

JAIVEER SINGH - CASE STUDY

Birth defect: Q41.0 Congenital absence, atresia and stenosis of duodenum

Rita and Ajay live at Sabalpur Jattan village in Bilaspur. Rita and Ajay have been married for 9 years. They have an elder daughter whose age is 8 years. Ajay's mother and his elder brother (who have some mental issues) also stay with them. Family is a green ration card holder. Ajay is a farmer by profession.

Rita's second pregnancy was progressing perfectly well till the eighth month. Her antenatal checkups were done from Usha Rathi Hospital, Yamunanagar. Rita got an ultrasound done at Dolly Diagnostic Center Yamunanagar in the ninth month of her pregnancy.

When Rita's ultrasound report was checked by her gynecologist at Usha Rathi Hospital, it was found that the baby's intestine was swollen. The gynecologist advised Rita to consult a doctor at PGI (Chandigarh) regarding the ultrasound reports.

Before going to PGI, Rita went to GMCH-32, Chandigarh to get her check-up done on 30th April 2018. Rita and Ajay reached the hospital at 4 pm. The staff asked them to come the next morning at OPD time. Next day when Rita and Ajay met the doctor at GMCH-32 in the morning, the doctor referred her to PGI.

Next morning Rita and Ajay went to PGI. When Rita showed her reports to the doctor, the doctor got Rita's ultrasound done again at PGI. Rita underwent 3 ultrasounds during the 9th month of her

pregnancy at PGI. Rita and Ajay used to visit PGI repeatedly from their village Sabalpur Jattan to get Rita's ultrasound done.

Although it was detected from ultrasound that there was swelling in the baby's intestine, it was not possible to ascertain the extent of the problem. The doctor had also told them that the baby's defect could not be treated before delivery. It is possible only after delivery.

The gynecologist also told Rita that whenever she would feel any problem, she should come to the PGI.

On 24th May, 2019 around 10 o'clock in the night, Rita started having labor pains. At that time Ajay's uncle was also at their place. Ajay's uncle said that they should take Rita to Yamunanagar hospital but Ajay refused. Ajay said that he would take her to PGI. Ajay's uncle said that it was not a wise decision. The journey to PGI is two and a half hours long. In such a long time, anything could happen to her on the way. It was better that they take her to Yamuna Nagar. Ajay said that he would go to PGI only and started preparations to go to PGI. The staff of PGI had already told Ajay and Rita that they would treat the child only if they would get the delivery done in PGI otherwise they would not take their case.

Fortunately, Ajay's uncle had a car so he did not have to waste the time in arranging the vehicle. Ajay and his uncle left the house with Rita in the night. It was a dark and stormy night. The wind was blowing very hard and strong. It was very difficult and

challenging to drive a car at that time. Facing a lot of problems on the way, they somehow managed to reach the PGI at 2:30 a.m..

The staff admitted Rita for delivery. Her gestation period was 36 weeks. Initially the doctor tried to do normal delivery but later the baby's heartbeat increased (started fluctuating) due to which C-section cesarean delivery had to be done. Rita gave birth to a baby boy (named Jaiveer Singh) on 25th May, 2019 at 12:37 pm. His birth weight was 2700 g. Rita's elder daughter was also delivered by C-section. Doctor showed the baby to Rita and told her that the baby boy had been born.

After that, the staff showed the baby to Ajay. He was very happy. He called his family and told them about a new member of the family. Everyone in the family was very happy.

But when the baby was first fed, he vomited all the milk. Powdered milk was given to him. Then the doctor came to know about the birth defect of the baby. He was born with a birth defect called Congenital absence, atresia and stenosis of duodenum.

When the doctor saw that the baby was not able to digest milk, he referred the baby to the pediatric ward the same day.

When Ajay heard from the doctor that the child was not able to digest the feed and was vomiting, he became very nervous and worried.

The doctor explained to the parents in simple language that the baby's intestine is twisted and milk was not being absorbed in the duodenum. The doctor explained to them about the intestinal

problem of the baby by making a drawing on paper and told them it could be repaired.

The hospital sent the baby to the pediatric department in an ambulance. Ajay went to the emergency (Pediatric department) with his baby Jaiveer. According to the couple, the doctor tried hard not to operate on the child. He tried to fix the twisted intestine of the child with the help of a pumping machine but did not succeed. Finally, he decided to operate on the baby. When Ajay heard that the baby would undergo surgery, he was shocked and speechless.

