

## **Garima - Case study**

### **Birth defect - Q37.90 Unspecified cleft palate with cleft lip specified as unilateral**

Rajni and Sushant live in Harnaul village of Naharpur. Rajni and Sushant have been married for 9 years. They have an elder daughter (Apurva) who is 8 years old. Sushant's father, sushant's brother, brother's wife and their son stay with them. Sushant is a green ration card holder. Sushant owns a sentry and a hardware shop. His monthly income is approximately Rs. 30,000 per month.

When Rajni's second pregnancy was confirmed, the couple went to Preeti Deswal Hospital for Rajni's antenatal checkup. Dr. Preeti Deswal (Gynecologist) asked Rajni to get all the tests done. Rajni got all the tests done and a high level of thyroid was diagnosed from reports.

After seeing the reports, Dr. Preeti advised the couple to consult a gynecologist at Santosh Hospital. Rajni and Sushant consulted Dr. Garg at Santosh Hospital. Rajni's thyroid test was done again at Santosh Hospital.

After seeing the reports, the gynecologist said that Rajni's thyroid is at a dangerous level. Gynecologist suggested to them that Rajni should get her check up done from PGI, Chandigarh. When Rajni and Sushant discussed her reports and gynaecologist's advice with their family, Rajni's brother told them about Aadesh Hospital. He said that Rajni should consult the gynecologist of Aadesh Hospital. Rajni and Sushant visited Aadesh Hospital. Based on the previous reports, the gynecologist there prescribed thyroid medicine to Rajni. Rajni started taking medicine

for thyroid prescribed by a gynaecologist. As a result, Rajni started facing a lot of problems.

She was not able to eat food. Rajni started getting weak day by day. She had also lost a lot of weight. She looked very ill and always lay lethargic on the bed. She was in a very bad condition for 2 months. Sushant thought that Rajni is going through all these problems due to her pregnancy. He felt that the problem should not increase much. Because of this, he thought of terminating Rajni's pregnancy. But after the couple's mutual discussion, this idea was dropped.

Rajni continued to take her thyroid medication. She took thyroid medicine for 2 months. Rajni got her thyroid test done again after 2 months, on advice of a gynaecologist. Reports showed that thyroid level was normal now. So, the gynecologist discontinued Rajni's medicine for thyroid.

Rajni and Sushant also believe that the medicine which should be given to Rajni for the baby's growth was not given to her by the gynaecologist.

Rajni had a stomach-ache throughout her pregnancy. When they consulted the doctor, she was not able to tell the reason behind this.

Rajni and Sushant were very disappointed with the doctors of that hospital. They were not able to trust the doctors of that hospital. Couple went there several times. During their every visit to the hospital, they met with a new gynaecologist. Same gynaecologist never met them. The couple felt that Rajni's examination was not being done properly at that hospital. Gynecologists were dealing with them only for the sake of formality.

So, the couple decided to go to another hospital for delivery. Rajni has no record of previous termination of pregnancy for malformation or birth defect, no previous stillbirth, no previous spontaneous abortion, no birth defect in previous live birth.

The couple then went to Dr. Anupama at Rana Hospital for delivery. Rajni's first delivery was also done by Dr. Anupma. Rajni gave birth to a baby girl (named Garima) by normal delivery on 24<sup>th</sup> January, 2018 at 4:00 pm. Her birth weight was 2500 g.

The baby was first shown to Sushant's mother and then shown to Sushant. Both of them got scared seeing the baby. They had never seen such a baby before. The baby was born with a birth defect known as 'Unspecified cleft palate with cleft lip specified as unilateral.'

The baby was not shown to Rajni though she was conscious after delivery. She could hear everything. The doctor had only told Rajni that she had delivered a baby girl.

The couple said that no one in the entire family had ever seen or heard of such a child. While telling this to the investigator, Rajni got emotional and started crying.

When Sushant saw the baby for the first time, he felt dizzy due to nervousness. He asked the doctor what all this was and asked whether this baby would live or die. Dr. Anupma told him that the baby girl was absolutely fit and fine. There was nothing to fear or panic about the baby.

Then Sushant told the gynecologist the whole story of Rajni's pregnancy and antenatal check-ups. Dr. Anupama told Sushant that the body undergoes some hormonal changes during pregnancy due to which

sometimes the thyroid level increases or decreases in the body. But there was no need to take medicine.

