

YUDHAV'S CASE STUDY

Birth defect- Hypospadias, coronal (Severe)

Manjeet, told me that I got married on **10th of July 2018**, after 2 months of marriage, I got pregnant (**first gravid**). She said that they wanted a child because our thinking was that if the child is conceived in the early days of marriage, then it is fine, otherwise the problem comes later.

In the 3rd month, I had my first ultrasound done, after that I got my treatment done by GABA (Yamuna Nager). After seeing my ultrasound, the doctor told me that there is less water in and air to breathe by the child was also very less. They did repeated ultrasound every week.

I had more than **8-9 ultrasounds in 9 months**. Doctor used to give me oral medicine and glucose during pregnancy. When I went to the GABA (yamunanagar) last month, the doctor said that the delivery will have to be done now, that time it was 10 days after completing 8 months of pregnancy. After seeing the ultrasound the doctor said that we will have to do your delivery soon because the child is very serious.

The doctor said that the child has **only 2 points left** of air which should be 8 points. They said that we will start giving glucose to the child if the child is fine then we will do normal delivery. Otherwise we will go with the operation, we become scared, automatically negative thoughts start coming, and don't know whether my child will survive or not.

After that we went to a pediatrician **Dr Preeti Deswal**, she checked and said don't be afraid, there is nothing to be afraid of. And she kept checking the baby's heartbeat every half an hour.

During pregnancy I took complete care over my diet. My husband and in-laws were very particular in my diet. They gave coconut water, juices, fruits and everything to me. I drank juice for nine months. They used to give me shells (khope) of desi ghee. Doctor gave me 3 injections in 4th, 7th and 9th months, worth **Rs 2200 during pregnancy because I had A negative blood group**.

At 11:23 in the night, I delivered a **baby boy with a major operation**. Mother said that when we came to know that it was a boy, we all were very happy that our first child was a boy. All the

family members started dancing. My family gave a box of sweets to everyone in the hospital. My mother also distributed 10 kg laddus in the house. Everyone was very happy but As soon as the child's disease was detected, we all became very disappointed. Everyone said that it would have been better if a girl would have been given to him.

Mother said that when he was born, the doctor **kept the baby under glass for 2 hours** because the child did not cry after birth and had breathing problems as well. We stayed in the hospital for 4 days. The doctor told us about the problem of hernia and the swelling under the child's penis but was not clear about the problem in the opening of the penis (hypospadias). Mother said we didn't notice hypospadias and didn't even bathe the baby because the baby was very weak. Mother said, Yudhav was born in summer, I remember that he had rashes over the body, so I applied powder and laid him down, then later I noticed that the child is passing urine from somewhere else, Then I told my husband to come and see that from where he is doing, then we immediately took him to Shyamlal Hospital (Yamuna Nagar).

They told us, take your child to Chandigarh, on 12th of May that time our child was 1 month old and the doctor told us that when the child will be 6 months old then they will operate on him.

The doctor said that you should give him medicine for 6 months, advice for good nurturing, whatever Ca deficiency is there recover it then only we will treat the child otherwise we will not do any surgery, they also gave pain killer. We kept giving medicine to the child for 6 months. Baby had a low **Hb level** so we took very good care of the baby and when the **Hb was 10 grams** then after 6 months we went to **Chandigarh PGI for operation**.

Until the operation of the child wasn't done, the child used to be very upset and used to keep **crying continuously**, he wanted to feed milk but because he was not able to pass his urine and his **stomach used to get bloated**, he was unable to feed. The child used to cry whole day and night and the condition used to get so bad that he used to **fall asleep after getting tired of continuous crying**.

To see the child's condition, the family used to **create pressure and blow into the child's navel** but the child did not pass the urine at all. The child was in so much trouble that he kept crying the whole day. The doctor had given medicine as well, we used to give medicine too, but the medicine did not give relief

from pain, it was difficult for us as children to continuously cry the whole night because of pain and swelling.

Whole night neither the child used to sleep nor did we sleep. When we ask anyone else for help, everyone used to tell us that operation is the only treatment, even though someone used to say, get its ear tied (**kan bindwa do**), Some used to say get a broom (**jhada lgwa do**) so that the child's stuck block (**naso ki akdan**) will open. We tried everything, gave **jadibuti** in his ear, which somehow relieved him from pain to some extent for 2 months. Then after 2 months the child started doing the same again, swelling and pain started again and the child started crying a lot. The child used to get so upset that he started **crying at 9:00 in the night and continuously crying till 5:00 in the morning**. We also used to roam around carrying the child here and there, but the child's pain did not stop.