The doctor asked Ajay that you already knew that the baby had such a problem, then why were you reacting like that. Ajay replied that he did not know that the problem was so severe that the baby would have to undergo surgery. Gynaecologist had told him that the baby's defect could be cured either by medicines or operation. But Ajay was expecting that it would be cured by medicines only. That's why; Ajay was shocked to hear about the baby's surgery.

Ajay completed all the formalities of the hospital. Ajay was made to sign a form in which it was written that the hospital would not be responsible if the baby dies. With great difficulty, Ajay gathered the courage to sign the form. The doctor had also said to Ajay that anything can happen to the baby. Ajay said to the doctor that he has full faith in him. He would save Jaiveer. Ajay said that he did not tell this to even Rita. Ajay thought that if Rita came to know about this, she would become anxious and restless and would not be able to recover.

On the other hand, there was a wave of happiness in Rita and Ajay's house. Family at the village was very happy and excited that a baby boy had been born in the family. Ajay had not told anything about Jaiveer's birth to anyone in the family. Only Rita, Ajay, Ajay's uncle and uncle's son knew about Jaiveer's birth defect.

Jaiveer's surgery was done the next day of his birth i.e. on 26-5-2019 between 2:30 pm to 4:00 pm by Dr. Salim. After surgery, the baby was kept in the ICU. Ajay said that the baby was not being seen by him. A tube was placed in the baby's nose (Nasogastric tube feeding; also called as NG tube). Glucose was continuously given to Jaiveer through drip. Another tube was inserted in the calf of the baby. Ajay said that he was not able to see his son in this condition.

The doctor had also asked to buy a special bed for Jaiveer, which cost Rs. 10,000. Jaiveer was made to lie on that bed in the ICU. Later that bed was taken by them to their home. Even after the child's surgery, Ajay faced a lot of trouble. According to Ajay, Jaiveer was a very active baby. He used to move his head, hands and legs very frequently. His nasal tube used to come out by shaking again and again. He used to repeatedly take out his nasal tube.

The nurse always asked Ajay to fix the nasal tube. Ajay was not able to put the tube in the baby's nose. Ajay said that he could not see Jaiveer like this. He was afraid to insert a tube in Jaiveer's nose and used to cry seeing children in such a horrible condition.

At that time, Ajay's uncle (who is retired from Air force) helped and supported him a lot. Ajay's uncle used to insert Jaiveer's nasal tube every time. He stayed with Ajay in the hospital. Jaiveer's head and face was also covered with a glass mask.

Ajay could not remain relaxed even for a moment. He had to take care of his wife Rita as well as his son Jaiveer. One of his feet would have been near Rita in the gynae ward and the other would have been near Jaiveer in the pediatric ward. The distance between the two buildings was about 2 kilometers. Ajay used to go 3-4 times from one building to another in a whole day. He had to take care of Rita as well as Jaiveer. He didn't even get a bed. He used to lie outside the jaiveer's room at night by spreading a sheet on the ground.

When the doctor asked to purchase medicine or other equipment, there was a lot of trouble in that too. Medical store was always crowded. Many times Ajay came back without getting medicine from the medical store. He kept waiting in a queue for his turn to come. When his turn came, the shopkeeper said that the same medicine was not available in their store. This way Ajay's lot of time was wasted standing in the queue at the medical store. At that time, Ajay's cousin helped him. Both of them made plans for purchasing medicines and other medical equipment required for treatment. They used to visit two different medical stores simultaneously. One store was in PGI and another store was outside PGI. Both of them went to two separate medical stores. If one person got the material from the store, he used to call

another person and tell him that he had bought things and the rest of the material was bought by another person. So, Ajay also faced difficulties even in purchasing medicines and medical equipment.

Ajay was completely broken internally. Ajay's uncle and cousin provided him emotional support. They motivated him that everything would be fine. Ajay's whole day was spent in going from one building to another.

The problem in feeding continued for 2-3 days after surgery. Whenever milk was injected into his nasal tube, he used to vomit it out. Rita used to take out her breast feed for the baby with the help of breast suction pump but the baby always vomits it.