Dr. Anupama took Sushant to her cabin and explained to him everything about the baby's defect. Dr. Anupama told him that such problems do occur in children, but there is nothing to worry about. This birth defect could be cured by surgery. She said that after the surgery, you would not even be able to tell that the girl had any such problem ever. Baby's face would be completely normal after surgery.

Sushant got some hope after hearing this. Dr. Anupama gave Sushant a lot of courage. She motivated him a lot.

Couple said that Rajni's first delivery was also done from Rana Hospital and by Dr. Anupama only. That's why those people knew Dr. Anupama. Couple said that Dr. Anupama is a very good gynaecologist. Both of them have a lot of faith in her.

Couple added that during this pregnancy, they did not know what happened to them so they went to another gynecologist for Rajni's ante-natal check ups.

Dr. Anupama gave Sushant contact numbers of 2-3 hospitals where surgery for this defect could be done. Dr. Anupama advised Sushant to consult the baby girl at Aashirwad Hospital for feeding her. The doctor would teach him how to feed the baby. Sushant wondered whether the baby would be able to take feed or not.

Dr. Anupama said that due to the birth defect of the baby, he had to be very careful while feeding the baby, otherwise, the milk would come out of the nose. She said that he would be taught feeding procedures in Ashirwad Hospital.

Dr. Anupama said that babies who have such problems have a different way of feeding them. Now, Sushant again got worried if there was some other way of feeding a baby.

Sushant asked the doctor whether the baby had any other problems. The doctor said that the baby was healthy and her birth weight was also fine. She added that Sushant should just ask the Ashirwad Hospital staff how to feed the baby.

Sushant took the baby to Ashirwad Hospital in his car. Sushant met a doctor at Ashirwad Hospital. The doctor told the nurse to take the baby inside. The nurse went inside with the baby. She put the baby on the bed.

Sushant was sitting outside the room and waiting for someone to come and teach him how to feed the baby. But no one came. Sushant waited for 2-3 hours. Baby was also lying hungry in the room. Then, Sushant called Dr. Anupama of Rana Hospital and told her that the baby was lying in the room and Sushant was sitting outside the room. No one was attending the baby. The doctors and nurses were not telling anything either.

Dr. Anupama told Sushant to tell the staff of Aashirwad Hospital to give the baby back to him and told them that he himself would manage everything. Dr. Anupama also told him that if the baby would stay there for 2-3 more hours then the staff might say that the baby had jaundice. And they would then admit the baby there only. Due to which you would have to spend extra money unnecessarily.

Sushant followed the gynaecologist's instructions and asked the doctor to give his baby back to him and he would manage everything himself.

The doctor discharged the baby. Sushant came back to Rana Hospital with the baby.

At Rana Hospital, Dr. Anupama taught Sushant to feed the baby. He told to feed her with a bowl and spoon. Dr. Anupama explained that take such a spoon which is narrow from the front. She said that first the baby has to be put on the lap and then take milk in that spoon and feed it directly to the baby's throat. So, the milk would go directly into the food pipe. The doctor explained that milk should neither be in the child's mouth nor should touch his palate.

Initially, Sushant was worried about how he would be able to feed such a small baby. But it had been a long time since the baby had not taken the bait. And he could not see the baby being hungry. Sushant's mother thought to give it a try. Sushant brought a bowl and spoon from the market and her mother started feeding the baby.

Initially Sushant's mother faced a lot of difficulty in feeding the baby. Whenever she tried to feed her with a spoon, the milk used to spread in the baby's mouth and many times it came out through nose.

When the doctor saw this, she suggested that Sushant should bring a *Diya* and should try to feed the baby with it. Sushant brought a *Diya* from the market and his mother tried to feed the baby with it. She was able to feed the baby easily with the help of a *Diya*. Baby was first fed after 4 hours of her birth.

When Rajni saw the baby for the first time, she was shocked but Sushant and Dr. Anupma made her understand everything. Sushant said to her that both of them would face it together and would try to solve this issue.

In the beginning, only powdered milk was being given to the baby. Later, both powdered and diluted cow's milk was given. Mother feed was never given to the baby. Even the doctors did not tell Rajni to give her feed to the baby. And Rajni also did not notice that she should give her feed to the baby.

Initially Baby's grandmother used to feed her. Rajni and sushant observed how the baby's grandmother fed the baby and then, started feeding her themselves.

