

## Anu's journey

Congenital anomalies – B/L Tessier 3 cleft , Enophthalmos

Poonam and Rakesh married for 8 years, first gravida baby conceived in the first month of marriage, her Antenatal check ups and treatment were done from Civil hospital Kharwan. USG was done from S.P. hospital Jagadhry. Normal pregnancy of 8 months with no incidence. Mother was administered an injection at 8 months at S.P. hospital which led to pains she was taken to the hospital at Kharwan where Kapil Sir told them that a wrong injection had been administered. She was referred to the Civil hospital at Yamunanagar where they were told that the amniotic fluid is very low and we will have to conduct an emergency delivery. A team conducted a normal delivery at 9 months full term at 2.43 AM on 12<sup>th</sup> July 2015. Father was called and told not to panic, what he saw he could not imagine, the baby had a Cleft lip up to and below the eye and she was blind from both eyes. The baby was referred to Civil hospital at Yamunanagar from there further to the PGIMER at 9.0 AM. The baby was checked up at 11.0 – 11.30 AM and the parents were told to take her back to Civil hospital at Yamunanagar for management. She was admitted for 3-4 days and then sent home. The treatment from PGIMER went on for 6 months and the baby was declared blind both eyes. She was taken to Shankar Netralya at Chennai where after tests was again confirmed blind. She was taken to Gango Mirza nursing home in Uttar Pradesh (U.P.) where the parents were told that they should have come here on the first day only instead of taking her here and there, as she can not be cured any where in the world and if there was he will send her there on his own expense. The parents were very sad and depressed. She was treated for the Cleft lip from TIPS hospital sector 34 Chandigarh, the Rotary club contacted them and sponsored the Surgery. Her weight was not fit for surgery initially and she was asked to come after 6 months although her Hb was okay. The surgery

for her "Kag " was done from Hisar hospital after her cleft lip was repaired. Anu was not sleeping and after treatment from PGIMER with medicines was able to sleep from 5.0 AM to 7.0 AM only. She was on her fathers stomach the whole night and was passing urine on her fathers stomach. She used to sleep with the fan on during the winters also with her father. She was passing stool also on the fathers stomach for 8-9 months. For 6 months she was sleeping for only 2 hours due to the medication. She did not sleep with her mother at all. Father came into contact with Swach foundation and was guided by Dr. Vijay Kumar and she started sleeping and eating food also. She stopped eating food for the last 3 years and is currently not taking any food at all. At the age of 3 years and 7 months her weight was 12.5 kgs and she had a fever and something like "Khasra", after that she lost weight, lesser food intake and at 3 years 8 months her weight went down to 11.5 kgs. Her Hb remained at 10 gm and currently is 10.5 gm. She was taken to the Civil hospital at Yamunanagar for treatment of a diet problem and also Private treatment was taken for the problem. She was under treatment from Parul Gupta for 2 to 2-1/2 months and on medicines but she did not take any food, only milk. She used to eat " Namkeen" only. Her weight dropped and her stool was very smelly due to the medicines. Her medicines were subsequently stopped and the parents were told to let her continue like this only without food. Vaccination of Anu has been done as per schedule and is complete. Anu gets up at 6.0 – 7.0 AM and has a cup of tea, between 11.0 – 12.0 Noon she has Tea and 1 katori "Namkeen", between 7.0 – 8.0 PM 1 cup Tea, 1 packet biscuit and 1 katori "Namkeen," she has 1 cup milk at 12.0 night. She has her own big cup in which she drinks Tea or milk.

Anu speaks when she wants to, sings when she wants to. She knows counting from 1- 100 and A-Z but she will only recite when she wants to, she does not respond when told to do so. She can recite poems and

bhajans on her own but only when she wants to. She has repetitive behavior and likes to play the "Dhol", "Tal bajati he", sings, plays with balloons or anything in her hand. She likes bathing, can take off clothes on her own, her mother or father whoever is free give her a bath. She likes "Namkeen " only and does not take food even if put in her mouth. She used to eat Daliya, Khichdi, Rice, Roti, Dal and Sabzi but now she has only Chips and Biscuits. She used to eat one and half Roti, Parontha, Dal and Sabzi. When her father used to come home she used to take him to the shop to buy her Chips and Kurkure. The parents gave her these food items out of Love, her Dadiji and Babaji also spoiled her for food. She likes to eat Jalebi at the shop. She has a younger brother Keshav who is 4 years old but the children do not have any fruits, only Fruity drink. The brother vomited out Mosambi Juice, they do not like Banana shake and Anu has only Tea or Coffee. Her brother likes Badam and takes them to his school in his pocket but Anu rejects everything. The village women come and sit on the roof in the sun and she enjoys their company. She can climb stairs on her own. One night the roof door was left open and the father woke up to find Anu missing and found her sitting alone on the roof at night in winter. She plays alone and the mother can do her housework, when the father comes home she forgets everything. She likes to go for rides with her father on the motorcycle in the village "Ghumna " when he comes home from work, she is waiting for him and he takes her for a round before entering his house. She communicates "Chai de do" even if there is no tea in the pan, she will gesture and tea will be made for her. She speaks "Mama susu kara do", "Potty kara do" and is fond of singing songs. She comes to know when the Electricity goes off, she can switch on the TV, light switch, fan switch. She switches off the TV if a serial is being watched and runs out. She used to play the "Dholki" on her mothers wedding "Almirah" and broke the paint and spoiled the doors, so the mother brought her the "Dholki" and now the marriage "Almirah" and doors are

