

Trishav's Journey

Rimpi mother is part of a joint family with her mother in law, father in law, mausi saas a total of 12 family members are residing together. She got married in 2016, conceived in December 2017 and delivered a healthy baby on 13th September 2018 at 7.24 PM. at City hospital Yamunanagar Dr. UshaRathi. First gravida baby's birth weight was 3200 grams. During her pregnancy mothers Antenatal checkups were done from City hospital Yamunanagar. Her delivery was normal and everything was fine. All the USG got done 3-4 were normal, no problem was detected. The Doctor said everything is fine and the pregnancy is progressing fine. The congenital anomaly was not detected at the time of delivery by the Doctor. After the delivery the mother and baby came home and she struggled to breast feed the baby for 3-4 days, but the baby was unable to take her feed. The parents were not told anything and the baby was given to us that he is normal. The mother said one day after seven days of feeding problems that let us get our baby's eyes, ears and complete body check up because she felt that newborn babies eyes and ears should be checked up. The baby was being fed mothers milk with a spoon as he could not latch on and suck the mothers feed. Mother was lactating but the baby could not breastfeed. The father accidently one day observed during the feeding problem that there appeared to be a big cleft in the roof of the mouth of the baby, so he searched on the Internet, downloaded the pic and shared his baby's mouth pic with Dr. Vijay Kumar Swach who counseled him to get the baby checked up in Ashirwad hospital. They took him for a check up consultation to Ashirwad hospital. During this period mother fed him with a bottle, after 2 -3 days of struggle her mother in law suggested that try to feed him with a bottle. He could not pass stool

properly also as he was not feeding well. They fed him cows milk undiluted without sugar initially with the bottle. The parents took him to "Ashirwad " hospital for check up and to consult for his feeding problem they had no clue till then about his congenital anomaly. Ashirwad hospital Yamunanagar conducted his check up inside the mouth and reported that he has Cleft palate complete since birth. This was done 7 days after birth. The parents were totally surprised and taken aback by the findings that Trishav has a congenital anomaly. This is the first time that they had heard of this problem. They have not had any type of congenital anomaly in the babies in their family. The Doctor told them that a Surgery will be done after one year and he will be fine after that. The parents consulted another hospital for a second opinion and the same diagnosis was given to them. Everybody in the whole family was surprised and shocked. Mothers "Mama ji's' ' son is Dr. Pankaj and she called him to discuss the problem. He counseled her that the Cleft palate can be treated and cured by Surgery. Dr. Pankaj also lives in Karnal and he is working in the Government hospital, he said that in six months itself we can get the Surgery done provided Trishav is fit for surgery. He counseled her on how to feed him and to give him a good diet. Dr. Pankaj got her in contact with the Doctor at Balaji hospital Karnal. He asked the parents to get a consultation for Trishav at Balaji hospital Karnal for one month. The Doctor at Balaji hospital told the mother "no tension, only attention". He had prescribed long nipple bottle feeding for Trishav so the parents procured it from Chandigarh and fed him Cows milk undiluted with it. He was able to take feed properly from it. Mother had tried to express her milk and feed him with a spoon but it was very problematic. The thought "No tension only attention" had a deep impact on the Mothers mind to the extent that

she stopped worrying about the problem and got focused on Nurturing Trishav to the best of her ability. She converted thought into action and decided in her mind that since there is a cure for this problem she will nurture him as per consultation with the Doctor and make him fit for Surgery. She looked after Trishav and nurtured him, the whole family provided support, her Mother in law, Father in law, everyone loves him a lot. Mother had full support and love from her in laws. Everyone contributed their time and energy in looking after him. He became very active as his parents were nurturing him well. Mother stopped going to functions and Party's so that he can get maximum care and to make him fit for surgery. Mother set a goal for herself and nurtured Trishav playing, feeding and talking with him. Surgery was performed at six months age as the Doctor had told them that his weight must be good and fit for surgery and they must provide him special care so that he does not have a cough, cold at the time of Surgery. He should not have any problem related to a cough or cold at all to be fit for Surgery. His weight was very good at the time of Surgery. The parents got his weight done every fifteen days. He was operated on at Balaji hospital Karnal on 17th March 2019 after being admitted the prior day. Palatoplasty was done and he was discharged on 19th March 2019 and advised only liquid diet for three weeks. The parents were told not to feed him with the long nipple bottle now after surgery and they started feeding him with a spoon. It was very problematic but they persisted with patience and did not feed him with the bottle at all. For 1-2 months they continued feeding him with spoon, they had been told that after one month from Surgery they can start giving him "PatliDaal, PatlaDaliya" so they started feeding him "Daal Ka Pani" at 7-8 months age. At 8-9 months age mother started feeding him milk with "Katori" and slowly he graduated