As the tip of *Diya* was pointed, Rajni and Sushant were scared while feeding the baby with a *diya*. The couple thought that the tip of the *diya* might hurt the baby. So they tried to feed the baby with a feeder bottle and succeeded.

Sushant used to feed the baby drop by drop from the feeder bottle and made sure that the feed should directly go to the throat. Rajni and Sushant used to feed the baby at an interval of 30-30 minutes so that the baby did not remain hungry.

Everyone in the family was saddened to see Garima's birth defect. The family did not differentiate between boy and girl. So it didn't make any difference to them having a second daughter. Everyone was upset just seeing that defect. But the baby girl was accepted by everyone with a lot of love and happiness and an open heart. The family felt bad by thinking that an innocent child would carry the burden of this defect for the rest of her life. But now the couple was not worried much.

Dr. Anupama had removed the fear from Sushant's mind and had given him a lot of courage. Sushant was very satisfied and encouraged by Dr. Anupama's explanation. She had given a ray of hope to the couple.

Sushant's father also encouraged him. He said that there is nothing to worry about. Everything would be fine after surgery. Just like the rest of the children in the house, she was also the member of the family. Sushant's father motivated Rajni and Sushant a lot. Rather, the whole family supported Rajni and Sushant and took equal care and gave attention to the baby throughout.

Sushant's father also said that many times problems arise even after the birth of children, then what could be done. Don't worry, if a baby is born with a birth defect! He said that the upbringing of the baby would be done with the same love and affection as was given to the rest of the children in the family. Like all children, she would not be deprived of anything.

When the baby was 9 days old, *Dasuthan* was done for her. It was a program in which all the members of a clan (family) were invited. After worshipping the God, *halwa puri* was distributed to everyone. Lunch was also organized for the entire clan.

One day Sushant got a call from the Asha worker. She told him that a team of doctors had come to Government school at a place named Jodhiyo. Asha worker advised Sushant to meet the doctor and asked him to consult about his baby Garima. Sushant went to meet the team of doctors. He did not take Garima with him.

The doctor asked Sushant about the baby's defect. Sushant talked about the problem of the baby's lips and palate. The doctor suggested to Sushant to take all the reports of the baby and consult the doctor in Civil Hospital (yamunanagar) room no.108.

Sushant and Rajni reached the civil hospital with the baby. They met a staff member in room no. 108. She said that the couple should contact



an organization named Smile. They would get all the treatment of the baby done free of cost.

Staff said that the Smile Foundation helps needy families. The children who need treatment get their treatment done free of cost. Foundation also makes arrangements for their stay and food during treatment.

Sushant asked in which hospital the treatment would be done. Staff members said that it would be done in PGI (Chandigarh) or Balaji Hospital (Karnal).

The staff member explained in detail about birth defects and surgery to Sushant and Rajni. She told me that this defect would be treated and the baby would be completely fine. She also showed pictures of many children with cleft lips and palates. Their pre-surgery and post-surgery pictures. Couple was very satisfied with seeing and hearing all this.

Then, Sushant thought that he would first consult a doctor at PGI. So, Sushant took an online appointment and met the doctor. The doctor and staff treated Sushant very well and scheduled Garima's surgery after one year. Sushant came back to his home with the baby.

The next day Sushant again went to Civil Hospital Yamuna Nagar. The staff advised him that the sooner the baby's surgery was done, the better it would be and she would also start speaking on time. If surgery would be delayed, the baby would also start talking late.

Then Rajni and Sushant decided that they would consult the doctor at Balaji Hospital. The staff of Civil Hospital told that Balaji Hospital is a private hospital (plastic surgery centre) but such children are treated there free of cost. Hospital staff would take the baby along with her

parents from home to hospital and after surgery they would drop them at home.

On the other hand, some people used to taunt him that such children did not survive. She would die. Sushant said that life and death are in God's hands. That is not in our hand.

About two months after the birth of Garima, Sushant got a call from his relative. He had come to know from someone else that Sushant and Rajni had a daughter and the baby had some problem. He had never seen the baby but started giving advice to Sushant that such children did not survive.

One of Sushant's relatives who did not know that this defect could be treated, said that being a girl with this severe defect, it would be very difficult for her to survive on earth. Who would marry her? How would she get a boy for her? Who would like her with this defect? He also said that such children did not survive. They die on their own in a few days.

