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# A Family's Advocacy:

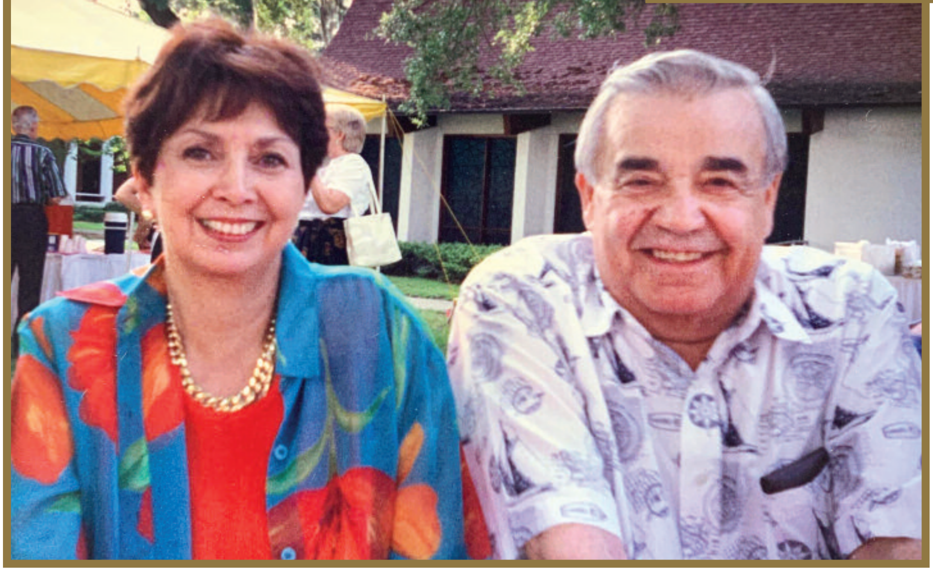
## Reflections of a Deaf Son

*By Oscar Ocuto*

I remember asking my mother at different points in my life why I could read better—generally handle English better—than my friends. Mama would always consider the unusual depth and speed of my language and literacy development and respond with a variation of the following: *"I refused to accept what the doctors were telling me. I refused to accept that you, my son, could not learn constructively and would not amount to more than a forever dependent individual in society just because you ended up being deaf."* This—her refusal to accept the negative opinions of some professionals and her determination to make sure that her son succeeded academically and socially—is perhaps what began my mother's advocacy. While my father's advocacy was less focused on my schooling, I have developed a sense of appreciation for the advocacy of both my parents. This meant that as an independent and self-sufficient adult, I have come to appreciate my parents' stories.

My mother, Elaine Fasquelle, was born in Tela, Honduras, in 1938. Her father, Oscar, who is my namesake, worked for the United Fruit Company (now Chiquita), the international banana exporter. Mama eventually found herself working for Taca, a small airline that flew between the United States and Central America. She later transitioned to Pan American Airways, a job that allowed her to travel the world through the 1960s and 1970s. My father, Arthur Ocuto, was

*Photos courtesy of Oscar Ocuto*

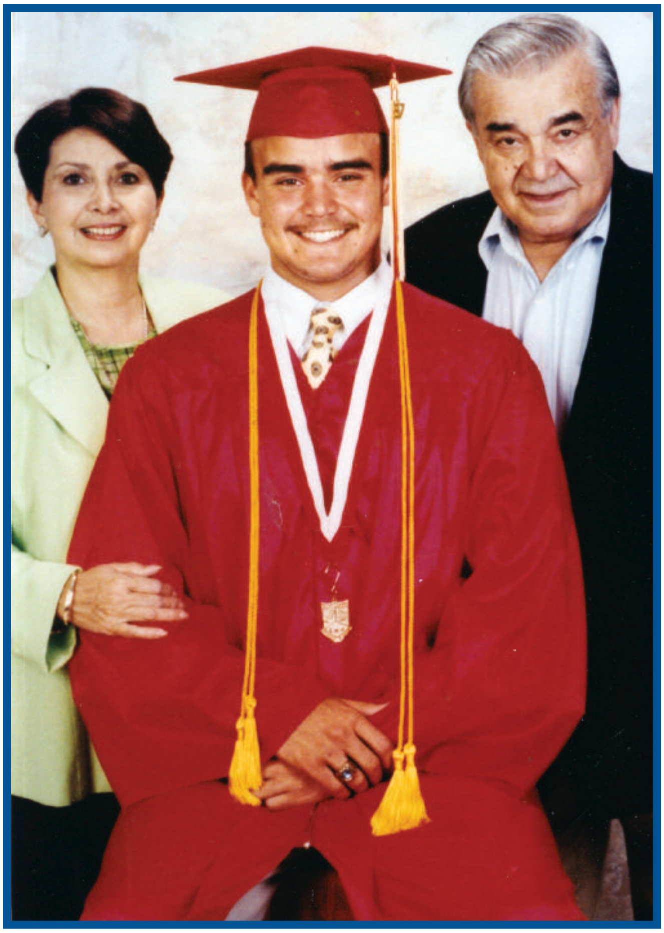


**Above, clockwise from left:** Ocuto with his father, Arthur; with his mother, Elaine, in 1988 as she spoke at a rally to support keeping FSDB open; supportive, involved parents.

