

## **Priyanshu Case Study**

### **Birth defect: Lumbar spina bifida without hydrocephalus and Diastematomyelia**

Sunita and Baljit, married for 15 years, live in a joint family at Azizpur kalan village in Bilaspur. Baljit's mother and his elder brother with his wife and four kids (2 daughters and 2 sons) also stay with them. They are white ration card holders. Baljit is a painter by profession and he earns handsome amounts.

Sunita and Baljit have 2 daughters (one 12 years old and another 8 years old) and Priyanshu is their third child. Sunita did not want a 3rd child but her husband wished for one male child. Baljit said "Ladke se hi to vansh chalta hai."

Sunita's gestation period for third gravida was 39 weeks. Her pregnancy was going very smoothly till the 8th month. Her antenatal checkups were done from a government hospital in Bilaspur. She also underwent 3 ultrasounds during her pregnancy. Everything seemed normal. The family was very excited and happy.

But during the 9th month of pregnancy, she started having problems like vomiting. Sunita and Baljit consulted the gynaecologist at the government hospital in Bilaspur. After the examination, the gynaecologist said that the reason behind vomiting was high blood pressure but it could be prevented. She advised her to take a balanced and healthy diet and to avoid fried or junk food.

Gynaecologist also told them that Sunita would undergo normal delivery, only if her BP would be normal otherwise there would be chances of C-section delivery. So, Sunita should take good care of herself to control her BP. Sunita followed the instructions given by the doctor but it did not work. The problem remained the same!!

Then, Baljit and Sunita consulted Dr. Poonam Chaudhary in Jagadhri. After examination, she prescribed her medication for blood pressure. Still, the problem was not resolved!!

Then the couple consulted another doctor at their village and he advised them to get Sunita's ultrasound done. Baljit and Sunita reached SP hospital to get her 4<sup>th</sup> ultrasound done.

In ultrasound, it was detected that the baby had pooped in the womb and mother and baby required immediate medical attention. With Baljit's consent, staff started preparations for delivery.

On November 23<sup>rd</sup>, 2019 at 4:30 am, Sunita delivered a baby boy (later named as Priyanshu) via C-section delivery. His birth weight was very low i.e. 2000 g. Unfortunately, the baby was born with a birth defect i.e. Lumbar spina bifida without hydrocephalus and Diastematomyelia!!

Doctor told Sunita that she had given birth to a baby boy but did not show the baby to her. Doctor told her that the baby has a minor problem, so he has been referred to another hospital. Sunita became anxious and restless. Doctor advised her to take rest and said that the baby would be fine in some time.

Staff member showed the baby to Baljit and told him that the baby had ingested meconium. Baby needed to be kept in an incubator but they did not have that facility. So, they referred him to Ashirwad hospital. Staff member also showed him the baby's birth defect. Externally, it looked like a small abscess (foda) on the baby's lower back.

When he saw the baby, he had mixed emotions. He was both happy and sad at the same time. He always desired a son but when the Lord granted his wish, he could not even express his happiness to anyone. The baby was in so much trouble that Baljeet could not even celebrate the baby's arrival.

Baljit thought "Parmatma ne ladka to diya vo bhi kami wala diya"

The baby was kept in an incubator at Ashirwad hospital for 5 days. Baljit stayed with Priyanshu in the hospital. He did not face any problem during his stay in hospital. Bed was available to him. Baljit's relatives used to bring food for him in the hospital.

Sunita's mother and sister stayed with her in another hospital. Sunita saw her child for the first time on the 3rd day of her delivery when she was discharged from hospital. She felt miserable and started crying. It was a very tough time for both of them!!

Proper treatment was provided to Priyanshu at Ashirwad hospital and he started recovering there.

The doctor told Baljeet that Priyanshu's back abscess could not be treated in that hospital but he would get it arranged in another hospital which will cost Rs. 50,000.

So, they decided that they would go to PGI for Priyanshu's surgery. The couple asked the doctor to discharge the baby. Doctor refused to discharge Priyanshu as the baby was suffering from Jaundice.

But Sunita and Baljeet did not listen to him and asked to discharge Priyanshu. Sunita said to the doctor that Jaundice is one of the most common problems in newborn babies. She added that babies do get jaundice. Parents said that they would manage it and would get the jaundice of their baby cured on their own.

PGI was the only hope for them!! The poor parents took the child to the PGI the next day. Doctors at PGI examined the child and asked Sunita and Baljit to admit Priyanshu in the hospital on January 4<sup>th</sup>, 2020. Priyanshu's operation was scheduled for January 5<sup>th</sup>, 2020.

Sunita and Baljit consulted Dr. Ayush at Bilaspur hospital. Dr. Ayush suggested consulting Budhiya hospital in Bilaspur. They took Priyanshu to Budhiya hospital in Bilaspur directly but no one entertained them. Parents again contacted Dr. Ayush. Then, Dr. Ayush made the baby's card and referred the baby to Budhiya Hospital. The doctor touched the abscess and examined it thoroughly. An ultrasound of Priyanshu's abscess (foda) on his back was also done at Budhiya Hospital but the doctor could not understand anything.