Sushant gave a befitting reply to his relative and said that all of this was in the hands of God. If the baby would be in his destiny then she would stay with him and if not, then no one could do anything.

Sushant said that he would keep trying to treat his baby. He said that he would do everything to save his baby.

Because now, Sushant had come to know a lot about this birth defect. Sushant told him in detail about this birth defect and said that it can also be treated.

Sushant's relative also asked how much it would cost for his treatment. Then Sushant said that the doctor had told that it would cost Rupees 3-4 lakh for one surgery in a private hospital. But now the government has

given convenience and facilities, due to which treatment could be done free of cost.

Rajni and Sushant never shared any picture of the baby with anyone. The couple never even showed their baby to anyone. Rajni and Sushant had also stopped attending social gatherings. They never used to go out with their baby. Rajni used to take the baby only to her maternal home.

Although the couple did not take the baby in front of anyone, sometimes while going to the hospital or going somewhere else, if any neighbour accidentally saw the baby's face, then they did not say anything negative about the baby, but they definitely used to ask, what had happened to the baby? Has she met with any accident?

Some people also used to say that Rajni must have picked up a knife during the eclipse, because of which the baby was born with this problem. Then Rajni used to reply to them that there was no eclipse at that time. Rajni also believes that during the eclipse caution should be taken.

Before surgery, Baby's blood test was done and her hemoglobin level was 8 g. Baby's haemoglobin was normal so hospital staff called Sushant for the baby's surgery. The ambulance came to pick the baby. Rajni and Sushant went with her. There were 2-3 other families also with them in the ambulance. They were also going for their children's surgery.

Staff admitted the baby to the hospital and examined her thoroughly and got all her tests done. Hemoglobin was again tested. When everything was normal, the baby was operated on the next day. Glucose was given to the baby through drip. At the time of the first surgery, the baby was 4 and half months old.

This surgery was done to repair my lips. It was a successful operation. Surgery took 1 and a half hours. Couple used to feed the baby by bottle only till her first surgery.

According to the couple, they stayed in hospital for 3 days. First day the baby was admitted to hospital, on the second day surgery was performed and they discharged the baby on the third day. Their stay during treatment was arranged by hospital and food was arranged by relatives.

The hospital staff had kept all the reports and records of the baby's first surgery with them. When the baby was discharged, she was also given syrup for 15 days.

After the surgery, bandages were tied on the baby's arms to prevent them from bending at the elbow. Because of this, the baby's arms would remain straight and she would not touch her lips. The doctor said that the baby would have to be taken care of for 15-20 days.

The doctor advised that if these stitches would be untied and the lip would be torn, it would not be able to join again like this. So, the family was asked to be more careful.

Sushant told that the stitches on the baby's lips were done very neatly and minutely. The doctor also said that the lip was very finely joined and if this joint would be opened, it would not be able to join again like this.

After a few days, Sushant felt that the stitches might have been infected and pus was filled in them. Then Sushant called the doctor and told about this. The doctor took all the details of the baby from Sushant and explained that there was nothing like that. Baby's stitches were fine and there was no infection in the stitches.

He added that the baby's lips would be completely repaired / cured in a few days.

They took good care of the baby after the surgery. The couple never left the baby alone. One or the other member of the family was always with the baby 24\*7. Even at night, Rajni and Sushant used to wake up repeatedly to check the baby. The couple did not even turn off the lights at night. They used to switch on the light all night.

Parents also used to take care at night that the baby should not turn to her left or right side.

Even then, whenever Rajni used to feed the baby, a lot of care had to be taken. She used to pour milk in the mouth very carefully by putting the spoon completely inside, so that the milk would go straight into the throat. At that time, Rajni used to feed the baby at an interval of one hour.

Rajni used to feed the baby very carefully so that the spoon did not touch the palate and the milk would go straight into the throat.

Even then, many times the milk used to come out of the baby's nose. They faced this problem again and again while feeding the baby.

By 25 days the baby's lip was fused very well. Until then, the baby was fed with a spoon only. But after a few days, Rajni started feeding the baby through a sipper. Baby used to drink milk easily from the sipper. Milk used to come out of the nose many times even after being fed with a sipper. At that time, the baby also used to drool a lot. So much saliva used to come out that the baby's clothes used to get wet. Rajni had to change the baby's clothes again and again.