born in Somerville, Mass. His parents, Giuseppe and Anna Ocuto, immigrated to the United States from Sicily, passing through Ellis Island in the early 1920s. Daddy would eventually do a stint in the Navy, working as part of the crew assigned to clean up in the aftermath of the Pearl Harbor attack. He came back home to New York City and then worked for the Ford Motor Company, a job that required a significant amount of travel. At one point, Daddy was a passenger on a Pan Am flight on which my mother was a flight attendant. She must have made an indelible impression! After the plane landed, he asked her out to dinner. It was November 1961, and, as they say, the rest is history.

For the first 13 months of my life, I was hearing. I learned to walk and to talk, following the normal timetable for developing toddlers and speaking Spanish, the language of my parents and my own first language. Then I contracted meningitis. The bacterial infection rendered me completely paralyzed on my right side and critically ill. My mother slept by my bed at the Sacred Heart Hospital in Philadelphia, Pa. She prayed every moment of the day and every night, but I continued to get worse. One night, as the realization of her son's impending death set in, she would always say she only felt divinely grateful. She thanked the Lord for bestowing on her the opportunity to experience motherhood, and she asked that God take her only son home with Him if that was how He saw fit. Not long after, she fell asleep. The next morning when she woke up, the doctors told her that her son had experienced a remarkable anomaly; the fever had finally broken and the paralysis had disappeared. I was recovering.

Days later we went home, and my family's life returned to normal except for one small detail. Mama noticed that when she called my name—Oscar most of the time, but *Oscar Lucanus!* when I was doing something I should not be doing—I showed no response, not even an acknowledgment of her voice. Mama tried the well-known pots and pans test, dropping them behind me with their attendant thud; I did not respond. We went back to the hospital for confirmation. The doctors said what Mama



**Left:** Ocuto with his parents at his high school graduation.

already knew: I had survived meningitis but at the expense of my hearing. I was deaf.

## Guidance Leads to Knowledge
### Knowledge to Advocacy

Fortunately, Sacred Heart, the hospital where I had undergone treatment for meningitis and had my deafness measured, had a relationship with the Parent Infant Program at the Pennsylvania School for the Deaf (PSD). My mother was referred there. Mama said that the first day she visited PSD and saw people moving their hands, she had no idea what the movements meant but she felt that using them made sense. Since my aural world was closed off, my visual world needed to be heightened. Sign language made sense to her.

Not long afterwards I was enrolled at PSD and Mama, having procured *The Joy of Signing*, was learning signs. She would thumb through the book for the signs she needed to make sentences to talk with me. She began volunteering at school. As she opened up communication with me at home and reinforced her learning in the halls and classrooms of PSD, she was already on her journey to advocacy.

I was in the Parent Infant Program when PSD announced the closing of its high school. My father was figuring out a way to start his own automotive export/import business. He had a group of clients from Central America and began thinking about relocating the family. With the upcoming changes at PSD and in his work, a family move made sense. Like so many parents of deaf and hard of hearing children, my parents prioritized my education as they considered moving. They looked for states with deaf programs and settled at first on a move to Miami, where they planned to enroll me at the Florida School for the Deaf and Blind (FSDB) because of its Total Communication policy. Total Communication, which later became known as Sign Supported Speech, was what we used at home. When Mama found out that Miami was a five-hour drive from FSDB, we instead decided to make our home in Jacksonville, about 35 miles north of the school, and we eventually settled in St. Augustine Beach, only a few minutes away. Mama took an early retirement from Pan Am so that she could stay home with me full time.

By now I was 7 years old, and Mama's sign skills had reached the point where she and I had meaningful conversations. Her signing enabled me to access language at home and to appreciate from a young age her interest in my education and, therefore, its importance. Daddy traveled extensively so our communication was a mix of rudimentary signs, spoken English, fingerspelling, and hand gestures, and our relationship became complicated because of our inability to converse without difficulty. Actions can, and do, speak louder than words, however, and I never doubted his love.

Daddy would bring back souvenirs from his work in Mexico, *luchadores*, tiny action figures, and recount as best as he could the experiences of enjoying *antojitos* that he bought from vendors on the way to the wrestling matches. He taught me to fish, filet my catch, cook it, and prepare meals on camping trips. As I grew older and became more involved in sports, my father was there for the vast majority of my games whether they were home games at FSDB or on the road against other schools. Daddy even traveled behind the football team bus by himself, driving 10+ hours from Florida to North Carolina to see me play football against the Eastern North Carolina School for the Deaf.

