

A Rare Diagnosis

Rev. Elaine Sanford, Executive Director
HER Faith Ministries
NBA Incubate Initiative Affiliate Ministry
October 2017



For many people, September 11th will forever be remembered as the infamous day in history when terrorists in the United States used airplanes to kill thousands of Americans. But, one Memphis mother will remember September 11, 2017 for another reason. It was the day that her youngest child, ten-year-old Doreen J., was diagnosed with a congenital medical condition that most people cannot even pronounce. It is called perisylvian microgyria, a brain disorder, which causes symptoms of memory loss, muscle spasms, slurred speech, difficulty speaking and seizures. The neurological condition, which causes patients to suddenly lose consciousness, is

extremely rare and apparently develops in vitro; although, symptoms may not show up for several years.

The diagnosis came as a surprise to the family because the ten-year-old has only had problems with hearing loss since childhood. In fact, Doreen has made numerous trips to the doctor to salvage what they can of his hearing; and he, in fact, he has a cochlear implant. But, Doreen's mother thought that the hearing problems were the extent of her son's medical problems. That's because, until this diagnosis, Doreen has been an otherwise normal, healthy and happy ten-year-old who loves to ride his bicycle, who runs and plays with his sisters; jumps and plays ball with his friends and does whatever he sees other boys his age doing.

But, all of that changed on September 11th when Doreen collapsed for the first time in his classroom at school. After being rushed to LeBonheur Children's Medical Center in Memphis, Tennessee, doctors performed a battery of tests on little Doreen who remained unconscious most of the time. Eventually, to the shock and dismay of his distraught single mother, doctors pronounced the unusual and rare disorder.

Where did it come from? Were there signs or symptoms? Well, Doreen's mother reflected on his life, and she recalls at least two or three other occasions

where her child has seemingly blacked out. But, each time, doctors advised her not to worry saying that it was nothing that a little rest and relaxation would not cure. They thought that Doreen had simply overexerted himself and that this was leading to his problems. Needless to say, no one could have guessed that his prognosis was much more severe.

Doctors have said that there are only 33 cases of bilateral perisylvian microgyria in the world; 23 are in the United States and one other case has been identified in Memphis. Doreen has one of the most severe forms of the condition. So, doctors have not been able to give a definitive prognosis on what the future might hold for Doreen. All they can do is to monitor his condition right now, try to keep him comfortable and try to control the blackouts and seizures as best they can. It is not known how long Doreen will be able to live with this condition.

HER Faith Ministries has been supporting this family throughout Doreen's medical journey. Thus far, the family has needed assistance with housing, utilities, emergency food, clothing and other basic needs. The ministry has assisted the family with funds to keep the vehicle operable, replaced a hot water tank, and replaced worn bedroom and living room furnishings. The mother has been unable to return to her job as a grocery store cashier, because she has not been able to establish a sitter to provide care for her son.

Doctors have said that Doreen will soon need a wheelchair, a soft helmet and other medical gear as his condition starts to progress. The ministry will continue to support this family as needs present themselves.

The NBA incubates new ministries, supporting social entrepreneurs of faith who are serving their communities in a variety of innovative ways and empowering these Disciples-led health and social service projects to focus on growth, impact, and sustainability. Learn more at nbacares.org/incubate or by contacting Rev. Ayanna Johnson Watkins, Director of the NBA Incubate Initiative, at awatkins@nbacares.org.