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Heart Song

By Janet Farrell Leontiou, Ph.D.

On Saturday afternoons, I take my son, Andreas, to Heart Song, a not-for-profit organization in Northern Westchester County, NY, that offers music and art therapy to children who have disabilities. The organization was founded by a mother whose daughter had cerebral palsy. Andreas, too, has cerebral palsy. He is 5 years old.

On one particular day, I wheeled Andreas into the classroom and kissed him goodbye, but because we were then new to Heart Song, I wanted to observe the class. I pulled up a chair to a window in the hallway that allowed me to look into the classroom. Through the window, I saw Daisy, whom we knew from the pool where she and Andreas both received aqua therapy. Daisy looks older than Andreas but she reminds me of him. She has knowing eyes that seem to look out from a non-cooperative body.

On this day, however, she looked sluggish and I wondered if she was on medication. I saw Leah, who has a host of disabilities that I learned about from speaking with her father. 12-year old William was absent. The previous week his mother had told me that he had suddenly begun having seizures after being seizure-free since infancy. I worked on stifling my panic as I listened to

the remarkable similarities between our sons—an uneventful pregnancy, seizures that began on the second day of life, no known cause, and the similarities went on.

When I am in these situations I sometimes think that if I do not listen, the similarities will end. I recognize that in part I am thinking like a little girl: If I close my ears, what frightens me will not come to pass. I asked William's mom if he had been diagnosed with cerebral palsy, something I have never done before; I have never asked a parent about the diagnosis of his or her child. I do not know if I was adhering to an unspoken rule within the world of children with disabilities or if I did not ask because it never mattered before. But William's story was too familiar and I felt compelled to ask. William's mother is the second parent I have met who said she regrets the label of cerebral palsy because it is too broad. Today, William was absent and I hoped it was not because of seizures.

From my vantage point outside the classroom, I also observed Nicholas. He comes to class in a wheelchair and with an oxygen tank. He looks about 13 years old; he has spina bifidia and hydrocephalus. From looking at him, I cannot tell if he can see.

The man who attends to Nicholas during the class is his grandfather. He is always pleasant and greets everyone by placing a microphone to his throat that amplifies a voice box. As it seemed Andreas was happy and engaged in the activities, for the rest of the lesson I watched the interaction between Nicholas and his grandfather.

Nicholas was seemingly non-responsive as his grandfather held his head and continually placed a series of musical instruments in his hand, replacing each one as it was dropped. If Nicholas's grandfather was growing impatient, I did not see it. I only saw him stroke the boy's face lovingly as if to say "come on." From my position outside the closed door, I took a picture of the two of them because I wanted to hold on to what I witnessed.

After class Andreas looked bright and happy. I put him in the car and as I placed his wheelchair in the trunk, I saw Nicholas's grandfather loading his van. I could see the effort required to get Nicholas to this class. The grandfather drove a van with a hydraulic lift and as we drove away he was still loading the van with equipment. I thought to myself that I had witnessed one of the most poignant portrayals of love that I had ever seen.

I have been carrying their picture in my mind since that day. I wrote down their story because I want to hold on to this picture forever.

Janet Farrell Leontiou is the mother of 5 year old twins and an assistant professor of communication at Nassau Community College.