A Brother's Gift of Love

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Ibadat (name changed), a young man in his early twenties, came to the Medical Genetics out-patient department for consultation regarding his younger brother who was seen about a decade ago in our department. He was depressed as his younger brother had become bedridden and the rapid deterioration and impending serious complications were obvious to the family. Ibadat's brother was seen at 8 years of age and was diagnosed to have Duchenne muscular dystrophy (DMD). Ibadat told us that we had told the family to keep in touch so that when the treatment becomes available, they can get information about it. As Ibadat grew older and could not see his brother suffering, he thought it was his responsibility to try his best. He was visibly disturbed and felt desperate. We often tell families to keep in touch as most of the patients are lost to follow up and we do not have any multidisciplinary special clinic for patients with muscular dystrophy. Over the last 3 decades, every time when I tell a family that there is hope for new treatment, I try to convey some positivity without giving dramatic hope. However, in my mind the hope of curative treatment for DMD continues to have highs and lows and over the last decade it is becoming lower and lower. I realistically feel that effective therapies are around the corner, but unsure about how many turns science will take before reaching the last turn.

Ibadat had come with great hope. He might have collected some information from the internet. My truthful negative answer for his bedridden brother at home brought sadness and wetness to his eyes. Just giving a few moments to him, I mentioned about the need of prevention. The need for carrier screening and genetic counseling was reiterated. I checked the patient records with Ibadat to see if the mutation had been identified. Yes, it was there. I drew the updated pedigree of the family. His two sisters had got married; one sister was of marriageable age. Did my job of reinforcing the need for carrier screening for such a serious disorder for which cure is still not in sight! I was not sure whether he was convinced or still drowned in the sea of sadness.

After a few weeks, he was there to meet me, on the date of appointment. His sisters, all three, and a nephew were with him. He again mentioned about the brother who was not well, but understood the formalities of the testing of sisters and started getting them done. Getting up from the floor was not easy for the four year old nephew. Over few more visits, some bond developed between us, as happens with many of my patients. It is not only a doctor-patient relationship, neither is it friendship, but it is strong on the one hand and gives strength to both the parties. Ibadat shared his emotions, which reflected positivity of doing right things for the sisters and for the family. He agreed that he will take care of getting prenatal diagnosis done for his sisters. Though the sisters themselves understood, they needed support and the brother took it up as his responsibility. I asked about the eldest sister whose son was affected. I asked him, whether he had disclosed the carrier status of the sister and the disease status of the nephew to his brother-in-law. This is a challenging situation and a dilemma for the family. The close relations between a husband and wife are sometimes fragile. Ibadat had the right qualities and the right approach. He said it is important to be truthful to avoid further problems. The sisters were nice and participated in the discussions to some extent. But the sensitive brother was the strong pillar of the family. He was truthful and logical, and understood and believed medical science. His visit initiated a useful chain of extended carrier screening. His prayers (Ibadat) will help the family and gave me the satisfaction of a fruitful genetic counseling experience!

Amen!

तथास्तु (Tathaastu)!