



LaJoy Johnson-Law

Chronic Obstructive
Pulmonary Disease (COPD)

My daughter, Abria, was born at just 23 weeks in utero. She was just one pound and six ounces. The doctors diagnosed her with chronic lung disease and epilepsy as well as a developmental delay, due to her extreme prematurity. New motherhood is a difficult time for anyone, but with a daughter with special health care needs, I was running on fumes. We had no car at the time and lived in an older building in Washington, D.C. that lacked an elevator. Imagine carrying this precious baby and her health equipment around—medications, oxygen, as well as diaper bags and other necessities, up three flights of stairs. Oftentimes this was my daily routine, and it was a lot for me to deal with. Physically and mentally, I was overwhelmed.

At first, I managed by just going into active warrior mom mode. I had no time to worry about myself because my baby needed to be taken care of. My motto was, “Abria comes first.” I would just pray to God to take care of the rest. The financial challenges felt impossible. I lost several jobs due to putting my daughter and her health care needs first. Between inpatient visits, outpatient doctor visits, therapy appointments, and her being too sick to go to school, it was a struggle to balance it all.

At one point, things got so bad that we even got a writ of eviction and were facing homelessness. My dad also passed at that time, and I was also going through a divorce on top of everything. That was the time of the biggest financial strains. Thankfully, Medicaid kicked in and I was able to cover most of the costs for her medications and treatments, however, the anxiety I felt then was crushing and seemingly inescapable.

I dealt with it by reasoning with myself: Am I stressed? Yes. But am I also fighting for my life? No – my daughter is, though. She was literally walking that fine line between life and death. It was heartbreaking. There were times when her doctor would say to me, “Abria is very weak right now. We’re not sure she’s going to make it.” They even had me plan a funeral for her in case things took a turn for the worse. There was just no telling which way it could go for my baby. In those moments, I leaned on my faith and my family. My mother and my godmother were an amazing support system for me. My mom would step in and care for Abria for a weekend

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every so often just to give me a break. My godmom would pick her up and take her to school sometimes. I was so grateful as every little bit and every act of kindness helped.

It has been a long journey, but Bria is now 12 years old and so much has changed. She is in much better shape now and so I call her my “miracle baby.” She is doing so well thanks to the health care and therapeutic providers, her school and the world of support we received from them and my family and friends. Despite having to take daily medication, she’s active and just a joy to be around. She is now enrolled in taekwondo classes and just started swimming classes. She has so much energy and curiosity and I am incredibly proud of and inspired by her every day.

My life has also changed a lot. As Abria started to get older, I decided that the best way I could help myself was to be of service to others. There is a whole community of support available for parents in situations like mine. I got involved a few years ago with an organization called Parents

Amplifying Voices in Education and I am currently on their board. I am also involved in various other social services organizations in a volunteer capacity.

It truly does take a village to raise children, especially when they have special needs. It is a team effort that includes doctors and clinicians, teachers, church groups, neighbors, family, and friends. I was not able to do this alone. What I want other families who may be going through similar situations to know is there are teams of people in place to be able to assist you and get your children what they need to thrive. Amazing people are out there who will wrap their arms around you and your family. You are not alone. You don't have to do it alone. We are your community and we support you. ●

Chronic Lung Disease (COPD)

Chronic Obstructive Pulmonary Disease (COPD) is a preventable and treatable lung disease. People with COPD must work harder to breathe, which can lead to shortness of breath and/or feeling tired. Some other facts about COPD are:

- Although the most common cause of COPD is tobacco smoke, there are several other factors that can cause or make COPD worse, including environmental exposures and genetic (inherited) risk.
- Common symptoms of COPD include feeling short of breath while resting or when doing physical activity, cough, wheezing, fatigue, and/or mucus production that does not go away.
- Some general classes of medications to treat COPD include those that aim to widen the airways (bronchodilators), reduce swelling in the airways (anti-inflammatory drugs, such as steroids), and/or treat infections (antibiotics).



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