to a small "Glassi". He had started taking a proper diet, he had a speech problem but started saying "Papa Papa" at one year old till two years age he kept saying "Papa, Baba, Mama" he could not say "Mum" for water but could say "Mama ". Parents were under tension as he could not speak in short sentences except for a few words. They were worried "does he have some bigger problem". After the Surgery they took him for follow-up consultation to the Doctor at Balaji hospital and discussed his speech problem. The Doctor reassured them that only one Surgery was required which was performed and his mouth is absolutely fine from inside "andar se mu thik he" and he will start speaking slowly with age. Mother was under tension that he will be admitted at a later age in School because of his speech problem and he will be behind other children in class. Trisha was assessed at the ENT head, neck, oncology center at three years six months age on 14th March 2022 with the complaint "does not speak clearly" problem. The center's report said "structurally and functionally normal, vegetative skills, blowing present, chewing present, sucking present and biting present, recommended speech therapy and follow up". Trishav was 4 years + age and could not speak properly. After 2 years he had started speaking broken sentences, so the mother stopped worrying and getting tense about his schooling and at 3 years 3 months old she got him admitted in School. She talked to the Madam who counseled her that when he mixes up and interacts with other children he will start speaking, so he was admitted in Playway and then in LKG in New Happy Public School Bilaspur. The Mother is a Teacher for 1st class in the same School. Father is working in DAV School KapalMochanBilaspur as clerical staff. Trishav has started speaking in sentences now, he does get stuck sometimes "Atakjyata he", but the Doctor has said this problem will reduce with age and by

undertaking speech therapy. About six to seven months back he got fever and the parents observed his nose and saw that his nose is a little deviated to one side, the nasal bone is not straight “Haddadi Hui hai”. The parents consulted Dr. Pankaj who told them that there is a Specialist here in Karnal they should come with Trishav and get a consultation. He used to take leave whenever they came to Karnal for consultation or follow up. He provided them invaluable support throughout. The Hospital Doctor they consulted for the Nose problem said that this problem sometimes resolves on its own and right now there is no Surgery for this problem. He can be operated for this problem at 14-15 years of age only as he has already undergone Palatoplasty and the nasal space may become empty “Khali ho sakti he”. He has no problem in breathing only that the nasal bone appears slightly crooked, the Doctor counseled them that there should be no other problem related to this and not to worry about the cosmetic shape of the nose.

The parents are nurturing him well but he is very naughty as you can see they said, he can not sit still in one place at all. One person is required with him at all times. They can not leave him alone and tell him to sit in one place and expect to find him sitting there, no not at all. He is constantly curious to explore everything, what it is, he wants to know about everything and asks questions. If he sees anything he will go close to it, open it, see it to study what it is, he is curious about everything like a young Scientist at play. He wants to know “Yeh kya he” “Andarka logic”. His mean IQ is 108 as assessed by the Swachpsychologists team recently in the field setting. Today while coming to Swach for the interview he kept asking the name of the car in which they were traveling from his Mother “Mama is gad di ka naam

kya he". She did not know which car it was so she said it is a big car to sidestep the question. He said all cars are big, tell me the name of the car. When they got off at Swach, he remembered his question and asked the Driver uncle the name of the car before coming in, "Bhaiyagaddikanaambataomereko". He wants to eat everything on his own "apne aap khane ki zid rehti he". Today in Swach he ate on his own his tiffin breakfast of "Roti, methi ki sabji and curd" himself. He did not ask his mother to feed him, his video has been shot. At one year his mother had started him on mashed Apple and Papaya till two years of age after which they started feeding him small pieces of food. He used to eat well but always preferred to eat by himself. Mother wakes him up at 6.30 AM – 6.45 AM, his School bus comes at 7.45 AM, he goes to the toilet, brushes his teeth, bathes him and feeds him. He can go to the washroom on his own during the day, but at night he sometimes does bed wetting. In the morning mother ensures he has a good breakfast since he started eating food, "Roti ,sabji with curd". In the morning at 6.0 AM she gives him milk in a cup, he has his own cup, he goes to the washroom and then has breakfast around 7.0 AM. His Teacher says that he is not naughty in School, he is absolutely fine and well adjusted in School. His mother communicates with his Teacher on the phone regularly to know if he did any activity which is unusual. The Teacher says that he does all the activities and studies well. Mother used to teach him at home using a Black board which they have at home since he was two years old. She used to teach him A for Apple, B for ball, C for cat, T for Trishav, to recognize alphabets which he started doing. He comes home from School, changes his dress, then he has lunch and mother makes him rest for some time. At lunch he has rice or whatever is cooked at home he has home food. Parents do not give him food from

