



GLOBIN GENE GAMES



Namitha Kumar receives one of her regular, live-saving blood transfusions; her transfusion nurse Sameena Mariam in attendance.

Only when this photograph was taken and the explanation for it given did Namitha and Sameena realise that they had both submitted stories and – respectively – won first and second prizes!

Namitha Kumar: India

In a hospital in India, I lie still as I go through a venipuncture for a blood transfusion. I watch as the needle enters my vein and blood rushes into the scalp vein set. I watch as I am hooked to the packet of blood that screams “B+ve.” This is a familiar routine each month since the age of four. I am now well into my thirties and this routine blood transfusion is my lifeline. My passport to a living. I have a genetic blood disorder called Thalassemia and my life depends on this lifeline of blood transfusions.

Call it fate, call it bad luck, misfortune, my life is a result of the game played by my familial genes and ancestry. I call it the trickery of delta and beta because of my delta-beta Thalassemia variant. Delta and beta played a cruel game with me. The globin gene supposed to produce sufficient hemoglobin to carry on life activities has a mutation preventing the production of normal hemoglobin.

My life has always revolved around blood. Either I am giving blood for lab tests or taking blood transfusions. The test tube with blood and the IV line are symbolic of my struggles with this blood disorder. As a child, I hated the sight of blood and didn’t want to look at it. I always looked away as I was being pricked and I never wanted to look at the blood packets. Soon I realized that I must make friends with my enemies if I have to live better and stay

positive. I started accepting that blood will be the fulcrum of my life till there is a therapeutic cure. I accepted the play of delta, beta and the globin gene games. I said "Hi" to Thalassemia and finally invited the rogue home. I realized that I have to pacify the enemy if I have to continue living and have a fairly decent life. After all life is not just about blood games but much more. In the midst of running circles over blood, I got an education, made friends, had fun and did everything that any normal human did.

I learnt to listen to the whispers and stories of delta, beta and the globin gene. I picked up early warning signs when things were not going well. Sometimes I pleaded with them to leave me in peace and let me be like any other normal person. Sometimes they left me alone and disasters were averted. At other times, disasters descended like angry, storm clouds. In such times, blood became the center of everything as a minor interruption would result in rapid hemolysis. I was left hanging on to packet after packet of blood as delta, beta and the globin gene waged a nuclear war in my body. There were times when I didn't know if I was alive or dead. I clung on to life hoping that the blood games would cease and let up. And truly it did. After the war abated, I was back to the driving seat of life in full control. Blood had played its games but it also saved the day as I always got enough transfusions to pull me through the several interruptions.

Life goes on it all its complexities yet I continue to see the beauty and thrill that it offers me. I am tied to blood always. My life timetable revolves around taking blood transfusions. Planning a transfusion, being prepared for emergencies and taking on everything that comes by – good or bad. I am hopeful that gene therapy will bring succour to the lives of all those with blood disorders like mine.

My identity is not just a clinical or medicalized one but a richer, deeper and more meaningful concept going beyond any genes. I learnt to live life for whatever it offers me and I am happy to be a part of this colorful world.

I know nobody is immortal, so as I lie dying someday...

"Let me not be filled with regrets.

Let my memories fill me with pleasure and happiness on the various thrills I experienced in this world.

Let me leave happily and at peace that I took the best and enjoyed what I could."



ELIXIR OF LIFE



Sameena Mariam: India

Hope is a four-lettered word. Hope is the thread that holds humankind together even when the worst disaster strikes. Hope is the magic that enables people to look into the future and wish for a better tomorrow. Hope is the light that we hold on to when there is darkness all around. With this hope, my young patient Nisha lives on waiting for a tomorrow that will bring her a cure. She is a survivor and she has swum against the tide of the most turbulent waters of life.

I hardly knew anything about her disorder when her father first came to my blood bank in Bangalore, India. The Rotary-TTK blood bank runs a day-care for transfusion-dependent rare/genetic disease patients. We have a mixed group of people with Thalassemia, Hemophilia, Aplastic anemia and other rare blood disorders. But Nisha was a unique case. I enrolled her into our centre after getting my supervisor's permission. Little did I realize what I was getting into. My heart had gone out to this young, suffering child whose pain I couldn't fathom though I could empathize. The recollection of her image is still a shock when I first saw her. Nisha had a blood-stained mouth, nasal plugs (to stop nasal bleeds) and was in a sorry state. She has factor VII bleeding disorder which is autosomal recessive (inherited through both parents who are carriers).

I saw her parents helplessly running from pillar to post, caught in the health care system trying to find a solution to keep their daughter alive. I was deeply moved and thought that I must do the best I can for this child. She had suffered enough having had 3 craniotomies till date. She had very poor hygiene as she could not brush her teeth or scrub her hair and skin vigorously. She was afraid to even rinse her mouth. Her blood stained teeth made people think that she chewed betel leaves. Even in school she didn't have friends as they were put off by her poor hygiene and blood stains. Not many blood bank staff was willing to handle her because of her sensitive and risky condition. She had hematomas all over her body and it was difficult to find a vein to transfuse.