When the couple consulted the doctor, the doctor told them that the baby was drooling so much because of the hole in the palate. He said that the baby was not able to swallow her spit. Rajni and Sushant bought bibs for the baby so that the baby's clothes do not get wet. Baby's mouth always remained open with her tongue always out.

While discharging the baby, the doctor had also advised Rajni and Sushant to get the baby's palate surgery done within 2-3 months. Otherwise it would be too late.

Rajni and Sushant asked the doctor that the baby's surgery had just been done and he was told to get a second surgery done again in 2-3 months. Then the doctor said that palate's surgery is very important. If palate's surgery would be done on time, then the baby would learn to speak soon. Otherwise there would be a delay in her speaking. And the baby would start speaking with the help of the nose and it would become a great problem. She would then always speak in the same way. Then, she would not be able to speak normally.

When the baby was 8 months old, the couple went to the hospital for the baby's second surgery. They first got the baby's blood test done. It was found from the reports that the baby's haemoglobin level was 2g less than normal haemoglobin level. So, the doctor advised to transfuse blood to the baby.

Sushant told the doctor that they would get the baby's surgery done after a month and till then they would try to increase the baby's hemoglobin level by feeding the baby healthy and iron-rich food.

Rajni and Sushant brought the baby back home. Family took great care of the baby at home and fed her nutritious and healthy items. They gave fruits, juices and other things to the baby.

The doctor at Civil Hospital had prescribed iron syrup for the baby. Iron-syrup was also given to her.

They fed her Pomegranate juice, dal ka paani, daliya after grinding it in a mixer and filtering it so that nothing would get stuck in the throat.

After one month, when the couple reached hospital for baby's surgery, hemoglobin level was still less by 1g. The doctor then advised that blood should be transfused to the baby, otherwise the surgery would be too late. The doctor said that parents should not be negligent.

Since Sushant's blood group matches with baby's blood group (B+), Sushant's blood was transfused to the baby.

Garima was admitted to the hospital on 16<sup>th</sup> October, 2018. Baby was operated on 19<sup>th</sup> October, 2018 by Dr. Rakesh Jindal. Duration of the surgery was 1 and a half hours. Garima's second surgery has also been successful. Rajni and Sushant stayed in the hospital for 5 days with the baby. For these five days, the couple did not face any problem regarding anything. The hospital had made all the arrangements for their stay. Their relatives arranged food for them.

This time too, after the surgery, Baby's arms were tied with the help of bandages so that Baby would not put his hands in her mouth and hurt her stitches. Garima was discharged from hospital on 20<sup>th</sup> October, 2018. At the time of discharge, nutritional advice given to the baby was to give her only liquid diet for 3 weeks. Two syrups were also given to the baby for 7 days.

After the surgery, the baby was given plain food, that too after grinding it in a mixer and then filtering it. They used to feed her food items in liquid

form like daliya, khichadi etc. They did not give salty food to her so that the wound could heal easily.

The family members never left Garima alone. There was always a member of the family with her. At that time, the baby had started sitting on her own and could stand with support.

Rajni and Sushant went to the hospital on 5<sup>th</sup> November, 2018 for follow-up of the baby. The doctor examined the baby and said that the baby was absolutely fine.

Food was fed to her very carefully by family. One member used to hold the baby and the other member used to feed her. The family had to work very hard on the baby and be very patient with her. Baby was never left alone for a minute till she was 1 year old. After the recovery from the second surgery, the baby had started eating food items on her own.

Sushant also said that he was told by the doctor that there is a tablet called progesterone which helps in the growth of the child. The doctor did not give that tablet to Rajni. Sushant said that she was given this tablet in her first pregnancy and as a result his elder daughter is absolutely fine. Sushant also added that his sister-in-law was also given this tablet during her pregnancy and her son is also doing well but Rajni was not given progesterone tablets during her second pregnancy. That's why the baby was born with a defect.

Sushant said that the doctor had told him that progesterone helps in the development of a baby's organs. The couple believes that such a problem had occurred in the baby because the doctor did not give progesterone pills to Rajni.



Rajni and Sushant were afraid that people would comment on seeing their baby. That's why the couple did not take the baby in front of anyone. They were afraid of society.