The doctor had also told him not to leave the baby alone. Someone should always be there with him 24*7. Only one person was allowed to stay with Jaiveer. Ajay or Ajay's uncle used to stay with the baby. No facility was provided to accompany the patient - neither room nor bed. Only a chair was there in the room. Ajay or Ajay's uncle used to sit on it turn by turn day and night. Whenever they got tired, they came outside for a while and lay down on the ground.

Nobody stayed there with Rita in the hospital. She was under the care of the doctor, nurse and staff of PGI. Whenever Ajay's uncle accompanied Jaiveer, only then Ajay used to go to see Rita for a while. Rita and Ajay get scared, even today, thinking about those days.

Generally, Ajay used to stay with the baby, but he also visited thrice a day. The poor fellow used to roam from one building to another the whole day. The baby was on the top floor but Ajay never went there by lift. He always used to go by stairs. He used to think that the little kids who were patients were more needy. They should go by lift.

On the fourth day, Jaiveer started taking feed. Now, he was not vomiting and he was able to digest the feed.

Staying in hospital was a very difficult task for Ajay and his uncle. It was the month of May and very hot outside. Ajay used to go out and purchase food for both of them in such a high temperature.

Ajay went through a lot of grief and shock during his stay in the hospital. There were 6 children with Jaiveer in the ICU room. 2 children died. Seeing and hearing all this, Ajay lost his senses. Ajay said that he was not able to see the conditions of the parents of those children. The children, whom he used to see being treated everyday, were dying one by one. Because of which he used to worry about Jaiveer even more. Ajay cried many times sitting alone in the hospital. He could not even share his feelings with anyone and used to suffocate alone. He couldn't even share this with Rita because she was already in trouble in the hospital. Sometimes Ajay could not even eat anything for the whole day.

Ajay had befriended a man there in the hospital. His child was also in the ICU. Ajay and that man used to always be together outside the ICU. But one day Ajay had gone out to buy medicines and when he came back, he did not see that friend. So, Ajay

asked the attendant about the man. The attendant told that he had left because his child had died. Ajay's condition worsened even more after hearing this.

Whenever Ajay met Rita, she used to ask about the baby's condition. Ajay always tried to hide his sorrows and told her that the baby was fine. Ajay didn't even show the baby's picture to Rita. He knew that Rita would be very scared to see such a picture of Jaiveer, so whenever she asked about Jaiveer, Ajay would say that the baby was fine.

Rita was discharged from the hospital on the sixth day after her delivery. Rita went straight to her child in the pediatric ward. Rita stayed with Jaiveer in the hospital the whole day. Since Rita underwent a C-section cesarean, she could not sit on the chair for a long time. If she wanted to take a rest, she would have to go outside and lie down on the ground.

So, Ajay booked a room in a hotel at a nearby village so that Rita could go there for the night and take a rest. Her body was also weak and she needed rest and good care for postpartum recovery.

Doctor asked Rita to breastfeed Jaiveer. Rita already had a daughter, so she already knew how to feed a baby. She handled everything on her own. Doctor asked Rita to feed the baby at intervals of 2-2 hours. Rita used to do the same. She followed doctor's instructions and fed the jaiveer at an interval of 2-2 hours. Jaiveer easily took the bait. The doctor observed

everything about Jaiveer the whole day and Jaiveer responded well.

Rita and Ajay faced another problem. During the night, when Rita was gone to the hotel to rest for a while, the doctor in the hospital asked Ajay to call Rita as the baby had to be fed. Ajay brought Rita to the hospital from such a distance in the midnight and after feeding the child, dropped her back at the hotel. . It was very difficult for Ajay to manage going from hospital to hotel and again hotel to hospital. Rita was also not comfortable with this. Ajay did not even have any vehicle, so he used to travel by auto rickshaw.

Reeta did not want to stay in the hotel. So, both of them decided not to stay in the hotel. Luckily, the next day (i.e. on 2nd June, 2019) the doctor discharged Jaiveer. So, Jaiveer was discharged from the hospital seven days after his surgery. Jaiveer had stitches on his abdomen at the time of discharge, but they dissolved on their own, so the couple did not need to take care of his stitches. Neither ointment nor any kind of medicine was given to the baby for home.

Both of them were very happy. Finally they were going back to their home with their bundle of joy!! Family welcomed them with great joy.

