

MOKSH CASE STUDY

Birth defect- Q 33.6 Hypoplasia and dysplasia of lung Q 24.0 Dextrocardia, Q 39.2 Congenital tracheo-oesophageal fistula NOS (Severe)

My name is **Suman Devi (3rd gravida)** and I got married on **18th of February 2012**. Moksh is my 3rd child before him. I have **2 daughters**, my **first delivery was in March 2013** and **second delivery was in March 2014**. Both my daughters were delivered by **normal delivery** in **Saini Hospital (Mullana)**. Both are good in studies, writing or in speaking, everything is absolutely fine with both of them.

Mother told me that Moksh was conceived on **10th of February 2017** and the whole 9 months were very good, I used to be **Nausi only for 4 months** afterwards there was no problem. During pregnancy I had **3 Ultrasound** done in **4th, 7th and 9th** month, and when the doctor of **Saini hospital (Mullana)** was shown, they did not tell us that the child had any problems and said that there is **too much water in your stomach**, so water, juices, milk all liquids has to be stopped and said even after eating has to drink only two sips of water. Then on **10th of December 2017 at 4:29 Am** I delivered a baby **boy by normal delivery** whose weight was **2800 grams**. Father told that when we came to know that after 2 girls there was a boy, we became very happy and started thinking that I will go home and distribute **“laddus”** to everyone, bring **“sweets”** and

will do celebrations, **then at 8 o'clock**, when I came to know that the child **had got pneumonia**, we all became very sad.

Mother told me that **after 2 hours** I saw my child. By then everything was fine. Then the doctor told me to feed the baby, then we saw that he was throwing the milk out. I fed the baby twice and both times the **milk was pumped out**. The mother said that when the child was in **her grandmother's lap**, she saw that the child was **having difficulty in breathing**; we got scared that why the child is breathing like this again and again. In starting the doctor **kept ignoring us**, did not listen to us, we were afraid that the child would die like this, but when the child started having **a lot of trouble**, then the doctor checked the child and said, take the son to **Ambala** because we do not have machines, then we brought the child from **Mullana to Ambala at 8 o'clock** in the morning, At that time he was **only 1 day**.

At that time **hospitals, shops were closed**, then one of my colleagues told me about “**Star Hospital**” that there is a “**Sikh doctor**” and he is very good, so we took the child to **Star Hospital (Private)**. There the doctor admitted the child and kept him in the **glass machine** because the child had a **problem in breathing** and had **developed pneumonia**, but I didn't tell him about the feeding problem. Only my mother and I were with the child, at that time **my wife was not with us** because she was admitted in **Mullana Hospital for one day only**.

The **sorrow was extreme** when the child was crying without a mother and we could not be able to do anything. Whenever we used to go to meet the child, he used to **lie in a glass machine**, sometimes he was not even conscious, and sometimes he was found sleeping. I still remember **on 11th of December 2017** they checked the child and **started glucose**. Then the next day **on 12th of December**, when the staff tried to feed milk, the child did not drink milk and pumped it out. The staff didn't tell us that the baby is pumping out milk, just said that the **chest is congested** and has pneumonia. The doctor had already doubted and then the doctor called me and said that there is **something wrong with the child** because such a case had come to us earlier also, then early morning on **12th December the doctor did all his tests and X-rays**.

Father said that only I know how I took care of the child and I still remember the day when I took the baby for his X-ray on **12th of December**, So that day it **was raining very heavily**. When I went for an X-ray alone without his mother by taking the **2-day-old baby in my arms**, there was also a fear that the baby might get wet in the rain. I wrapped the child in a **double blanket** and covered myself too with the bed sheet and **took him to the X-ray in the rain**, so that he doesn't get cold. I still started to cry when I remembered that day, when I reached for an X-ray, the doctor said to **take off the child's clothes** and lay him **on the table**. I felt so sad that **during December** when it was **so cold outside**, I had to **naked a 2 days child**. My soul trembled and I cried because I would have **to hold the child with cold hands** and at that time my hands were so cold due to getting wet in the rain. Then I requested to the doctor that can you

please put the child to table, than he also **felt pity on me** and helped me to put him on table and did X-ray. I **waited for half an hour**, then when the report came, I took the report to show the doctor.

