



The Patient Charity

## **"I don't want another mother & baby to have to go through what we did."**

**A young mother who survived a life-threatening tear in her body's biggest artery while three months pregnant is publishing new advice for women at risk of aortic dissection during pregnancy.**

Three months into her first pregnancy, at the age of 21, Haleema Saadia suffered an acute aortic dissection - a life-threatening tear in her body's largest artery, which carries oxygenated blood from the heart to the brain, limbs and vital organs, including the womb and her unborn baby. A lack of awareness of this lethal condition meant that it took 30 hours for the medical team at her local hospital to diagnose Haleema's serious illness with a CT scan of her aorta. When it was eventually discovered that she had an aortic dissection, in Haleema's words "all hell broke loose", and she was transferred by blue-light ambulance to the QEII hospital, Birmingham. Once there, cardiothoracic surgeon Mr. Jorge Mascaro performed extensive open-heart surgery to save the life of Haleema and her unborn child.



Miraculously, Haleema's beautiful baby daughter Ruqqayah was born four months later. This week, she celebrates her 5th birthday. Although Ruqqayah and Haleema both have lifelong medical issues due to the delayed diagnosis of her aortic dissection and extensive open-heart surgery during the pregnancy, they are now at the forefront of the campaign Haleema leads to prevent this from happening to other women and their babies.

"What troubles me most is that this was all so avoidable", says Haleema. "I come from a family with Marfan syndrome, one of a number of inherited

genetic conditions which significantly increase the risk of having an aortic dissection. I was under the care of a cardiologist at my local hospital in Birmingham, but no-one ever told me about the risks of this happening during pregnancy. I was not referred for pre-pregnancy counselling, as I should have been. When I became pregnant and attended the maternity clinic, I told them I had Marfan Syndrome, but I was not identified as being at risk of aortic dissection during my pregnancy and I was not managed any differently from women who don't have this risk. Consequently, no-one thought about aortic dissection when I went to A&E, three months pregnant, in the worst pain I have ever experienced in my life. If someone had just said something to me about the risk, my life could have been completely different."

Dr. Stephanie Curtis, a consultant cardiologist from Bristol who specialises in aortic disease and obstetric cardiology, has worked with Haleema on the new leaflet, titled: 'Planning Pregnancy with Aortic Disease'. She explains, "Haleema's case highlighted an unmet need for written advice to be given to women at risk of an aortic dissection during their pregnancy. To meet this need, we worked together with the national patient charity, Aortic Dissection Awareness UK & Ireland, and produced a patient-friendly advice leaflet for women who are at risk. This leaflet is particularly important for women with known genetic aortic diseases, such as Marfan syndrome, Vascular Ehlers-Danlos syndrome (vEDS), Loeys-Dietz syndrome, Turner syndrome and other aortic diseases which run in families. Women with these conditions are all at increased risk of aortic dissection during pregnancy. They need pre-pregnancy advice & counselling, as well as careful surveillance and management during their pregnancy and immediately afterwards."

The new leaflet is available as a PDF download from the national patient charity's website [www.aorticdissectionawareness.org](http://www.aorticdissectionawareness.org). Launched on the 4<sup>th</sup> September, Ruqqayah's 5<sup>th</sup> birthday, the charity plans to distribute the advice leaflet to women at risk of aortic dissection during pregnancy directly, via the cardiologists, geneticists, obstetricians and midwives who care for them, and via other relevant charities such as The Marfan Trust and Annabelle's Challenge (the vEDS charity).

The Chair of Aortic Dissection Awareness UK & Ireland, Mr. Gareth Owens, said, "This leaflet is a fantastic new information resource for women who are at risk of aortic dissection during pregnancy. It will prevent other mothers and their babies from having to endure the ordeal that Haleema & Ruqqayah faced, or the tragic worst-case outcome, where some mothers and their babies have sadly not survived. I commend this leaflet to the medical profession as one way in which we can get better at managing aortic dissection, which continues to be a leading cause of cardiac maternal death and more generally, is responsible for more deaths in the UK each year than road traffic accidents. This is a really important initiative that Haleema is leading. It deserves our full support." The leaflet can be downloaded here: [tinyurl.com/AortaBaby](http://tinyurl.com/AortaBaby)