the shop but his Chachaji gives him out of love to spoil him. Mother does get angry but does not say much as it is an expression of his love for Trishav. He buys him Chocolate, candies and biscuits. His mother gives him milk in the evening, then he sits with his mother and does his homework, then he plays with his father and “Dada ji”. He plays with his cousin brother “Jethanis son who is studying in fourth class. In the evening he watches TV or on the mobile. He has dinner and between 9.0 – 10 PM he goes to sleep. He has milk before sleeping. He is fond of Paratha, Aloo and Aloo gajar ki sabji is his favorite. Dal he has sometimes when he feels like but is fond off Aloo.

Mother makes him count from objects at home, count the fans in the house, she makes him do activities in which creativity is involved to make him brain smart. She utilizes household objects like a door for teaching Trishav like “Beta door ko dekhkar 5 lines bolo” and he can say, this is a door, its color is brown, it has a handle, I like it very much. She gives him an Apple and says speak 5 lines with creativity on an Apple. She tells him to recite poems with creativity and to practice addition with the help of objects, count using your fingers, add, subtract, “ I gave you 2 toffees, I took one, how many are left with you. Mother kept doing such activities with him even before he started speaking. He started speaking at one year nine months to two years of age. She makes him count with an activity. Mother asks him to read, he can tell alphabets. They have a joint family and they are two brothers. His brother has his own factory making tiles. Mother and Jethani both are teachers. Dada ji is an Agriculturist, and Dadiji is a housewife. They have very good family relations, no problems or tension. They had tension only regarding Trishav’s problem initially until they were counseled by the Doctor. They got support from Dr. Pankaj and God, “Parmatma par

astha he". They go to Beas and listen to "Baba ji ", so they get peace of mind. Their main support is from "Baba ji". Mother also interacted with a child and his parents who had Cleft lip and Palate who goes with her in the School bus, studying in 3rd class. He is very intelligent and has had four Surgeries for his lip and throat from Chandigarh. She talked to his parents about how they have nurtured and cared for their son and also regarding his treatment. Mother sent Trishav for speech therapy to a Private lady tutor at Bilaspur for one week, but she did not like the lady's therapy. Mother is training him to speak on her own like hindi "matra" and words which are spoken from the throat, she makes him practice those words to improve his speech. He is a little "Totla ", the Teacher in School can understand him but sometimes he speaks very fast and people can not understand his communication. Mother has got guidance from Dr. Vijay Kumar Swach regarding his treatment, nurturing and speech therapy. Use less medicines and focus on home care he says to her. If Trishav has any problem she consults him. She is in the Divyang Shakti group. Trishav's current weight is 17kgs.the parents got it done a few days back.The family had no problem nurturing him, everyone has supported him, and mother has given maximum time to him. Mother was teaching in the School when she got pregnant but left at 3-4 months of pregnancy and rejoined only when he was 10-11 months old. Mother was contacted by the Madam when he was 4-5 months old but she did not join because of his problem and because the baby comes first. After his Surgery the Madam contacted her again and this time she got support from her Mother –in –law and she rejoined School. Trishav spends maximum time in her care.During Covid he used to stay at home as there was no School, he started going to School afterwards when he was 3 years 3 months old so there was no impact of Covid on his

Schooling. There was no impact of Covid on their finances as they are a joint family with Agriculture in their background.No body in the family got Covid And they all are Vaccinated for protection. The School is CBSE board with 2000 strength. The school teaches alphabets by using sound pronunciation and activities using the play way method. LEDs are used for visual presentation. Parents have one child and they are satisfied with him. They want him to not get into bad company. Mother keeps an eye on him in School, if he has a problem the teacher calls her. He wants to become a Doctor when he grows up. Dr. Pankaj is his role model. Mother is MA Bed, and Father is PGDCA (computer applications).

Trishav has learned to take “Roti” in a plate to his “Baba ji” or family member. He makes his “Majlis” bed everyday, “Majimeneaapkabistragaladiya’. He can fold clothes, towel, handkerchief in a square shape.He knows where everything is kept. Mother has taught him in Playway mode by involving him in the activities at home. He knows that this is my new dress and which occasion he is going to wear it. These are my old clothes, I will wear them at home. This is my School uniform and the day mother sends him to School without it he insists, “Madam dantegi”. He plays with his cousin brother and sometimes mother also hide and seek. Mother is only worried about his speech problem “Tutlana ho” when he grows up.