

# One BRIGT Shining Light

## Luz's Story: The Power of Family Love

My name is Luz Elena Aponte, but everyone calls me Lucy. Since my parents know me, my dreams and my struggles better than anybody else, they are writing this article on my behalf. I hope that you will be inspired, like my parents and me, to dare to dream and see the possibilities and the abilities and not the barriers that are present before us. My mom always tells me that we need to see challenges as opportunities to learn and to make things better, not just for me, but for other individuals and families like ours. My family's mission is "To Love, To Learn, To Share and To Serve." Having that mission has helped us to move forward and overcome obstacles.

I am the youngest of three children. I was 10 years old when we moved to Florida. My name, "Luz," is Spanish for "light." My parents say that I have been a light in my family, and an inspiration for them. My parents, Milton Aponte and Berthy De La Rosa-Aponte, have always taught us that family relationship is very important. My brother Milton and my sister Diana and my parents will always be my advocates.

I was born with a clubfoot in my right leg. My mom tells me that as soon as I was born she noticed that I made a strange noise while breathing. I had problems with my trachea and laryngomalacia (softening of the tissues of the larynx). Every time my parents took me to the pediatrician he said, "Don't worry about it; she will outgrow it." Well, he was wrong. At six months old, I needed a tracheostomy and a machine with a tube to help me breathe, which I used for eight months. My sister Diana, though she was only 10, helped me a lot with everything, including suctioning the trach and even changing the trach tube. Eventually all of that went away and I grew up overcoming one obstacle after another.

### THE ROAD TO A GOOD EDUCATION

All this time, my parents were becoming involved in advocacy groups, where they met and became friends with other families like ours. They understood that I had the right to go to my local school with my peers, and get a public education in the "least restrictive environment" with appropriate services and supports. At my Individualized Education Plan (IEP) meeting, my parents insisted that I be present part of the time, know the people involved and listen to their input.

Today I have a wonderful IEP team--and we are a real TEAM. IEP meetings were not always smooth and easy, as they are now. At the beginning they were intimidating.

There were rough times: for instance, the team was advocating that I needed a school bus to pick me up by our apartment but the school district did not want to do it. They claimed that the school bus could not get into our apartment complex and that "the closest safe stop" was a busy bus stop several blocks away from where I was living. I had to be wheeled there, rain or shine, hot or cold, to be picked up. My parents filed for due process under former P.L. 94-142, which later, as amended, became IDEA.

My parents, however, took pictures and a video, which refuted the school excuses one by one. For instance, where the school showed the school bus not being able to get through the gate of the complex, my parents' video tape showed an 18-wheeler truck coming in without difficulties. My mom even went to City Hall and got the city ordinances and plans with specifications of streets in our apartment complex that allowed large vehicles to enter the complex. My dad studied the law and argued my case with the school board attorney. The school finally settled the due process complaint before the hearing before the administrative law judge began. The school was so concerned about their violations of my rights that the following day, two separate private bus companies came to pick me up at our apartment. My parents were also forced to advocate for my necessary therapies in school. Always armed with the provisions of the law, they pressed on. Slowly but surely, the school learned that my parents and I were committed to my education under the law. We have come a long way since then. I am now a student at Cooper City High School in Cooper City, Florida. Many of my classmates have known me since elementary school--when I attended my neighborhood school--and understand my abilities and my disabilities. Fifty percent of my time is spent in classes with other kids with disabilities, but none as significant as mine. The rest of the time I attend classes with non-disabled peers. It was not always like that; when we moved here from Cleveland, Ohio in 1990, I attended the Quest Center, a school for children with special needs which was not my neighborhood school. My parents and I are much happier with my present situation. My parents firmly believe that attending school with my peers will prepare me for adult life. They also believe that it is important for me to meet people in my community who will get to know me and, one day, can help advocate for me when I am no longer in school. Now I am making other people aware that people with disabilities have the right to be educated with everyone else, and that we too can do, learn and give back to others if we have the opportunity.

### GETTING HEALTHCARE SERVICES

We also overcame a few challenges with the healthcare system. I needed a communication device, and our insurance provider refused to cover it. My parents exhausted all the agency's administrative remedies, and appealed the case to

the Florida Insurance Commissioner. With the help of Florida's Advocacy Center for Persons with Disabilities we proved that the device met the definition of prosthetic device, as it replaced a body function. The insurance company was ordered to pay for the device. After the case was decided, the Advocacy Center used the same argument with the state Medicaid office, and now people in Florida and in other states are covered for augmentative communication devices.

More recently, in 1998, my local hospital refused to provide me with service. My mom told them that just as people are free to shop for groceries and clothes where it is more convenient, we also have the right to purchase healthcare services where we feel it is more convenient. Though the hospital finally did provide the needed services, my parents filed a complaint under ADA (the Americans with Disabilities Act) on my behalf and that of others in similar situations. The hospital was ordered to comply, and a settlement agreement was signed in 2000. One year later, however, I was rushed from school in an ambulance to the same hospital, and they again refused the procedure that they had refused in 1998. At that time we called a meeting with the hospital CEO and the administrator. My doctor, Dr. Patiño, and Jennifer Aubrey, my good friend and waiver support coordinator, accompanied my parents to the meeting. My parents saw this challenge as an opportunity to make things better, so they made a few recommendations to the hospital. The hospital took these recommendations very positively and seriously. It has hired a Special Needs Coordinator to coordinate services for individuals with disabilities; has formed an advisory committee, of which my mom and Dr. Patiño are members; and has made this program a top priority, with a goal of making it a model for other hospitals across the state.

