy being upset when our daughter was born so perfect?!

Sophie's first surgery date arrived in December 2018 when she had just turned 3 months old. She was to have her cleft lip repaired and tubes put in her ears. Children with a cleft palate often have trouble draining fluid from their eustachian tubes and this can affect their hearing and speech development. We were in a strange place of terror and mourning. The thought of my tiny baby daughter having surgery was scary enough, but knowing that her sweet cleft smile, her perfect little face, would look different afterwards was bitter-sweet. I took as many pictures and videos of her beautiful face

as I could in the days leading up to her surgery. I melted into tears in Matt's arms when the nurse took her into the operating room at Children's Health in Dallas.

We spent the next 5 hours awaiting the news that her surgery was complete. Dr. Seaward spoke to us before we saw Sophie and he warned us to brace ourselves because



joneses, continued from pg 3

she would look so different.

We were walked into the PACU where Sophie was recovering, and we finally saw her forever smile. Her little face was so swollen. She had a black eye from the procedure. Her little lip was now in one piece. We calmly observed her as we took in the changes, seeing our daughter's new face for the first time, and fell in love with her smile all over again. The absolute strength Sophie exhibited during her recovery was inspirational. How could such a tiny little girl take on something so traumatic with such stride?! She continued to improve so smoothly and gracefully, as her scars lightened and her new smile shone brightly every day.

Sophie's palate repair came when she was 10 months old. It felt as if we were reliving the first surgery, but with less fear and anticipation. And again, Sophie displayed her strength and courage throughout the entire process. Within a few days, she was back to her beautiful happy self. We knew it would be smooth sailing from then.

Today, Sophie is a hilarious, sassy, cuddly 4-year-old. She loves playing with Oliver (who is now 6) and being an absolute princess. She loves make-up and dresses and shopping. She loves playing with the three family dogs and pretending to be Queen Elsa from Frozen. She's a phenomenal singer and makes up the cleverest lyrics to her favorite tunes. She loves cooking in the kitchen and pretending to be a veterinarian to

4 her army of stuffed animals.



The only hurdle that remains is making sure she is hearing well and that her ear tubes are functioning. She is now on her 4th set of tubes, and is doing so well with them. We follow up with Dr. Seaward every year, and so far, things seem to be going smoothly! Sophie has shown us true strength and resiliency throughout her existence and we are so in love and thankful to have her in our lives.

We love you so much, sweet girl!



gingertown 2022 raises \$24,500

by Christine Andler

The annual Gingertown is one of the biggest gingerbread house events in Texas and all proceeds benefit Children's Craniofacial Association. Gingertown brings together talent from more than 25 local design, engineering, and construction firms in Dallas/ Fort Worth for a live gingerbread building competition and exhibition to help spread joy and hope during the holidays at Dallas' premier shopping destination NorthPark Center. Millions of people nationally and internationally visit the Center each year.

For 2022, the theme was "Base Camp" and showcased all things in an imaginary space village! The night began with a speech from our Executive Director, **Erica Klauber**, thanking everyone for making the effort to attend and fundraise for CCA.

In total, the event raised \$24,500 that will go directly to CCA. We are so grateful for all those that came out to support us and wanted to especially thank **Nancy Nasher** and her children for attending the build. **RJ Ressig** and his staff for all they do to make this a huge success each year. And last but not least, **The Kimberlin Family** and **The Alvey Family** for participating in the build and building the CCA kid's gingerbread house! It was truly an evening that was "out of this world!" 🍪



requesting nominations for The David Roche Award of Excellence in Advocacy

by Khadija Moten

On September 29, we held the very first Encounter event! Encounter was the first of an annual event where we unveiled: **The David Roche Award of Excellence in Advocacy**. The award is named in honor of the esteemed **David Roche, Member of the Order of Canada**, for his lifelong dedication to opening minds and connecting hearts and his invaluable mentorship and support

to the staff of Children's Craniofacial Association.