## Mama's Advocacy Grows
### From Teacher Meetings to Conferences

My mother became a certified interpreter and, with three languages at her command, she interpreted part time and was eventually hired at the school. Working at FSDB allowed Mama to build her knowledge of the special education laws and regulations through her relationships with administrators. She attended parent-teacher meetings, including my Individualized Education Program meetings. She would arrive with her confidence, her signs, and her high expectations but as

I grew older, she would not speak for me. My mother would make sure I answered the educators for myself. She felt it was important that I actively be involved in shaping my own long-term goals.

Mama participated in parent advocacy groups (i.e., Florida Concerned Parents of the Deaf, American Society for Deaf Children), and she cultivated relationships with officials both at FSDB and at the mainstream schools I attended through FSDB. She also went to the biannual conferences of the Convention of American Instructors of the Deaf as well as the Conference of Educational Administrators of Schools and Programs for the Deaf to further expand her network of advocacy. As I progressed through school, she continued developing her understanding of how special education laws could benefit my educational needs.

Mama's personal involvement enabled her to communicate to my teachers her high expectations for my academics both at school and at home. She would meet with each of my teachers to ensure she understood what support was needed at home to bolster academic performance at school. Often I kept a journal, recording events as they transpired and facilitating communication between home and school. We were fortunate that the school responded well to Mama's expectations. In a sense, Mama was the quintessential networker—she knew the value of taking the initiative in communicating expectations, understanding how these expectations could be met, and then applying the process at home to ensure my academic development.

In fifth grade, a threat to the FSDB budget led to a rally in the state capital of Tallahassee. My mother took the opportunity to explain to me PL 94-142, the original federal law that mandated free and appropriate public education for deaf children, and I began to understand my rights as a deaf child. I addressed the rally, too, explaining how my education—attending some classes within FSDB and other classes in nearby mainstream environments—conformed to the parameters of the law and were essential to me as a young deaf individual.

## Not Limited to School Hours

### Ongoing Advocacy

Mama used her sign skills to continuously interpret and explain things to me. Her constant signing showed me so much about the world, including the fact that it continued moving on regardless of whether or not I was attuned to it.

I have fond memories of the summers we spent with my cousins in Honduras. Although I knew rudimentary Spanish, my mother was ever present, always interpreting and making sure that I knew what was going on around me. Whenever possible, Mama insisted that I chronicle these trips via journaling and brought artifacts back to school so that my teachers could integrate my experiences into formal educational

**Left and below:** Ocuto with his mother on Gallaudet's football field; a recent family photo.

activities. Sometimes I felt Mama—in her continuous interaction with the school staff, her fluent communication skills, and her determination that I learn about the world and how to navigate through it—could be overbearing. In fact, she was a "helicopter parent" at a time before the term was invented. When I asked her about this, she would respond, *"One day you will understand why my fight now will benefit you as an adult."*

Daddy died while I was still in graduate school, and I so regret that he never had the opportunity to see me become a man, start a family, and be a father. Mama, who had risen to become executive assistant to the superintendent at FSDB before she retired, lived to see me progress through graduate school, get married, and welcome her first grandchild. She died in 2014, but I see the effect of her work and that of my father every day in our lives. As I try to pass on their values to my children, I realize that my mother was unusual in the skill, depth, and persistence of her advocacy. Her determination to communicate with me, her advocacy within the schools and in my personal life, as well as her love, made me the man I am today.

# Resources for Parents and Educators

The following resources may be helpful for parents and educators who seek more information about working together to benefit deaf and hard of hearing students.

## Websites

- American Society for Deaf Children (see Parents & Families), *www.deafchildren.org*
- Hands and Voices, *www.handsandvoices.org*
- Laurent Clerc National Deaf Education Center, *http://clerccenter.gallaudet.edu*
- LEAD-K, *www.lead-k.org*
- National Association of the Deaf, *www.nad.org*
- Parents of Deaf Kids: Sign Language, Community, Culture, *www.facebook.com/groups/ParentsofDeafKidsSignLanguageCommunityCulture/permalink/612005225816289/*
- Visual Language & Visual Learning (VL2) Parent Package, *http://vl2parentspackage.org*

## Books

Marschark, M. (2007). *Raising and educating a deaf child: A comprehensive guide to the choices, controversies, and decisions faced by parents and educators.* New York: Oxford University Press.

Marschark, M., & Hauser, P. C. (2012). *How deaf children learn: What parents and teachers need to know.* New York: Oxford University Press.

Putz, K. (2012). *The parenting journey: Raising deaf and hard of hearing children.* Cambridge, MA: Barefoot Publications.

Spencer, P. E., Erting, C. J., & Marschark, M. (2000). *The deaf child in the family and at school: Essays in honor of Kathryn P. Meadow-Orlans.* Mahwah, NJ: Lawrence Erlbaum Associates.

Stewart, D. A., & Clarke, B. R. (2003). *Literacy and your deaf child: What every parent should know.* Washington, DC: Gallaudet University Press.