### THE ROAD TO THE FUTURE

I will finish high school in 2004, and I am now very busy getting ready to transition to life after school. Getting ready for transition takes a long time. In my case, my parents started formally addressing my transition plan six years ago. It was not easy to come up with a plan. After a few years of meeting they decided to use a future-planning tool called PATH to help me to identify what I liked to do, and what I was able to do. We had the meeting in my house. I baked cookies for everyone, and we had facilitators who assisted us with the meeting. After discussing possibilities, my friend Jennifer came up with an idea: I could be a presenter, someone who uses audio/video technology to make presentations of information to groups of people. Dr. McGuire of Nova Southeastern University agreed, and said that the University could possibly hire me to do presentations. Al Farias, my former vocational rehabilitation (VR) counselor, said that his agency could help me to get the assistive technology that I would need to do presentations. Later, Al Farias and a few other school staff met and developed the first script for my presentation.

By the end of last academic year, I finally started practicing for that transition. With the help of my IEP team—which includes my parents, friends, professional staff from the community, the school, and their agencies, and me—I have my first PowerPoint presentation, “My Life is My Message.” I am learning to present it with the use of switches. I practice every day at home and in school. I have presented to students in my high school, undergraduate and graduate students at the University, healthcare staff at my local hospital, individuals with disabilities, and families.

With the help of my parents and Dr. Sherri Feldman, I am also developing an art business of my own. I do spin art using an adaptive switch and some adaptive brushes. I am now working with a few rehabilitation engineers to design a device to heighten my independence. I try to use my art as part of a useful product. I have started to test-market my first product: water bottles (with straws) that are decorated with sections of my paintings.

### WITH A LITTLE HELP FROM MY FRIENDS

I have been very blessed with many wonderful friends who have been a bridge in my life, helping me reach my goals and dreams. They know how much they mean to me, and I know how much they appreciate and love me. Besides my parents, my direct support professionals (DSPs) Sandra, Martha, and Marie are the ones that facilitate my participation at home and in the community. They are like family.

God has been very good to me by surrounding me with so many wonderful people. All the current members of my IEP team are my good friends and advocates. Dr. Patiño is my very good friend. Thanks to him, I survived a serious health crisis a little over a year ago. He also comes to my IEP meetings and to visit my family and me at home. My friend Al Farias is still on my team even though he no longer works with VR. He is going to help me write a book about my life, and has made presentations with me at local and statewide conferences.

Dr. Sherri Feldman and Denise Rusnack have been on my team the longest. Even though Denise works for the school district, she has been a great friend and advocate. Sherri is my private speech-language pathologist and the one helping me to develop my art business for my life when I've finished school. Dr. McGuire has given us wonderful ideas.

Without all of their help I would not be where I am today. I thank them for what they are doing to help me.

### THE BEST FRIEND OF ALL

Jeb Bush, our state's governor, has become one of the best friends to me and to my family. He has actually become our strongest “voice.” Even though he is now the Governor, to me, he is just my good friend Jeb. When he met my family and me, he wanted to learn about what it was like to be a person with a disability, and to understand the needs of families like ours. He didn't care about our political affiliation, or who we were. He was really serious about wanting to learn more about our concerns, our dreams, our ideas, and our struggles. The Governor wanted to know about the education of students with disabilities, about the services that we need in order to live dignified lives in our communities and with our loved ones. He was also interested in learning how people choose services and the services that were available. He was so interested that he came to our house, where he met several other families and individuals with disabilities, including some who live in group homes and other residential facilities, and some of our DSPs. He

visited with us, and with many of our friends. It has been an exciting journey for us and for him since we became friends. We still cannot believe all the wonderful things that he has done for people with disabilities since he became our Governor. Big changes in a very short time! (See "An Interview with Governor Jeb Bush" in this issue.) As he has met other people and families like ours, his understanding and commitment continue to grow.

Although I do not speak, it does not mean that I do not have anything to say. My life has moved my parents to be advocates for many people with disabilities. My mom and dad have been active leaders of the Family Care Council movement in Florida. My dad is a board member of the Advocacy Center for Persons with Disabilities, Inc., the protection and advocacy agency for the state of Florida. My mom sits on the Broward County Disability Committee and the Statewide ESE Advisory Council. Both are involved in other advocacy groups, as well.

I want to leave you with the message that no matter how unimportant you think you are you can still make your dreams come true, and you can still make a difference in your life and in the lives of others. We can't just wait for things to happen to us; we need to be active participants to make our dreams and our goals become reality. We all need to get involved, and make things happen. I am sure that you, like us, will continue to encounter challenges, but I assure you that if you view those challenges as opportunities To Love, To Learn, To Share, and To Serve, the results will always be positive.