This September will be the second year in a row where we hope to award this honor. **Mark your calendars for June 1st -July 30th where we will begin requesting nominations for the award.**

The award will be selected in August by the David Roche Award for Excellence in Advocacy

committee, which is made up of Children's Craniofacial Association's Executive Director, Outreach Director, David Roche, and past award recipients.

Learn more about the award by visiting the link, [here](#).

For questions or concerns please email me at: kmoten@ccakids.com

letter from DOD, continued from the cover

work making sure CCA continues to grow. We hope you are starting to see our efforts in real time such as: More diversity and inclusion content on our marketing channels, growing our resources available to families, and building stronger relationships with our individual donors.

As the Director of Development, I am so excited to embark on taking our fundraising efforts to new heights! One of the goals of mine has been to connect with donors and families on a regional level. I am thrilled to be giving our thanks back to those who support us on such a personal level.

As I write this note, I am gearing up to be in one of CCA regions, Phoenix, Arizona in March. The catalyst to spur this visit is to speak, support and celebrate a long-time donor's company's 30th anniversary party with their fundraising efforts going directly to CCA! We hope to feature this effort in an upcoming newsletter soon. In May, we will be in Raleigh, North Carolina for the ACPA conference and plan to meet with donors one-one-one and in segmented groups while in town.

In June many of you will join us

in Minneapolis, Minnesota and one of our best successes was inviting a select few donors to see some of the magic we call Retreat. Many of these people had supported CCA's Retreat (and other programs) but had never seen how their donation truly made a difference. The feedback we received was incredible and opened their eyes to the important work we do. Following Retreat, we look forward to our biggest annual fundraiser - The Meck Invitational in Southern California and using our valuable time there to connect with the many supporters in this region.

If you have any recommendations for people to meet in any of these locations above; please let me know. Without you, CCA and our programs would not be possible. Thank you for all the creative ways you have helped us in the past and as we look forward to the growth of CCA with you!

- Christine Andler
CCA's Director of Development



upcoming events

APRIL 22, 2023 | 9am to 11am

PHOENIX CHILDREN'S CENTER FOR CLEFT AND CRANIOFACIAL CARE PICNIC

RSVP at: Thughes4@phoenixchildrens.com
by Tuesday, April 18th

MAY 15-19, 2023 | all day
International

INTERNATIONAL FACE EQUALITY WEEK

JUNE 10 2023 | 4pm to 7pm

Grand Rapids, MI | Cascade Township Park
3810 Thornapple River Dr SE, Grand Rapids, MI 49546

MICHIGAN SPRING CRANIOFACIAL PICNIC

CONTACT: Tricia Brusk, tbrusk@yahoo.com

JUNE 22-25, 2023

Minneapolis, MN | Hyatt Regency Minneapolis
1300 Nicollet Mall, Minneapolis, Minnesota, 55403

33RD ANNUAL FAMILY RETREAT AND EDUCATION SYMPOSIUM

REGISTRATION IS CLOSED.

OCTOBER 8-9, 2023

Las Colinas, TX | Hackberry Country Club.

7TH ANNUAL DFW PAR PREMIER GOLF TOURNAMENT FOR CCAKIDS

CONTACT: Christine Andler, candler@ccakids.com

SEPTEMBER IS CRANIOFACIAL ACCEPTANCE MONTH

SEPTEMBER 9, 2023

Nationwide

NATIONAL PICNIC DAY

CONTACT: Annie Reeves,
areeves@ccakids.com to host a picnic

SEPTEMBER
California

MECK INVITATIONAL

CONTACT: Christine Andler, candler@ccakids.com

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ccaadult

meet karen

hi, I am Karen and I am 38 years old. I had over 40 surgeries by the time I was 18 years old. I am from Williamsport, Pennsylvania, the home of the Little League World Series, where every year 20,000 people come to our small town. When I was little, I used to attend every game. Now, I go to my uncle's house to help him park cars, watch traffic, and watch the games on TV.