Neighbors of Rajni's parents encouraged her a lot. Those people used to motivate them by saying the baby would be fine. One of the families said that a child in their relationship also had such a problem, but he underwent surgery and that child is completely fine now. Rajni and Sushant's courage increased a lot after hearing this incident. Now she started hoping that her baby would also be completely fine.

Apart from this, the couple believes that they have not received proper guidance from the doctors. Secondly, the couple said that they accept that it was their fault that even after Rajni's first delivery was done by Dr. Anupampa and everything was fine, the couple went to another hospital for an ante-natal check up of Rajni's second pregnancy.

The couple said that many of their relatives went to Preeti Deswal hospital for delivery, so they thought that this time they should get the delivery done by her. Sushant said that even once it did not strike in his mind that they should go to Dr. Anupama for Rajni's antenatal check-ups.

But now, the couple never goes to any other gynaecologist. They always consult Dr. Anupma at Rana Hospital only.

Now the baby's lip was cured and she could eat or drink anything, the family was very happy. When the baby turned 1 year old, her birthday was celebrated with great fanfare. During the day, Garima's grandmother organised kirtan. She invited neighbours, friends and all the relatives – Garima's nana-nani, mama-mami, their kids, chacha, tau, and their families. Everyone had come to the house since morning.

There was a cake cutting program in the evening. Sushant had brought a beautiful cake for Garima. The cake was cut in the evening. Everyone danced to music. After that, everyone's dinner was organized. Everyone enjoyed it a lot. There was happiness and only happiness everywhere.

Now Garima had started eating everything like the rest of the children, so Rajni and Sushant used to worry less for Garima. Garima had started sitting, getting up and walking on her own. The whole family had started living a normal life. Garima's second birthday was also celebrated with great joy and gaiety. The family celebrated her second birthday at Hotel. The whole family also had dinner there.

Garima is 5 years old now. Her current weight is 16 Kg 800 g and current height is 110 cm. She has an MCP card but the weight chart is not updated in MCP card. She is fully vaccinated but she has not taken Vitamin D3, iron syrup and medicine for deworming.

Garima eats biscuits very fondly but eats only the cream part of the biscuits. She likes *aloo puri*. Garima likes to eat whatever her elder sister eats. Garima likes to drink milk.

Garima likes to eat *Poori Chole*, aloo ki sabji, Khichdi with curd, pyaz ka Paratha with curd or with tea. She likes bananas, apples, and guava. Garima's favorite fruit is guava. Garima does not eat fast/junk food from the market. If Rajni and Sushant are eating junk food, she only tastes it but does not eat it by choice. Rajni gives milk to Garima thrice a day.

The couple said that they took great care of Garima's diet; rather they took extra care of it. The couple said that when they first came to know that the baby's haemoglobin level is low, they had decided that they would never leave any stone unturned regarding the diet for the baby.

Couple said that they always wanted the hemoglobin level of Garima to increase naturally.

Garima wakes up between 7:30 and 7:45 in the morning. Garima brushes her teeth. Garima brushes herself but sometimes Rajni also makes her brush. Then, Rajni gives her a bath. . She can wear some clothes on her own like socks, shoes, and a jacket. Rajni dresses her.

She drinks milk in the morning. She goes to school by 8:30 in the morning. She takes lunch to school, in which Rajni sometimes gives puri with aloo ki sabji or gobhi ki sabji or sometimes parantha. In this way, Rajni gives different food items to Garima for lunch. But Garima doesn't finish her tiffin. Garima comes back home from school at 2:30 p.m.

After coming back to home, Garima first changes her uniform, then washes her hands and eats food. After that Garima plays for a while and then starts doing her school homework. She eats her dinner at night and sleeps till 10 o'clock. The couple said that Garima does not take time to fall asleep. As soon as she lies down on the bed, she falls asleep within 5 minutes.

Garima studies in a private school in L K G. She was able to adjust in school. Garima happily goes to school. Garima is of calm nature. She understands whatever her parents and family members say. She also listens to everyone. She obeys everyone. Rajni said that she speaks less in school but is good in studies. Whatever the teacher teaches her, she understands everything and she does her work very well. Whatever the teacher asks, she answers. She does not talk unnecessarily in class. She can count up to 20. He knows from A to Z. She knows Hindi

varnamala. She also recites poems in both Hindi and English. Her mean IQ was assessed 96. Rajni said that Garima's handwriting is very clear and beautiful. Rajni teaches her at home. Garima's elder sister also teaches her. Garima has friends in school and she talks and plays with them. She does not face any discrimination at school.

