



## National Center for Cultural Competence

Georgetown University Center for Child & Human Development  
University Centers for Excellence in Developmental Disabilities

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### Nivea's Life By Haydee Avilan

My precious 5 year old daughter Nivea was born in Puerto Rico. Nivea has Spina Bifida (she was born with an opening on her spine S-1) classified as a Mielomelingocele with hydrocephaly (accumulation of fluid on her brain). Also, according to the doctors she has a brain lesion. During my pregnancy, I was unaware that my daughter would be born with this condition, since the routine tests and exams did not diagnose this problem. After her birth, Nivea spent 7 days in the hospital so that her spinal opening could be closed. During this surgery she acquired Meningitis, which caused an unknown number of convulsions and hydrocephalus.

My daughter was in intensive care for 2 months. Later she was transferred to Children's Hospital in Puerto Rico so that her VP shunt (a valve that is placed under the skin in her head) that she will have for the rest of her life. Back then, I thought that my daughter was going to die, and that she would never be able to walk, run, speak, hear or do anything that other children her age could do. After the placement of the shunt, everything was going well and when we went to have her stitches removed, an intern told me that her shunt was not working properly and that she needed a new one. I told the intern no, as she was not displaying symptoms and I needed to consult with her regular doctor.

During this emotional time, my daughter's father was in New York and I received my major support through my six-year old daughter, my parents and God. The experience was not easy. Later he moved to Washington, DC to respond to a job opportunity. I remember calling my daughter's father and telling him what was happening and that I needed to leave Puerto Rico as I felt that Nivea was not going to receive the treatment that she needed.

In January of 2002, I moved to Washington, DC. When I arrived from Puerto Rico, my daughter's father was not living under the best circumstances. He was renting a room, which made it difficult for all of us to be together. Because of Nivea's condition, the manager only allowed us to sleep there. We had to leave in the mornings and spend all day on the streets as if we were homeless, and it was so cold...but God always took care of us.

Through the grace of God I found Dr. Cordero Bello who was the first U.S. doctor to care for my daughter. She referred us to Children's Hospital's Spina Bifida Department. At the same time, I was able to find an apartment in Maryland, in

which we lived for ten months. The apartment was expensive, and I was not able to work due to Nivea's health. With the help of my aunt, I found an apartment in DC which was closer to Children's Hospital.

I recognize that I was a little overprotective of Nivea, but I don't regret it because that helped her to recuperate sooner. I sought help from the Early Intervention Program for services for Nivea. It took a few months to get it, but Nivea soon received physical, occupational and speech therapies in my humble home. These therapies helped Nivea with her motor problems. I can't say that it was easy to accept Nivea's condition; I can say that in accepting our children's condition, it gives us power to help them to love themselves and to learn everyday how to live a happy life without damaging their self-esteem.

It was hard for me to get help from Medicaid. I think the major obstacles were related to an expectation that families from Hispanic/Latino origins are undocumented, and therefore not entitled to federal health assistance. In our case, we are Puerto Rican and American citizens by birth, making my daughter eligible to receive a range of federal benefits. In my opinion, there is a lack of awareness and knowledge about the citizenship and rights of those from Puerto Rico. So while it wasn't easy to get medical assistance, I finally got it through my perseverance.

Nivea has had 6 surgeries (1 on her bladder, 1 navel-colon resection to support the function of her intestines, 2 on the spine to help her with her growth, and 2 shunt repairs on her head). Nivea requires daily catheterization every three-four hours to empty her bladder, so that her kidneys won't get damaged. She also has intestinal problems as she also does not have sensation in that area. She usually wears Pull-Ups, something that makes her feel bad when people say "such a big girl to wear pampers". She now understands her condition, and doesn't pay so much attention to what people may say.

In school, Nivea is doing very well, even though she demonstrates some delays in learning and reading. I know that some day she will succeed, it doesn't matter how long it takes her. To me the most important thing is that she tries to succeed. It is important to mention that due to hydrocephaly, Nivea experiences some loss of memory, so that what she learns today, she forgets tomorrow or the same day. This makes learning very difficult, but that's how it goes.

I never thought that I would have a daughter with limitations, but today I am so proud to have her as my daughter. I believe that she has been the best gift that God has given me and the most beautiful experience of my life. It hasn't been easy, and I had so many sleepless nights, but the results have been excellent. Nivea is one of God's miracles because he has given her the opportunity to walk, which is not common for children with Spina Bifida, so I really can't complain too much.

*“Thank you God for the beautiful daughter that you have given me, whom I love with all of my heart.”*

My advice to all parents of children with disabilities is:

- The most important thing is to accept our children with all of their challenges, and
- It is imperative to learn about our children’s conditions as if we were the doctors, nurses and professionals that we become in the care of our children.

By thinking this way, we will see them strong, sure of themselves, and willing to rise above the challenges of this world.

*“Love, understanding, and dedication are the basis of family.”*

*“God gives exceptional children to extraordinary parents.”*