Father told me that my **maternal uncle's grandson also** had the same **problem and there was no food pipe**. So even before showing the X-ray reports to the doctor, **I saw the X-ray image** and had a doubt that my child might also have same problem and started thinking that **there is no pipe in X-ray, that's why the milk is pouring into the stomach and falling into the lungs** and that's why pneumonia is happening again and again, Then I was scared even thinking about it because if he had died then what would happen to my child.

After seeing the X-ray report, the doctor called me so that Son sat with me for a minute and said, you will have to go to PGI, he will have surgery. The doctor **didn't shock us at once** but **told us gently** so that we wouldn't panic. Initially the doctor did not tell us about the defect, only said that you will have to go to PGI and I said ok will take but what is the problem, Then he **explained with great love that don't be afraid**, the baby's feeding pipe is a bit small, When we feed milk to the child, it falls into the kidneys, due to which the chest gets congested. I was scared about how I will go because I have never been to PGI before and have never seen it. There were many questions in my mind too, then the doctor said that you will have to go.

The **doctor was very nice** and said, son if I had a machine, I would have treated this child. He **encouraged me** that the child has a **99% chance out of 100 to survive in PGI**, so don't worry, your child will be cured from PGI. My mind wandered, I started crying, then **on 12th December, in the evening I reached PGI**. I came to know that my “Maasad Ji” and an “uncle” from the villages work in the same PGI, Then I called them, then with their help I got the child admitted. After that there was a lady doctor, she asked what is the problem of the child; I told all the problems of the child. Then for the operation the doctor got me to **sign the consent paper** but before signing he did not tell me about the consent paper. Then when I asked, they said that we have no responsibility for the operation and the doctor also said that when the **child will be 5 years old** then we **will do another operation** of the child and change the **small pipe and insert the long pipe** and at that time the weight of child should be more **than 15 kg**, I was alone at that time, so I was just putting my hope on God that somehow the child would be saved. Then I called my brother-in-law and he came to me at night because the next day **on the 13th of December, the child was to be operated on**.

My mother was together while taking the child to PGI and we used to **continuously cry the whole time on the way** till the time we did not reach the PGI. Father said that I used to **cry while telling** anyone that my **child had not eaten anything for 4 days**, only **glucose was given to him via IV route**. It used to be very difficult for us to have a baby in one hand and a glucose bottle in the other. But sometimes my mother was also with me when I used to do other work,

then she took care of the child and before reaching PGI the **glucose bottle was removed**. The 3 day old baby was in the hospital without a mother in my lap, then they took the child in the morning to the operation theater and they started the operation. The child's **operation had to be started at 11 am**, so the doctor gave us a complete list of the items and told us about a **“Plate”** that is necessary. So it was not found in PGI, then we searched a lot and then somehow arranged from outside. Before the operation, the doctor had given us the complete details about the surgery. **After 1 hour of surgery**, the child is brought out of the operation theater and **remains unconscious** at that time. **After one and half hours**, when the child regained consciousness, he started crying, at that time a **pipe was placed in the left side of his stomach to remove the waste** because one lung of the child was **damaged due to freezing of milk**. Father told that the doctor called the child's mother **after 6 days to breastfeed him** and the mother told **that till 5 days she did not know anything about the child defect** because no one had told me or when I asked them, they used to say that he is admitted in Ambala as he has pneumonia so I used to keep thinking and praying that my child should get well soon.

Mother told me that when **I was 4 months pregnant**, I had gone to my **maternal uncle's house**. There was **“Grahan”** that day. I didn't know and I ate food in the **“Grahan”** so maybe that's why the child had a **“problem with the food pipe”** all these thoughts used to come in my mind. When I told my mother the same thing, she also said that because you had eaten in **“Grahan”** the child may have been suffering from a defect.

