

#it\_is\_our\_story

I was born in a small village in Bangladesh. After four-year latter, one of renowned child specialist diagnosed me as E-beta thalassemia and given a prognosis that my lifespan will be 15 to 20 years. My parents expected another child for their future security and focus on my sister's education. I had grown up with inadequate transfusion and series of maltreatment. sometimes my parents took India for better treatment but most time they can't follow the treatment procedure due to the high cost. Till my university admission, my father come with me when I'm going for transfusion. My entire life most of the time I had took transfusion in Rajshahi Medical College. In the medical college, some of the doctors had a good manner but most of the intern doctor treated thalassemia patient like an animal. Thalassemia patients were low priority because the emergency word has lots of serious emergency patient. When I was in honors 3rd-year student one lab assistant in blood bank yell me badly. He told me that you are a patient, why your name is too big. I replied him next transfusion time I will entry my first name only. Twenty years I had taken whole blood cell transfusion instead of packed cell blood. Due to technical blindness in our medical system. Still our country 80% thalassemia patient transfused by whole blood cell. In 2015 I have admitted in the profession MS degree on clinical psychology in Dhaka university so I had shifted in the capital city Dhaka. In Dhaka condition is a little bit improved. Here I could manage pack cell blood with respect. My blood group is A negative which is quite rare in our country. Most of the blood donor is flexible but some of have the mentality to donate blood only for emergency operation, child, poor people, and a pregnant woman. But I am an adult with transfusion-dependent thalassemia. Last three month ago I have visited India for better treatment and my LDH report is high so doctor suggest me for phenotype blood transfusion. In Bangladesh, only two centers have this capacity to provide phenotype blood matching but it is not hassle-free yet. In Bangladesh every day 20 children born with thalassemia. Every month I'm getting news of thalassemia patient death due to a transfusion reaction, iron overload or splenectomy. Our government is still reluctant on this issue. Last year I have shifted another location due to my workstation which is 416 far from Dhaka. Every 15 days later I need to travel 416 kilometers to complete my transfusion procedure. Still, I'm fighting with hope. I don't know how many days I will do this.