Every year our town has a Mummer's Parade. I was a junior member of the Mummers until I was 18 years old and then I became an official member. Some of my responsibilities include selling ads for the Mummer's book, and on the day of the parade I make sure everyone is there, in their assigned place and then I drive the division car so the people watching the parade know that there is a new division starting. I went to a Macy's Day Parade, but was not able to see anything except for the floats and the balloons. So, I think ours is better! We have the Mummer's from Philadelphia come to our small town.

I love football. I have a cut out of Drew Brees in my apartment. I watch the New Orleans Saints. My favorite High School team is the Southern Columbia Tigers. They have won six state championships in a row.

One of my favorite things to do

all year round is going out to eat. As you can imagine in a town that has so many people coming to visit once a year, we have a lot of restaurants. However, I do not just stay here. I have traveled to many states. One of my favorites was Maine. I also went to the Four Corners this past year. I have a huge collection of magnets. I have at least one from every state and some from other countries.

I have gone to eight concerts for country singers and have seen Darcie Lynn. You may wonder how I afford all this. I have worked 10 jobs over the years. I would have liked to work at certain jobs longer, but the stores declared bankruptcy and closed such as JC Penney's, Bon Ton, and K-Mart. I currently work at Kohl's and I am hoping that I left the curse behind at K-Mart.



I have attended several CCA Retreats over the years. I have been to Florida, Colorado, Myrtle Beach as well as my own state. Disney World was my favorite, of course, followed by Colorado, St. Louis, Myrtle Beach, and then Hershey, PA, I always left feeling like a normal person.

As I look back on my life I wonder what my dad would think (he passed away when I was in high school). My goals are to get a better job and a different apartment, 🍀



who is peter dankelson?

by Kara Jackman

Peter Dankelson is a well-known name around the CCA community. Many will recognize him as a guitar enthusiast and motivational speaker. You've seen him in ballrooms, clubs, and classrooms from New York to California. How was this renaissance man born? Let's take a look.

CCA Mom, **Dede Dankelson** and Peter began sharing his story of living with Goldenhar syndrome with thousands of students across the country starting in 2012 shortly after the New York Times best-selling book, "Wonder" debuted and changed our lives forever. This work later grew into **Pete's Diary**, a company that manages, publishes, and distributes books and music to encourage people to choose kindness, stay motivated, positive, and manage those familiar high-intensity emotions. The name came from the diary and later blog his mother kept, after Peter's birth. Now he's in business with his mother, Dede, who Peter freely admits,

"does all the boring stuff so that I can play more guitar."

Yes, the guitar. The instrument would be Peter's life-altering catalyst, helping him get through some of his toughest surgical recoveries during his teenage years. Peter reflects, "I think I had surgery every summer during high school."

Peter continues to grow his positive impact through his music career, playing on social media, in clubs with his own band, also named Pete's Diary. He began playing the guitar at 15 years old. His curiosity was piqued thanks to his parents' interest in classic rock. Whether in the car headed to his brother, **Jacob's**, hockey practice, or at home, they listened to bands like AC/DC, KISS, Guns N Roses, Van Halen, and many other influential bands from the late 1970s and 1980s. "AC/DC really sparked something for me." After a quick chat with his father about learning how to play, they dug his father's high school guitar out of storage, set it up, and thus began his love affair with the guitar. Darin's parting words on that day were, "Have fun!" Soon after, Peter found a treasure trove of lessons, songs, and more on YouTube, all of which helped him learn how to play.

Guitar was therapeutic and calming for Peter. Teaching himself to play was integral to him hammering through those tough teenage years on his ax of choice, a Gibson guitar. He says, "[Music] helped me cope with all the stress and anxiety." And there was plenty more ahead of him with some of the biggest surgeries and a big family move from Michigan to Illinois. This meant a new slate of medical providers, a much bigger high school, and the first-of-its-kind jaw replacement surgery ahead of him in 2017. Peter, armed, with his guitar and an iPhone, spent every free moment away from medicine, surgeries, high school, and speaking engagements practicing his art. It's something he continues to do to this day.