The mother told that when the child wasn't pass urine the lower part of the penis (scrotum) go all the way up in pain and due to pain the baby starts cry a lot it (**scrotum**) **just didn't show up and disappeared** until that part came down till two days or three days, till the child remained restless and in pain. Then seeing the child's condition, we also used to cry and thought that God better not give him in life.

When Yudhav was small, the **supply of breast milk** was very good, it wet all my clothes. We remember when the child used to feel hungry and used to cry in pain, we used to get so upset and always think, could someone tell me something that will reduce his pain and give him relief. We try to feed the baby with **droppers and spoons**. But because the child was in so much pain that he was not fed and kept on crying. As my grandmother said, we used to give **fennel milk** to the child. Many times there was a problem of gas, then **again used to give** in little water as well. They used to **give kada to Tulsi and manakha**, but after all the attempts the child's pain did not stop.

Just can't tell you, the condition was very bad, the child used to feel hungry, but he could not drink due to pain. He had such intense pain that **he kicked himself upward like a pregnant lady feels the pain**. The pain was so much that he used to **climb upwards and used to push himself upwards**. When we saw the child's condition we couldn't stop our emotions and started crying. The child's condition was very bad, it could not be seen,

Everyone talked about their own way. Someone said that this problem has happened because of the **eclipse (grahan)** . Someone said that you might **cut or peeled something in the eclipse (grahan)**, but I said that I did not do anything. The people of the village also used to say that it might be someone who did some **trickery (totka)** over the child. We have tried our best and brought up the child with great difficulties.

Only we know how we spent those 6 months, now when I remember those days, I got **goosebumps**. My heart was broken, when I heard from villagers that your son is a **eunuch (kinnar)**. It made me felt so bad, that people are calling my son **eunuch (kinnar)** because of small size of penis, then I told people that please do not say like this, because my son is fine he has no problem, we have consult with the doctor and he said that when you get it treated, the child will be fine. Mother convinced everyone that he has both the openings to pass urine and stool, so don't say rubbish about him, but they talk like what they think so we ignore them.

I also used to feel bad when others used to go out and **take off his underwear and see their private parts**, then I used to get very angry. They said that we are only seeing each other. I say if you want to see, then ask me first. Villagers also said that to hide your child from **eunuchs (kinnar)** they might come to your house or if the **eunuch (kinnar)** comes to know, the **eunuch (kinnar) may take away your child**.

We again faced the crises. On **5th of December** the child told about his **stomach pain for the first time**. He said that mummy, my stomach is ringing, he used to feel pain in every few intervals (**thodi thodi der mai**) He started **beating himself because of pain, the child had fever, typhoid and the cells in the child's test were also less**. So we got all the tests done, then the doctor told us that the child has got an infection in the stomach.

When the test was done in Khizrabad, they told that the child has **stomach infection**, they injected him and kept him in the hospital all night, then they discharged him next day, when we came home, the child started having stomach pain again, then I told my husband that I can't see my baby to suffer like this. Then we got an ultrasound done by **Dr. Sharma then** he said that the child's **intestines were entangled with each other**. After hearing this, we were like, what to do, to see the

child's condition as he had also **dropped his head down due to severe weakness** and it seemed that he would not survive, me and my husband started crying. So they referred us to the trauma **center (Yamuna Nagar) 8 number emergency room.**

Doctor said that the child is very serious. They made our file without delay and referred us to **Sector 12 PGI, Chandigarh.** They admitted the child after getting all the tests done like ultrasound and blood test of the child.