When they came back home, they organized a function and invited relatives and friends. They worshiped their kul devi and distributed Prasad. Lunch was also arranged for guests.

After one month, Rita and Ajay went to PGI for jaiveer's follow up. It was a very bad experience. On the way, they met with an accident. A car hit their car. Rita and Ajay got very nervous and scared. They were worried about their little baby jaiveer. Rita held his son tightly. Luckily, no one got hurt and everyone was safe. Both of them managed to handle themselves. They encouraged each other and left for the hospital. Whenever Ajay and Rita had to go to PGI, they used to leave their house between 5:30 and 6:00 in the morning so that they could reach the hospital on time.

After reaching the hospital, they faced a lot of difficulties like going from one counter to another, standing in a queue and going from one floor to another with a small baby in their arms in such a crowd. Above all, the weather was so hot. It was really very tough for them to manage everything.

When they met Dr. Salim, he asked whether the baby was taking feed properly or not. How often did she feed the baby? Was the baby urinating and pooping properly? How many times did he urinate and poop in a day? Rita and Ajay answered everything to the doctor. Within 5 minutes the doctor asked all the details of the baby and did a proper check-up. Dr. Salim examined Jaiveer thoroughly and said that the baby was fine.

Jaiveer's next follow up was scheduled after 3 months. When the couple reached PGI, Dr. Salim examined Jaiveer thoroughly and said everything was fine. For the next follow up, the doctor said

that now the couple could come after 6 months or whenever they wanted to come or if the baby would face any kind of problem.

Rita and Ajay thought that their child was absolutely fine so they never visited PGI again. Now, Jaiveer is absolutely fine. He eats everything and whatever he eats he digests.

Ajay and Rita were repeatedly saying that they faced a lot of difficulties during their stay at hospital. They kept saying “bhagwan na kare ki kisi ko aisi pareshani ka samna karna pade”.

Jaiveer is 3 years and 7 months old now. His Current weight is 15 kg and current height is 96.5 cm. Jaiveer is fully vaccinated and Iron syrup, Vitamin D3 drops and medicine for deworming had been given to him.

The family thinks that Jaiveer's grandfather has returned in the form of Jaiveer. Jaiveer has many habits similar to his grandfather. The family loves Jaiveer a lot.

Rita exclusively breast fed jaiveer for 6 months. Jaiveer has an MCP card and a weight chart is filled in it. After 6 months, Rita also started giving cow's milk and complementary food to Jaiveer. She also used to breast feed him after 6 months. Along with this, Rita started feeding Jaiveer *khichadi, dalia, doodh me kela mesh karke, dahi, suji ki kheer, chawal ki kheer*. According to Rita, she had read all this in an MCP card.

At present, Jaiveer likes to eat everything cooked by his mother. But Rita thinks that when Jaiveer drinks milk, it makes mucus in him. Still, Rita gives Jaiveer half a cup of milk thrice a day. She

gives him cow milk. The parents said that buffalo milk does not suit Jaiveer.

Jaiveer likes *sukhe allu* (cooked potatoes) very much. Rita gives home-made juice to jaiveer.

Every morning, Rita gives *Sandha* (made up of dry fruits) along with milk to Jaiveer. Rita is also active in Divyang Shakti Group. After reading from the group, Rita has also made Panjiri for Jaiveer, in which she has mixed grinded pumpkin seeds, peanuts, watermelon seeds and dry fruits.

He likes to eat biscuits. He likes to eat apples, bananas, cherries, pomegranate, sugar-cane, and kinnu. His favorite fruit is grapes. He eats *dal, roti, sabji, chawal, makki ki roti aur saag, paratha,* home-made *mathri*. He drinks both milk and tea. He likes *lassi* and curd very much. He also likes chips, kurkure, chocolates etc. but Rita and Ajay rarely give these eatables to Jaiveer. Rita added that last year, Jaiveer ate too many chocolates. Ajay also used to bring chocolates to Jaiveer everyday. Jaiveer used to eat 2-3 chocolates in a day. Because of which Jaiveer's stomach got infected. Rita and Ajay took him to Jagdhari's Pediatrician (Dr. Jitender Gupta). After examining Jaiveer, the doctor advised them not to feed Jaiveer such food items (chips, kurkure, candies, chocolates etc.). From that day, Rita and Ajay do not allow Jaiveer to eat such food items.