We put her on plasma transfusions to stop her from bleeding profusely. She also needed frequent blood transfusions as her Hb would go low from the many bleeds. Her blood group was B-ve and it was very hard to find packed cells that she needed. We did our best to get her transfusions on time. The little time I got with her in the blood bank I added my healing touch. This little angel who was suffering so much for no fault of hers! I tried to prick her as gently as possible. Let me not add to her existing pains. I felt very pained each time I saw her sufferings. With her the family also suffered. She studied in the same class as her younger brother who helped her in studies. She often missed school and lost out on classes. Still she hung on with hope that something good will happen. She and her family lived on hope. It was the elixir of life along with the blood and components.

Nisha's life took a turn for the positive after we put her on prophylactic transfusions. This treatment changed her life totally. She became better with fewer bleeds. Her health improved and she started going to school regularly. She made friends, played and did well in studies. She was able to maintain better hygiene with simple tips. Her parents were relieved and they could focus on other aspects of life apart from running around hospitals! At least some semblance of normal lives in their family. This treatment really set them on a positive track and they became hopeful of better times to come.

Today, Nisha leads a somewhat normal life as any other school kid. She studies, plays and has fun. She lives in hope that someday she may be cured. She may be like other kids. She has big dreams that she will study and research into this disease and maybe bring out a cure. She dreams of a world free of such disorders that take away childhoods and rob a child of fun and play. We take a leaf of hope from her life. All her pain she conceals with smiles and courage. She wants to live and she wants to live well and do everything that any other child can do. I am thankful that I took on the task of her transfusion support and care and helped her in her journey. I look back at the day I first saw her with her nose and teeth stained and crusted with blood. I look at her today and feel hopeful that she will do well in life. She will go forward positively and it is this hope that propels all of us to move ahead in life no matter how hard it knocks us down. Nisha to me is a symbol of living hope. I hope for a better and painless future for her and all kids like her.





DONATE TO SAVE LIVES



Dr. Muneeba Azmat: Pakistan

Of all the things, Haematology? That's like a subspecialty! Why aren't you going for something for Surgery or Gynaecology?

Ever since I have cleared M.B.B.S (Bachelor of Medicine and Bachelor of Surgery) and told people in Pakistan about my future aspirations to choose blood related field, this has been the unequivocal response. How did I ever get here?

2nd Year M.B.B.S:

6th August, 2011. We had little patient interaction back then learning mostly from books. We organized blood cancer awareness day, I was in charge of patient psychotherapy stall where young leukemic patients were taken care of and were busy playing games. That's where I met Hassan, a child of 4 years suffering from ALL, a type of cancer that destroys blood cells.

His father told me about the troubles they have to go through to arrange blood for Hassan, as he needs transfusion every week. As fate would have it, Hassan started bleeding from his nose and mouth. His platelets had dropped precariously low. He was rushed to the hospital where he was stabilized for some time. The disappointment I felt when I rallied for collecting donation was immense; people were reluctant to donate blood. Hassan would receive blood at times and at other times he'd go back without getting transfused. This continued for a few weeks. Hassan died one month after I met him, on the 6th of September. While he was being rushed from his village to the hospital, he slowly bled to death.



Hasan and his Dad

4th Year M.B.B.S:

Bijloo was with a child. It was a complicated pregnancy and C-section was indicated. However it was still pending since Bijloo's Hb was 6 g/dl and operating under such condition could take a toll on her heart and cause her death. She was from Kabul and couldn't understand a word we said when we tried to convey she has to arrange blood. Ultimately we contacted her husband and told him operation would be impossible without arrangement of blood. The husband looked at us calmly and said, "Our men do not bleed for women, donate blood yourself if you want to save her, I leave her in Allah's hands" Bijloo was saved by donations from medical students. But in a tertiary care hospital with daily influx of hundreds of patients, relying on students alone is inadequate. When the Gynaecology and Obstetrical ward made it compulsory for patients to submit one bag of blood in order to admit the patients to avoid cases like Bijloo, they were called butchers and sadist by the patients' attendants.

Final Year M.B.B.S:

16th December, 2014. A group of terrorists attacked Peshawar in an army school to seek revenge. More than 250 school-going, unarmed kids were made hostage and then butchered. Those who survived saw lines upon lines of volunteers teemed outside Peshawar hospital to donate blood. People collected blood from other cities and transported blood bags to Peshawar. There has been no audit on the donated blood and the optimist would say that the excess blood was stored in Hospital for future use. However, the number of donations far exceeded the hospital storage capacity. Some speculate that the blood was wasted; others maintain that any disastrous situation that calls for donation camps is misused by private unregulated blood banks which store the blood and later sell the blood to patients.

The above stories are just a glimpse of how distorted the Blood Transfusion Services are in Pakistan. The concept of voluntary blood donation is absent, the patients are supposed to arrange blood for themselves usually asking help from family and friends. In case of a mass disaster, when people do come to donate blood, the collection and transport is highly unregulated. I am already a part of Safe Blood Transfusion Programme aimed at straightening the highly kinked and complex transfusion system of Pakistan. Let's see how far it goes.