Garima likes to play hide and seek and teacher-teacher with her sister. Couple added that Garima's sister loves her very much. Garima used to fight with her elder sister but Apurva never beat her. She always loves her.

Garima plays in her own house. Rajni and Sushant's house is near the main road, so they don't send her out to play. She likes cycling very much. She rides a bicycle in her own home. The baby also has a lot of toys and she plays with them happily. The baby girl also likes to play *saanp-seedhi* and ludo on the phone.

The couple believes that Garima is as calm as her father. She likes all the festivals very much. She enjoys the festival with her elder brother and sister.

Garima is able to control his urine and stool. She needs her mothers help in cleaning her after she passes stool.

Garima loves to travel and attend functions. She dances a lot at functions. She mixes quickly with the other children.

Rajni said that because of Garima, her elder daughter was not neglected in her care and upbringing. She said that by that time the elder daughter had turned 3 years old, so she had started doing many things on her own. If she wanted something, she could ask for that. Rajni used to serve her food on a plate and Apurva (elder daughter) used to eat it on her own. Rajni had to bathe and dress her only. Apart from this, Garima's grandmother and *Tai* also took good care of her. So there was no negligence in the upbringing of their elder daughter.

The alarm on the right side of Garima's nose is slightly flattened, due to which the nose appears to be slightly flattened from one side and Garima is unable to breathe from the nostrils on the right.

One of the teeth of Garima erupted from the palate near the gums. When this deciduous tooth will be replaced by permanent, only then dental surgery can be performed. This surgery will be done when Garima will be about 8-9 years old.

Dental surgery will be done by the dentist at Balaji hospital. It is not necessary to get this surgery done, but if the family wants to get it done, it can be done.

When Garima will be 12 years old, she will undergo her nose surgery at the same Balaji Hospital.

The couple is still not sure about the nose surgery- whether the breathing problem of Garima will be cured by getting it done or not. But they say that this surgery has to be done for the beauty purpose of the girl child.

There is still a slight lisp in Garima's speech. For this, the doctor had advised the couple to undergo speech therapy for her. Speech therapy

can be done at home too. For speech therapy, the doctor said that never lisp in front of the child. Whatever parents or family members want to talk with Garima, they have to say it in very clear words. Just as everyone speaks normally, in the same way family has to talk with her. The whole family talks with Garima as instructed by the doctor. So, speech therapy is given regularly at home. Rajni and Sushant also said that Garima does not even have a uvula in her mouth.

The doctor had also advised that a whistle and a flute should be given to Garima and she should play these instruments. Couple has given these instruments to Garima.

Sushant said that the doctor had also said that if Garima ever has pain in her ear or feels that she is facing any problem in hearing, then she must see the doctor. Sushant also said that till now Garima has not faced any such problem.

Sushant said that he asked the doctor the reason why Garima may have an ear problem. Doctor told him in local terms that the ear, nose and throat are connected and the child had a throat problem as well as a nose problem, so there may be chances of having problem in the ear. And if there will be any problem, consult a doctor.

The family did not attend social gatherings until the child was one year old, but now they go to attend social functions. So, initially some members of society showed discrimination towards Garima but now she does not face any discrimination. Rajni and Sushant also said that now they do not tell anything about Garima's birth defect or surgery to anyone (who does not know anything about it). They never mention this in their conversations with anyone.

Rajni and Sushant have their own car, so they did not face any problem in going anywhere for Garima's treatment. They also did not face any problem during lockdown.

The couple said that nowadays Garima is suffering from cough and cold, due to which her diet has probably reduced. Couple believes that the girl child is more prone to cough and cold as compared to other children in the family. She suffers from coughs and colds every winter. Garima snores very loudly while sleeping.

Dr. Anupama and Sushant's father encouraged Sushant and Rajni a lot. Because of their motivation and support the couple could easily face all the difficulties. Apart from that, the whole family was co-operative. This shows garima never faced discrimination at home.

**24 hours recall:** Last morning she had milk. She had *aloo gobhi ki sabzi ke sath parantha* at school. For lunch at home, she ate *pyaz ka parantha* with curd. For dinner she ate '*dal chawal* milk. At bedtime, she had milk. Next morning she had tea.

Thank You