Initially, the doctor advised them not to give spicy food to Jaiveer and Rita followed doctor's instructions, but now Jaiveer has developed that taste in him. He does not eat spicy food at all. He

likes simple food. He eats spicy samosas and bread pakoras bought from the market only but does not like to eat spicy home made food.

Jaiveer gets up at 6:30 in the morning. Rita does not wake him up in the morning. She only turns on the light of the room and Jaiveer wakes up on his own. Jaiveer demands to turn on the television first as soon as he wakes up and also asks her mother for milk.

After that, Jaiveer brushes his teeth. Sometimes he brushes himself and sometimes Rita makes him brush. Then Rita gives him a bath. Jaiveer insists his mother that he will take bath on his own like his *Didi* but Rita does not allow him to take bath on his own.

Jaiveer tries to wear clothes on his own. He can wear some clothes on his own like socks, shoes, and a jacket. Rita dresses him.

Jaiveer takes his breakfast between 7:30 a.m. and 8:00 a.m. Jaiveer studies in Pre-nursery in private school. Jaiveer's school van comes at 8 o' clock. Jaiveer comes back from school at 1:00 p.m. Rita first changes Jaiveer's uniform and then Jaiveer starts his mischief. Rita feeds Jaiveer in the midst of those mischiefs.

Jaiveer did not face any discrimination at home.

Jaiveer is a very active child. Whatever jaiveer's parents or family members or school teachers say to him, he understands everything. He obeys everyone. Jaiveer is also good in studies. He can hold a pencil and write on his own. He can count up to 20.

He knows from A to Z. He knows Hindi varnamala. He also recites poems in both Hindi and English. His mean IQ was assessed 100. Rita teaches Jaiveer at home. Jaiveer's elder sister also teaches him.

Jaiveer does not face any discrimination at school as well as from society. Parents celebrate Jaiveer and his sister's birthday every year with joy. Birthdays are celebrated at home only in the presence of family members and few neighborhood friends.

There is also a pet (dog) at their house. His name is Sofy. Jaiveer plays a lot with him. Rita and Ajay also have cows and buffaloes at their home. Reason for keeping them is that children can get pure milk.

Ajay takes great care of his children's health. He wants his children to get only pure food and fruits. Vegetables and fruits grown in the fields are only fed to the children.

Jaiveer plays with his sister at home. Jaiveer said that he has 3 friends in the neighborhood - Vanshu, Dakshu, Dhruv and he plays football and bat-ball with them. Jaiveer also rides a bicycle with his friends.

Rita also said that in the eighth month of her pregnancy, she had fallen very hard on her stomach at home. She was all alone at that time. Rita was not hurt and she got up and drank water.

But for a while she did not feel the movement of the baby. After 20 minutes, she started feeling the baby's movement, so she did not

pay much attention to it. But now, Rita feels that this birth defect in the baby might have happened due to that fall.

Rita had never discussed this incident with any doctor but after Jaiveer's post surgery, she shared this with Ajay.

The couple said that Ajay's uncle helped them a lot. The cost of the entire treatment was more than one lakh rupees. The cost of commuting was separate. This amount was huge for Ajay. Ajay's uncle and his son helped him financially too.

He did not face any problem during the lockdown. Vegetables and grains were grown in their fields, so shortage of food was not there. Jaiveer's surgery had already been done, so there was no need to go to the hospital.

Jaiveer is able to control his urine and stool. He needs his mothers help in cleaning him after he passes stool. Jaiveer can wash his hands himself.

Ajay and Rita accepted that initially they neglected their daughter for 2-3 months. Rita had sent her to Rita's mother's house. But after 3 months when she came back, Rita took good care of her both children.

Rita said that she keeps talking to Dr. Vijay over the phone. Whenever Jaiveer has any problem, she calls Vijay sir first. Whether it is cough, cold or any other problem, Vijay sir gives her best solution for every problem. The couple is very thankful to Dr. Vijay who encourages them and provides time to time help and support to them.

24 hours recall: Last morning he ate aloo ka parantha with a cup of milk for breakfast. For lunch, he ate white chane, mixed veg and chapati and for dinner he ate '*roti par makkan aur namak laga kar*'. Next morning he had *makkan ke sath* roti with a cup of milk.

Thank you