safe. She likes to sing songs, goes to “Satsangs” and “Kirtans” with her mother. She claps and talks now but previously she used to cry at the “Satsangs”. The vegetable vendor who comes to the street daily and shouts. She used to start crying but now she copies “Aloo lelo” “Gobi lelo”. The Milk man also asks the mother to bring her when she is taking milk supply, he provides free milk for her for one – one and half years. She started crying one day at the “Patang” shop and wanted a “Patang” from the shop. She is the life of the house “Raunak” and she keeps everyone busy. In the evening she wants to go for a walk, she is fond of going out. For a marriage function she opted for “Fauji” dress and shoes instead of “Lehenga”. Her favorite game is bat ball and she breaks the plastic bat by banging on the floor but loves playing with the ball. She loves the “Damroo” and although she breaks it yet she will sleep with the “Damroo”. She plays “Kabaddi” on the bed with her brother, they face off and she catches his leg and sits on his stomach and claps “ I have won”. She has broken many phones. If the song stops or slows down at the end she throws the phone against the wall. She can bang her feet the whole night. She goes to School with a copy of a bottle of water and a pencil. “Masti me raha” Anu as said by the Mother. The family comprises three brothers, two brothers live side by side in the village and the third brother lives a little distance in the village. Anu likes to play with her cousins “Laddu”, Harsh and Rohan and asks to go to their house. When Keshav comes home from School, she comes to know at 1.0 PM and says lets get him from school, he touches her feet and she touches his head to bless him with a long life. Anu can sense and smell her fathers presence. If anyone else tries to pick her up she feels their face and pushes them away and asks to be put down. When her father comes home he picks her up. She starts playing and kisses his face and says “Papa ageya”. She plays with her younger brother and sings songs they fight and she complains to her father “Daddy marya” and the brother complains to his mother. There is no stigma,

discrimination with her in the family or in the village. The whole village came to see Anu when she was born and came home. The milk man provided free milk for a period of 1-1 and half years for Anu. Mother and father have no problems in bringing up Anu and they provide the necessary emotional and financial support along with others. They consider her as a "God's gift" and have accepted her. There are no arguments or tension in the house over her. They wanted their first child to be a Girl. Some relatives and neighbor women used to say "why she does not die", the mother used to fight with them that Anu is their daughter and eating from their house and not theirs. We will nurture her and any problem is their daughters and not others. Relatives at a satsang used to say why they are spending so much money on Anu, mother used to say they are spending their own money and nothing is more important than her life. Father used to say we will not have another child " Anu sab kuch hai hamara" but the Grand parents prevailed as they wanted a sibling. Her treatment cost on medicines, tests and travel came to around 3.5 lakhs which was the fathers bank balance which is Nil now. Father works as a "Mistri " fixing tiles and "Pathar ". He used to take Anu to the PGIMER OPD on Tuesday, Wednesday she was seen in the birth defects clinic and on Thursday by the Genetic clinic. They were doing up and down travel from his in-laws house in Garhi kotaha Raipur rani and they used to come back at night. On Friday he used to come home and go to work two days in a week. The family also took loans for her treatment and travel to Chennai. Father had done work at a veterinarian's house. He helped him to get a loan from Jan lakshmi bank now Jena bank.

Father and mother want that their precious daughter when she grows up to become self-sufficient can manage on her own and has a skill set. Anu does communicate her daily needs and routine, the parents are teaching her and take her to the washroom, they undress her but she

can manage on her own. They clothe her, wash her face but there is no guidance yet on how to make her independent. There is Sarv Memorial blind school / hostel in Dehradun, when she starts talking then they will admit her. There is a blind school in Ambala but only for boys. There is one in Panipat which will admit her. The eligible age for admission is 10 years and there are no fees. There is an ITI in Dehradun which provides skills training.