

## Ayaana Daruka

Hi! My name is Manisha Daruka. I live in Jaipur in India. I have a 5 year old son, Ahaan, and a 1 year old daughter, Ayaana. Neither my husband nor I have any family history of FMD or any stroke related disease, but my daughter Ayaana has been diagnosed with FMD recently. Till the age of 7 months, Ayaana was perfectly healthy and a normal kid with no symptoms of any kind of illness.

On 12th April 2011 when Ayaana was 7 months, she was cranky and irritable all day. We consulted her pediatrician who suggested it might be a stomachache or urinary infection, which is quite common at that age. Two days after that Ayaana had convulsions. We rushed her to hospital, and after inspection doctors told us that she had a stroke, which affected the right side of her body. There were no pre stroke symptoms. The stroke was confirmed by the CT scan, which showed infarcts on the left side of the brain. The doctors at that time could not diagnose the reason for the stroke. For the next 2 weeks she was playful and improving physically with physiotherapy.

After 20 days, Ayaana was very irritable and crying all day. We took her to the doctor but they suggested we should wait as they didn't see anything specific. Later that night, when I woke up to feed Ayaana, I noticed her left limbs were not moving. Doctors confirmed another stroke, this time on the other side of the brain, the right side. The brain MRI and MRA studies revealed an acute infarct in right occipitoparietal frontal. Jaipur, being a small city with no advanced medical facilities, we were suggested by the doctors there to move Ayaana to another hospital in Mumbai.

Ayaana was admitted to the hospital in Mumbai. After running various tests and scans, investigations showed B/L internal carotid artery stenosis and marginally thinned out MCA. She was also found to have baseline high BP above the 95<sup>th</sup> percentiles. Hence renal Doppler was done, but were normal. Rheumatologist was referred to rule out the possibility of vasculitis. PET CT for vessels showed no activity. As the investigations were not so conclusive doctors decided to give a 2-week steroid trial.

On 23rd May 2011, Color Doppler examination of the Arterial System of both upper and lower extremities was done. In the lower extremities the left PTA was found tortuous with intimal thickening and beading. As for upper extremities, a significant stenosis (>75 % diameter reduction) was seen in distal left axillary proximal brachial artery. On the right side there was an area of stenosis (>50% diameter reduction) in the axillary proximal brachial artery.

On 2nd June 2011, we got another renal Doppler done. Investigation showed both the kidneys were normal in size but the intrarenal arteries on both sides showed mildly raised velocities (>200 cm/sec) with borderline high RI values. A color aliasing was seen in proximal renal arteries bilaterally suggesting proximal segment stenosis.

On the evening of 2<sup>nd</sup> June, Ayaana got very cranky and we rushed her to the hospital where it was found that her BP was 177/102. The interventional Radiologist at the hospital reviewed her MRI and MRA films and decided to do balloon angioplasty of both the carotids to avoid further stroke.

On 4<sup>th</sup> June 2011, DSA was done s/o FMD involving carotids & left renal artery. Angioplasty was done for the left ICA.

On 8<sup>th</sup> June 2011, just 15 minutes before she was to be taken for a second plasty, Ayaana collapsed with left focal convulsion following a small dose of IV Midazolam. She was intubated and a short CPR of 15 sec was given to her. After this collapse MRI + MRA showed a new infarct on the right frontal periventricular white matter, focal stenosis in the proximal right cervical ICA. She was kept ventilated for 48 hr.

On 10<sup>th</sup> June 2011, second balloon angioplasty for the RICA was done. Renal films taken at that time did not show any remarkable renal vessel narrowing. Decision was made not to plasty the renal vessels at this time. No stents were used in both the angioplasty citing her age.

Due to the repeated punctures on the right thigh for the Angioplasty (puncture was always made on the right because there was a higher stenosis in the left leg), blood flow reduced considerably in her right leg. Just by touching I could feel her right feet colder than the left. Doctors suggested that this is a common phenomenon after punctures and will improve with time.

She was discharged after a few days and put on regular physiotherapy. Her blood pressure continued to be of concern and we were advised to check it at least 3-4 times a day. She was put on labetalol, ACE-inhibitors and amlodipine. Her BP slowly came back to the target of 120 systolic with these medicines. But for the last one month it has been rising again and doctors advise that she is already on maximum doses of these medicines. Currently she averages 160 systolic. We are scheduled for another CT Angio this week to see if there have been any developments on the renal artery stenosis. The last carotid Doppler revealed a mild narrowing in her left carotid compared to the state after balloon angioplasty, but doctors suggest its not threatening right now.

Doctors here are taking Ayaana's case as it comes. Ayaana is 14 months old now. They say that at her age, the disease can be more aggressive than in adults, though we are hoping that Ayaana grows up to be a normal kid. She is always smiling and happy like nothing has ever been wrong with her. I am very proud of her. Her smile gives my family and me a lot of strength and hope. I am waiting for the day when she walks and talks to me.

I hope story of Ayaana helps others and those who read her story can probably help her too.