Sunita and Baljit observed that most of the doctors in Budhiya hospital were those students who were doing their internship. So, they were not able to trust them and parents finally decided that they would get their son treated from PGI only.

Sunita and Baljit reached PGI and admitted their son on January 4<sup>th</sup>, 2020. Priyanshu underwent surgery for his abscess (foda) on January 5<sup>th</sup>, 2020. The parents did not face any problem in the baby's treatment as some known person at PGI had helped them and made everything trouble-free to them. The cost of the entire treatment was Rs.30,000. Priyanshu was discharged from PGI on January 10<sup>th</sup>, 2020. Sunita's brothers helped them financially.

Before discharging the baby, the doctor provided gloves and healing ointment to parents and taught them how to clean and bandage the baby's wound. Sunita said that the abscess (foda) was small but post-surgery the wound was big in size as compared to abscess. There were 8 stitches on the wound. Sunita used to do the dressing of Priyanshu's wound at home. The wound was healed within 5 days. A bottle of syrup was also given to Priyanshu for 5 days by the doctor.

Sunita and Baljit visited PGI after one month for follow-up. Doctor examined the wound and told me that the wound has healed completely.

At the time of the operation, the doctor had said that postoperative there would be problems either in the head or in the feet of the child. The baby's head is absolutely fine, but one leg is a little

twisted outward. So, the baby walks with a slight limp and it can only be recognized when someone observes him very carefully.

For this, the doctor has asked parents to get Priyanshu's MRI done but they have not yet gone to get his MRI done.

Only after seeing the reports of the MRI, the doctor could tell which treatment should be given to priyanshu. Sunita and Baljit thought that getting Priyanshu's MRI done would be a very difficult task for them because Priyanshu was too young for this. They also knew that MRI required the child to be calm and still, but Priyanshu could not remain still at that time. Lockdown was another reason for not getting his MRI done.

Sunita and Baljit are planning to visit PGI at the end of February 2023.

Sunita has tried her best to give the best of care to her son. Priyanshu was exclusively breast fed by Sunita for 6 months and after that she started giving complementary food to him which included *Dal, Chawal, Khichdi*, etc.

Priyanshu is 3 years 2 months old now. His current weight is 9 Kg 500 g and current height is 84 cm. Priyanshu is underweight and has wasted and stunted growth.

At present, Priyanshu likes to eat everything cooked by his mother like *Dal, Chawal, Sabji, Roti* etc. Priyanshu can eat food on his own. He also likes to eat seasonal fruits. Mixtures of doodh, chawal, and cheeni are Priyanshu's favourite food. His favourite fruit is banana.

Priyanshu wakes up between 7 to 8 o'clock in the morning and daily brushes his teeth himself.

In summer, Priyanshu takes bath daily but in winters, he takes bath at the gap of one day. He cannot bathe by himself. His mother, Sunita, gives bath to him. He can wear his clothes himself. Sunita used to massage her son's legs with mustard oil.

Priyanshu loves to play with his sisters and cousins. He also plays with other kids from their neighbourhood. He has a bicycle and he likes to ride his bicycle. Priyanshu also likes to play with his toys. His favourite toy is a tractor.

He is able to control his urine and stool. He is also suffering from constipation. He needs his parents' help in cleaning him after he passes stool.

They have Priyanshu's MCP card but the weight chart is not filled in it. Complete vaccination was given to Priyanshu.

Priyanshu goes to Anganwadi. He was able to adjust in Anganwadi. He does not face any discrimination at home as well as at anganwadi.

He can count up to 5 and recognises the first 5 alphabets. He can hold the pencil himself but is not able to write. His mother and elder sisters also teach him at home.

Priyanshu understands everything his parents or other family members say. Priyanshu is an active child but his father feels that he gets tired quickly as compared to other children of his age.

Initially some people used to say to them “ye to karmo ka fal hai” and “jaisa boya vesa hi katoge”. Some people said that everything would be fine. They used to assure them that this defect would be cured or repaired.

Priyanshu shares a special bond with his father. Priyanshu loves his father's company more than his mother's. He plays with his father. Whenever his father is not with him at home, Priyanshu looks for him only.

Time to time support was provided to the family by Anganwadi worker, Asha worker and SWACH team.

The parents believe that there is a deficiency in the feeding of the child from their side. According to them, initially they were not able to feed him fruits and juices and because of this, Priyanshu has stunted and wasted growth. But now they used to give him seasonal food, juices and home-made food regularly.

**24 hours recall:** Last morning he ate aloo matar ki sabji aur roti with a cup of tea for breakfast. He ate murmure at anganwadi. For lunch he ate aloo matar ki sabji aur roti and for dinner he ate 'dal-roti. Next morning he had roti with a cup of tea.

Thank you