

Celebrate Alondra: A Family's Story

by Mom, Glenda (Fall 2021)



I'd like to share about our journey with Alondra, my first born. Back in November 2007, I was 7 months pregnant, expecting my daughter, the first baby in the family. My Mom would become a grandma for the first time and with my siblings, uncles and aunties, everyone was living these wonderful emotions that a baby brings to the whole family.

As one of life's surprises, Alondra was born two months early, by emergency C-section. I had all the regular check ups, ultrasounds, tests that any pregnant women receives, but it wasn't until the day of Alondra's birth when I learned that she was born with all her five senses affected. Within a week of her birth, Doctors had a name for the rare condition, Nager Syndrome, which the doctors had very little information on.

I recall the doctor who came into my hospital room as I was waking up from the sedation from the surgery. Six hours later, he was holding up his hand ready to list all the complications that our baby was born with while asking us if we were aware of these conditions. He explained, "Your Daughter was born with cleft lip and palate with a very small recessed lower jaw which affects her taste and smell. Her airway is compromised and she might not be able to sit up straight and will need remain laying down on her back or side. Her eyes slanted downwards and there's some malformation in her face, so might have difficulties with her sight. She has missing thumbs on both hands and some abnormalities on her arms which may affect her sense of touch. She was born with no ear canals and her hearing may be impaired."

I was 26 years old. This was all new to me, it felt overwhelming. I had many, many questions, many worries and concerns for my daughter's future, for her life, her development, her growth, her learning. Alondra spent three months in the Neonatal Intensive Care Unit. When she was discharged, her trajectory of surgeries had begun. For me, as her mother, a LIFETIME of LEARNING had begun.

When she was four months of age we began receiving Home visits from Specialists from CEID, Speech Therapist (Jennifer Wayman), DHH Teacher (Kim Burke-Giusti), and a nurse from the hospital. As soon as I learned specifically what Alondra's hearing differences were, I was eager to learn what I needed for her to succeed and learn. Alondra was diagnosed with Bilateral Moderate to Severe Conductive Hearing Loss. Her speech was affected and delayed due to her hearing and her facial anomalies.

CEID's Home visits opened my eyes to the unknown, they taught me how to live my day to day routines with my daughter with hearing differences. They coached me on how I could give her more learning in the smallest things.



Joyful with Special Gift

CEID has provided lots of services to Alondra and our family, educational support, emotional support for me and my family, physical therapy, occupational therapy, speech therapy. CEID basically held my hand throughout the months and years that Alondra was a student there. They taught me means of communication. With their Parent Sign Class every Thursday, I learned how to communicate with Alondra via visual cues, facial expressions, talking to her in singing tones, always having eye contact, and to be a "parrot" - to repeat and sign everything, to label with a signed picture every item possible at home, in the car.

I learned with CEID how to advocate for my daughter and her needs with the parent workshops held at the Center and met many parents who were in similar situations. We shared a special bond that survives throughout the years. This is because CEID's staff would make sure we got connected and sharing our experiences. Every family that I meet in the years attending CEID will forever hold a special spot in my heart.



Balancing @ CEID

The staff at CEID is very understanding and compassionate about your child as an individual with their unique needs. I always felt heard, understood, cared for, listened to. I found the support that has no comparison. They welcome and helped us learn everything we needed, including many hugs to keep me going through Alondra's surgical procedures. CEID helped Alondra understand and prepare for her upcoming surgeries with images and pictures of what was going to happen and celebrated every accomplished milestone with us. CEID became our family. CEID provides every parent with the necessary tool box for their children's specific needs.

Now that Alondra is nearly 14 years old, I look back at everything that we lived together and feel BLESSED and fortunate that a Center like CEID exists, that every child with hearing differences can succeed with their professional support and their caring hearts.

I thank you for your contributions and for your support to CEID.

May CEID continue being a great place helping other families the way they helped us.



Alondra's Loving Family