The father said that I used to be so scared all the time about my child's health, The **tension was so much** that I could not explain in words, the condition had worsened that even **my hair had turned white** and this was in my mind that nothing should ever happen to my child because my uncle's grandson had also died due to "Negligence of PGI staff". For a **one and a half month (45 days)** we were in PGI only and to be very honest, it was not easy at all to stay in the hospital. There were many problems in the hospital **e.g.**, to take blood from another building, to collect the items for the operation, I **did not sleep for 2 nights**, because of running here and there and sometimes due to tension.

As the child was to be operated, I arranged the bottle for "**A**" **blood group**, but the **doctor changed the blood group**, don't know how but the problem came when it was found that the **child's operation was stopped** because of wrong blood group, then he said that the operation of the child will not be done, his blood group is different, then I ran away to collect his blood again and in the meantime, they operated on another child, I got **very angry**, but what did I say, they were all big doctors and we are illiterate people because I have heard so much before also that some doctors have done a **lot of atrocities (Atyachaar) with the children**. I heard from someone, that a child had difficulty in breathing, so **water was poured into his oxygen tube by staff**, I saw another case like a little girl of my child's age came from the "**Panchkula**" She was operated upon and after surgery she was stitched and discharged the next day, then after reaching home all her **stitches got opened and all the "mass" inside the stomach came out**,

then the family brought her back again **at 10 o'clock** in the night, I used to sleep outside at that time and the next day at **5 o'clock the baby had died**.

I remember **after 10 days of the operation** the pipe of the child came out from which **dirt used to come out**, so the doctor there was **so dangerous** that I used to request him that sir please make the child unconscious and insert the tube, but he was not ready to listen or without making him unconscious, he used to **hold the hands and feet of the child** and **forcefully insert the tube** into his stomach and he was **crying so loud due to pain**, because he did not able to insert the pipe at once, then he used to insert the **pipe into the stomach 2-3 times**. It felt very bad to see the child cry so much but we didn't say anything to anyone. Then when the pipe came out again, we said don't put the pipe like this, first make the child unconscious, then he put the pipe only after making him unconscious. There was a **lot of anger** but we could not do anything because before also we have heard many things from others about PGI staff and doctors because that they start **being abusive or use bad words** or If someone says something, they would have said, "What is the use of you here, get out of here. By the way, they never spoke wrong with us, but this image was created in the mind for which we did not speak even though we saw the wrong thing and thought that he is a doctor, **don't know what to do with my child in anger**. Before coming home, when I asked to the doctor Madam, what will be the problem of the child in future and asked about operation that has to be done after 5 years, so they said that there will be **no operation of the child after 5 years** and said that we have **pulled its food pipe and**

stitched together. We were very happy to hear that there would be no operation for the child, than we came home. After coming home the child drank its mother's milk directly because for one and a half months the child was **fed through nasal tube** and mother also used to give him breast milk via nasal tube only, then after reaching home they removed his nasal tube and mother started his breast feed directly to child without tube. When we came home, it **started causing trouble in breathing**, then **at 8 o'clock** the same night, we again went to “Star Hospital” and the child remained **admitted for 2 days**, then they did **nebulizer twice** a day in the morning and evening and said you will have to go to PGI again, then we drove to PGI and **reached at 2pm in the night**. The father said that till the time the child was in the PGI, the child was fine, there was no problem, there was a **problem in breathing only after coming home**.

Then they **gave oxygen** to the child and we came back again then they told to **give him steam for 2 days**. Then after that the child got rest he used to start drinking mother's milk comfortably. Doctor also called us for **follow-up after 10 days**, then they saw the report of the child and gave the medicine to the child to **be dissolved in water** and we started the same medicine. After that **there was a lockdown**, at that time the doctor had also told us for **the MRI of the child**, but we did not get it done because of the lockdown. By the time the child was **6 months old the surgery had been done** and the child had recovered. Then we went to the doctor **after 1.5 years**, that time **he was 2.5 years old**, then we did not go to the doctor after the lock down. They had called us for follow-up but now our child is fine so we did not go to the doctor.