Peter says, "When we speak at schools, I tell students that playing guitar is what helps me celebrate the good times and persevere through the tough times. Having any kind of creative outlet or activity you enjoy is a healthy way to express your feelings."



peter, continued from pg 9

Peter practices for 2-3 hours every day, consistently improving his craft by listening to YouTube backing tracks, learning the history of genres like the blues, and writing some of his own riffs. After a few years, he started playing with **Libertyville School of Rock**, where he got to play in a band. Thanks to the connections made at the School of Rock, Peter was able to pull together a trio that love rock and roll.



Today, he works at School of Rock Libertyville, and his band, Pete's Diary, practices in their drummer's garage, "all set up with everything we need." He also continues to "practice every day learning and recording cover songs" for his social media audience." As of March 2023, Peter has 538,700 followers on TikTok and over 9 million likes on his channel. His fans keep coming back for his music and positivity. Pete's Diary released their debut EP, "All Screwed Up" in 2022. Some of the songs, "Can't Stop Staring" and "Another Lonely Night," reflect on lost love and struggles with being different. The band is clearly influenced by the classic rock era titans, Van Halen, Led Zeppelin, and blues greats like Joe Bonamassa and Stevie Ray Vaughn. Their EP is available on Apple, Spotify, Amazon Music,

and YouTube, streaming under **Peter Dankelson Band**.

Away from his band, Peter has played with such greats as **Jared James Nichols, Buckcherry, Dirty Honey, Hinder**, and her majesty, **Orianthi**, guitar royalty that played with legends like **Michael Jackson** and **Alice Cooper**.

Music is Peter's "medicine of choice" as he puts it. It can be yours too. If you are starting to play, he recommends thinking about how you like to learn. "You can teach yourself just about anything with access to Google." Speaking for himself Peter says, "Going at my own pace and teaching myself kept me excited and having fun, while others might benefit from in-person lessons." He recommends finding songs you want to play, to make practice fun. Further, he says to truly reap the emotional and mental benefits of playing he encourages budding musicians to "do it for you, not for attention. It's therapeutic when you're playing for your own enjoyment."



Can't Stop, Won't Stop,

Peter and Dede wrote two books during the COVID-19 pandemic, when speaking engagements slowed to a halt. His autobiography, "**How I Learned To Rock My Life**" and a children's book, "**Peter's Rockin' Ear**," are expertly written, receiving 5-Star reviews from Readers' Favorite. Additionally, "**Peter's Rockin' Ear**" was awarded a Mom's Choice Gold Star Honoree.

It's been an honor to watch Peter mature and grow over the years. His CCA family is beyond impressed with the courage it takes to talk in front of large auditoriums filled with kids and adults, sharing intimate details about his surgeries, medical appointments, and staring and teasing that come with a facial difference. Going from the uncertainty he'd make it out of the NICU to taking the stage with platinum-record, performing artists, to working with guitar industry experts on the latest and greatest new guitars...now that's a story worth reading! We cannot wait to see what the future holds. Rock on, Peter! **Learn more about Peter, buy his books, merch, and see where he plays next at PetesDiary.com**



hi, my name is Abigail and I am 12 years old. I will be 13 on November 9th. I was born with Treacher Collins Syndrome. I've had a lot of surgeries but I always tell myself that I am brave and I can do this. A lot of people stare at me because of the way I look but I don't pay attention to them.

One of my favorite hobbies is reading. My favorite book is "Wonder" because it reminds me of myself. My favorite subject is math because I like challenges and I love to solve problems plus I think it is easy. I love to play with my sister, Lily, because she is fun to play with. I love to play video games with my brother Joseph. I love to watch movies with my dad and mom. My favorite movie is "Harry Potter and the Chamber of Secrets" - I love Hermione and even though it is an unpopular opinion I like Malfoy as well. I also love to watch Big Brother.

I always tell myself that you're amazing just the way you are because everyone is different. This year will be my 5th CCA Retreat (even though one was virtual). I can't wait to go back so that I can see my friends from previous years and make new friends and see people like me. 🧡



ccakid

ccasupersibs

meet joseph

hello, my name is **Joseph** and I turned 14 on December 31, 2022. I am in 8th grade and will be going to high school next school year. I am excited because

I can finally take culinary classes in high school.