After admitting him, he administered **glucose to the child throughout** the night. When the child was in a lot of pain, he **tried to throw all the needles out.** The child used to cry a lot and said to mother, I am in a lot of pain and the doctor also refused to eat anything for the child. The doctor said that if you give the child even water to drink, then your child will die. Then they **took us down to the COPD.** They did not operate the child, just opened the entangled intestine by **creating pressure by inserting a pipe through the private part.** He had also said that when we give pressure, there is a fear of rupture of the intestine of the child. So they said that the child's life can also be in danger, there is a **complete risk in** it, they got us signed on our form if anything happened we will not be responsible. We also decided that once the risk had to be taken for the child, the child remained in the operation theater for half an hour and **after giving three pressures in 1 hour, when the child's entangled intestine opened,** the doctors also started clapping in the operation theater. It was **4 days that he didn't eat anything.** The child's lips were also very **dry.** Due to lack of water, the child's lips were **crusted and the child's lips became black too.**

After bringing the child home I took full care of the cleanliness around the child. I used to clean all the toys, all the places around the child with **Dettol.** She used to wash everything with Dettol, no one used to come inside the house with slippers. I took very good care of the child, whoever used to come home and touch the child first **sanitize their hand.** Then after 1 month we took the child to the doctor again for checkup, he said the child is absolutely fine and swelling was cured after the operation. When the operation was done after 6 months, the **lockdown happened for 2 years.** The operation of **hypospadias has to be done in December 2022** but it has not happened yet due to the Covid, but now we are relieved that the child is no longer in pain.

Baby **doesn't urinate while standing** but he passes the **urine while sitting**. These days there is no problem or pain complained by the child, earlier the opening or point of the child's penis is not visible. But as the child grows and the size of the penis has increased, the opening has also started to appear. The doctor also said that we will do the operation only when the opening of the penis is visible, before that we will not do the operation. Mom said, in childhood, the part of penis looked like it was a **small grain of mustard seed**, but now it is growing and becoming visible and increasing in size as well. When we talked to the doctor he said that the weather is not right now, so **come April 2023, then we will operate on the child**.

Yudhav's father said that since childhood till now, **3 to 4 lakhs** have been spent on the child. I work in a **salon in Bangalore** and stay there. We took money on interest and got the child treated. We still have a **loan of 170000** and are trying to clear. We have taken the money on interest at **10-15%**, My husband's salary is **25000**, we have got the children's Life **Insurance and Jeevan Bima** has now we will also get his **Health Insurance** done.

Now my son is 5 years old, father said that when we see other children in the hospital, we feel that our **sorrow is less than the sorrow of others**. We get courage, but when we see our child getting needles and crying, **our soul is filled with that time**. We can't see him cry a lot. The child is **so scared** that if we take him to the hospital or somewhere, he is so scared that he starts crying and says mom, I do not want to go there, she is afraid that **they might prick me again**. The child jokingly says that mom, I will also become a doctor, I will also give needles to everyone like this.

Our son started **speaking Maa Ji Papa Ji at 9 months and started talking about susu potty at 1.5 years**. Now it's 5 years old and does everything on its own. Mother said that I will **not plan my second child** until my first child is completely cured. Because my age is still 23 years old, I am not even thinking about having another child. If we have another baby, we will not be able to take care of yudhav. If another baby comes, then the expenses will also increase, the child will not be able to be taken care of.

Baby's catching is very good, he catches everything very fast. He knows **A, B, C, D and counting 1-10**. We gave **iron syrup, deworming and vitamin D3** medicine to the child. Lentils are

his favorite in eating. Most of the time he happily **demand for Dal, Roti, Rice**. He also likes pizza, burger shakes, and guava whenever we go outside we give shakes to him. At home I gave myself a sandwich , **chilla, and muli paratha**. We do **not give cashew, almonds and other nuts** to the child, and make **homemade ladoos** at home and give them to the child. Earlier the child used to go to **Anganwadi**. Now we will get his admission done in March. Schools were not opened in our side, primary schools are still closed, now they have started so we will get the **child admission in March**.

Father told me that there was a boy with me also, he also had the same problem, and didn't get any treatment but now he got married and has a baby boy so because I know that problem (hypospadias) already I was not scared and have faith that my baby will recover soon.

Mother said there were a **lot of problems due to Covid**. We faced so many problems. My husband came back home without earning , had **no money for food when going for the ration**, they refused because of no money. The care of the child could not be done properly. My husband also used to go for **work as mistri** and came back with only **150 Rs, something** there is no money for. Sometimes babies were sick then we used to borrow medicines from doctors but now whatever problem happens, we are able to pay well, now our condition is fine.

Now our child has grown up, the **society is in favor**, neighbors ask when is the operation, we tell that the operation is in March and April Those who used to speak wrong before, now **everyone speaks right** Now we are happy to see that they have also come to know that there is nothing wrong in the child, **he is not a eunuch**.

Thanks.....