There was no problem in taking the child to PGI during Covid, no one stopped us, we used to go in our car comfortably for follow up. There was **no problem even at home**, but I used to get more worried about money because he demanded food from outside but I was not able to get it. At the time of Covid, we used to go to the fields “khet” no one used to stop us. By the way, the child is fine, just sometimes complaining about a normal **cough**.

When we came back home, the doctor told us not to lay the baby straight on bed for that, they told us to get **a chair which we could straighten or lay down too** on that chair only if we make the child laid down. Mother said that I did not feed my child, even lying down so his head should be in an upward position. **For 6 months we had made the child lie on the same chair only and not on the bed.**

The mother said that when the child turned 6 months old, we slowly started feeding the child **khichdi, oatmeal, and semolina pudding**. In the beginning the doctor told us to feed him a little, if the child starts eating well, then only you have **to increase the diet slowly**. The child always used to eat well and whenever he became choked, we slowly used to tap him on his shoulder or back, then he would be fine. My child took my **feed for 5 years**.

Now my child is 5 years old and whenever he feels hungry and **demands for food** or by himself eats cashews, almonds, fruits, everything. During pregnancy, I only took calcium capsules prescribed by the doctor. There is also an ASHA worker in our village who works in

Mullana Hospital, she didn't give us any medicine she used to take medicines from the government, but didn't give them to anyone in the villages or used to sell them. Whenever we used to ask her for medicine, she used to give us an excuse that the government has not sent from behind. We would have come to know from someone that she used to give it to her known or relatives but not to us. I did not take any medicine even at the time of both my daughters from ASHA workers, which I took only from a private doctor.

Now my child is grown up, goes to school and is good at studies. Child knows **A, B, C, D, 1 to 20 counting** and knows the “**Johny Johny Yes Papa poem**”. We did **not get any discrimination** from school and society, everyone used to cooperate. They used to say that he is a “**God's gift, and he will be alright**”.

The child wakes up in the morning and asks for **biscuits and tea, potato paratha** is his favorite or says mummy can you make **French Fries** for me. He mostly demands Oreo **biscuits, chocolates, ice-creams** mostly. My son has a lot of love with both his sisters, but also fights a lot. When I beat my daughters, he stands in front of me or stops me from beating them. My elder daughter also took very good care of her. In the first 3-4 months she helped me to hold him in her lap and make him sleep.

The **operation cost was 25,000 to 30,000** and till now around **50,000 expenditure was done** over child's treatment. Even for the operation of the child, I had taken money **on 2% interest**

than he was treated. Now we have repaid all our loans. Father said that we have **farms and when our child was born**, Wheat crop got damaged due to water, so there was a lot of trouble in the house. Then as the crop kept getting profit, I kept reducing the interest gradually and in **around 1.5 years I repaid the entire loan**. There was a lot of tension till the interest was not paid.

It used to take me **3 hours** to go to hospital and every time we used to take money on interest to go to PGI because we didn't have a car or I didn't know how to drive, so we used to **bring the car and give 1000 rupees** to the driver for one time for follow up. Till now we have **done 10 trips and had to pay Rs. 1000 for each trip**.

As now the child is fine, we have to think that we will send the child outside to some big country like **America or Canada**, so that the future of the child can be made and educated. By the way, **both our daughters are very close to heart**, but since childhood my son has suffered so much, so there is more concern towards him. My elder daughter says that **you do not love us**, you love him more because whenever he asks for something or demands for money you fulfill all his wishes and give money to him, then I try to make them understand that there is nothing like this, he is younger one, so we do a little more.

We are also in **“Divyang Shakti Group”** and also keep posting **videos of children's activities**.