When I am not in school, which feels like it is 24/7, I usually am playing video games, spending time with our dog (Dobby the house dog), cooking, or annoying the pants off of everyone around me.

My favorite food is mostly anything I come across!



My favorite foods to cook are pancakes, grilled cheese, tortilla pizza, and eggs. My favorite color is orange.

My favorite book series are Harry Potter, Land of

Stories, and Percy Jackson. My favorite movies are the Star Wars movies. (I even like Jar Jar Binks!) I also like criticizing Disney Channel movies, which ANNOYS my sisters (which if you recall was one of my favorite pastimes). Some of my favorite video games are Animal Crossing, Among Us, Star Craft, Ratchet and Clank, Abe's Odyssey, and Subnautica.

My sister Abigail is nice. She doesn't get bullied too much—thank goodness. I would want to do more than annoy someone that bullies her. 🐶



meet liliana

hi everyone - my name is **Liliana Rose** and I turn 9 in May. I am in 3rd grade. I have an older brother and sister who are both in middle school. My sister has Treacher Collins and she is the best sister ever because we play and do everything together,

like some of our favorite hobbies. My older brother wrestles with me on the trampoline. I like my sister because she has Treacher Collins and I don't want her to change without it because I love her. I also have a pet dog, Dobby, like the House Elf from Harry Potter.

I like to paint (even though my mom doesn't let me very often because I make a mess) and I like to color. I like sleeping with my stuffies, especially on

the weekends when I sleep in. My favorite thing to do is to bug my mom and when it storms I am

scared I come bug my mom and sleep with her and then my dad carries me to my room later, that is the funny part.

I like Legos, my favorite color is blue, and I like to eat toast with butter and black pepper. My favorite movie is **The Little Mermaid** and my favorite tv show is **Lilo and Stitch** the series.



financial assistance testimonial

by Jessica Puccetti-Hoffman

my happy, resilient little girl, **Adelaide Shae**, was born on July 23rd, 2022 in Oregon. We found out she would be born with a left-sided cleft lip and palate on my 20-week ultrasound. Addy may need around 10-20 surgeries before she is 18. She has the potential for having hearing issues (she has failed both hearing tests so far, but her team is hopeful she will have normal hearing after palatal surgery and ear tubes), speech and language delays, potential chronic ear infections, and misaligned/missing teeth.

We live about 3 1/2 hours away from Adelaide's Craniofacial team, we make this drive for all of her cleft-related appointments. We are lucky enough to have a pediatric orthodontist on her team, **Dr. Judah Garfinkle**. Dr. Garfinkle created a device for Adelaide called nasoalveolar molding (NAM), which is a pre-surgical therapy that reduces the size of the lip, gums and nose before her first surgery. We drive to Portland every week to every other week to have Dr. Garfinkle adjust this device. Not only is this drive long, but usually includes dangerous conditions during the winter, between freezing fog, black ice, and snow storms. Oftentimes, we drive up the day before the appointment, stay the night, and then drive home the next day. This quickly became hard on us financially.

The costs of travel, accommodations, additional time away from work needed for her appointments, and medical costs that haven't been covered by

insurance began piling up. We were lucky to run into a family at one of Addy's NAM appointments, whom had been through the same procedures with their son two years prior. They had done the NAM device through Dr. Garfinkle and just happened to live in the town right next to us. They had done the same drives to and from Portland and found the extra costs to be a strain. This family found Children's Craniofacial Association and had only amazing things to say about this organization as well as all the help they received through them.



I contacted CCA the next week and was directed to **Annie**, the Program Director. Annie is such a blessing and has been so incredible for us through this journey. Thank you CCA for the financial assistance and helping us give our Adelaide the best care possible. We appreciate you all and the amazing work you do!

- Jessica, Beau, Seodna & Adelaide



children's craniofacial association

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