

#ThinkABILITY

OLIVIA BLUE DE'FELICE

Our Story, Our Blessing!

By: Brian & Sher De'Felice

On October 11, 2007, our beautiful twins were born. Olivia Blue was first, one minute later Jayce Rock was born. It was the most bittersweet day of my life. The nurse brought the babies to me to breastfeed. Jayce was first and with no success, she then handed me my Olivia. When she opened her tiny slanted eye, out of nowhere I asked... "Does she have Down syndrome or something?" The nurse replied "babies with Down syndrome just 'don't get it'... from the first suck Olivia 'got it'!!!

Later that day the pediatrician came in to tell us he thought she had Down syndrome because she had several 'markers'. As family came in to visit us, we told them we thought Olivia had Down syndrome... they asked, "is the little boy NORMAL"? To us BOTH of our babies were NORMAL!!!

One the 3rd day, we were able to take both babies home with us. A week later it was confirmed... she had Trisomy 21 (the most common type of 3 different types of Down syndrome). We were then sent to a cardiologist because that was routine for babies born with Down syndrome. We learned she has a Patent ductus arteriosus (PDA). It's a heart issue and at



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19 Days old Olivia had closed heart surgery to correct the heart vessel. What was supposed to be a couple of weeks of recovery turned into only one week. We were back home and back to what we thought was a normal life. Then we realized we knew nothing about Down syndrome, except for what it 'looked like'.

As we began to learn the facts about Down syndrome, we also learned so much more. Throughout the past 9 years, we have learned so much from Olivia. She didn't have many of the Down syndrome related issues. She ate well, she slept well, she sat up independently, crawled and did many things with minimal delay, she was even walking independently at 16 months. She went to school when her twin brother went to school. Today they are both in 3rd grade and doing well. She even started Karate when he started at 4 years old. He is now a Jr Instructor, as well as, a Black Belt in Tae Kwon Do. She is a yellow belt who won't quit until she is a Black Belt too. She took dancing and so far, has danced on stage with the typical little girls for 2 years. She likes to fish, play ball, play with barbies and baby dolls, she plays video games with her brother, understands and navigates an iPad, cell phone, etc... she dresses herself, and more.

We feel her greatest teacher has been Jayce... as their mother, I knew she has also been his greatest teacher in life. He is so loving & accepting of others. He is well behaved, very disciplined and a high achiever. They spend so much time together, share their life with each other... however, as their mother, I also know I don't want to limit him, because of his sister's diagnosis.

We want to teach Olivia to be independent and work hard daily to prepare for her and Jayce's future. We have recently purchased a service dog for her. A best friend, a protector, to lead, guide and help her along the way as she grows. They are becoming the perfect pair. I believe that one day she will fulfill HER dreams. It is so important that we as parents ADVOCATE for our children's future and NOT limit them. We allow Olivia to show us what she can do, instead of assuming she can't simply because she was born with Down syndrome.

We do NOT put limits on Olivia, nor do we allow anyone else to limit her ABILITIES!!! She excels at what SHE enjoys, like ANY OTHER CHILD. She is just an AMAZING little girl, NOT at all the little girl we envisioned from the first doctor's description of what a child with Down syndrome would be. She

is SO MUCH more. She has touched so many lives in her 9 years and I pray she continues to touch others in a positive way... EVERY DAY OF HER LIFE.

She has changed my life, my perception of Down syndrome and my direction in life. I am more aware of the importance of advocating and paving the way for those who follow. When the twins were about 2 years old I started a 501 C3 organization called Blessed by Downs. We are the Southeast LA affiliate of the National Down Syndrome Society. We host the Southeast LA Buddy Walk® each year in the Fall. We advocate, educate, provide resources, promote inclusion and acceptance and so much more. I wanted everyone to see the positive side of Down syndrome. I wanted the FACTS out there... everywhere, so that when a parent is told: "your child may have Down syndrome"... that parent will understand everything will be OK and that there are other parents who welcome them and understand what they may be going through.

Our babies are our life. I thank God every day for our unexpected exceptional pair He has blessed us with. To us, SHE IS A TYPICAL LITTLE GIRL, who happens to have Down syndrome. We are THANKFUL and we wouldn't change a thing about her (or her twin brother), not even if we could... they are BOTH PERFECT EXACTLY THE WAY GOD CREATED THEM!!!



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#Think**ABILITY** is a month long social media campaign to celebrate the accomplishments of individuals with disabilities. The campaign is coordinated by Families Helping Families of Jefferson and held annually during the month of **March**. Learn more about it at <http://fhfjefferson.org/whats-going-on/special-events/thinkability>

Changing Lives. Every Day.