



Struck by Cleft - twice

In a small village close to Warangal lives Jakobi (20 years old) together with her husband Jamal and their two children. Both parents are daily wage labourers in a nearby cotton field and quarry. Together they earn around 450 rupees a day. The family lives in a small house with just one room in front of which they cook outside using a fireplace. A washroom does not exist- the family fetches water from the well in the village and bathe their children in a bucket.

During her third pregnancy, the family tried to save some money to do a scanning. They got the information that the baby was healthy and without a cleft. But the doctor was wrong and also their little girl, Hasina was born with a cleft lip and palate. The family was very sad and afraid of how to handle their daily life with two cleft children. The parents felt guilty and ashamed that they were not able to have a healthy child. Jakobi thought it was her fault because she had married her uncle and because of the significant age difference between them.

Added to these emotional hardships, the couple was highly worried about the costs for the treatment of their children. Still, Saleem's palate was open and Hasina would need a long-term treatment as well. Just like her older brother, Hasina was also underweight and feeding her was very difficult due to the cleft lip.

She was a very weak child and the parents had to bear the cost to treat flu and ear infections. Taking care of Hasina took so much time that Jakobi couldn't go to work anymore and the family income further diminished.

After Jamal's first wife died, he married his young niece Jokabi, his sister's daughter. The couple was shocked when Jakobi delivered her first baby Saleem. The boy was born with a cleft lip and palate. In the hospital, no one took care of the family and they didn't get any information about the treatment of cleft. The parents were worrying very much about the future of their son. Moreover, neither Jakobi nor

Jamal went to school and their capability to search for information and help was limited. The family struggled a lot with feeding the underweight boy. After a year, the family heard about an organization that would help treat their son for free. So finally, Saleem's lip was operated, but with a poor result.

During that time, Jakobi was pregnant again. They were looking forward to having a healthy second child, but that wish did not come true. Quite the contrary happened: What a traumatic experience it was when the young woman delivered a stillborn child. The family suffered from depression for a long time and they were highly thankful for the emotional support of their neighbours and family members.

Finally, there was an end to their misfortune. A social worker from ABMSS visited their village and informed our Cleft Center in Hyderabad headed by Dr Vijay Kumar about the family. The project animator visited the family and saw under what conditions they had to raise their children and how much they struggled to pay for essential things like food and clothes.

Hasina's lip and Saleem's palate were operated in Hyderabad and the parents were very happy with the result this time. After the surgery, they received nutrition supplements to counter the malnourishment.

Saleem is now three years old and a very shy boy who just speaks a few words. Due to his palate operation, he is able to eat normally and his speech has already improved. For further improvement, he is soon going to start with speech therapy sessions. Hasina's lip has already begun to heal and in a few weeks, the scar will reduce. Her parents are looking forward to having her palate operated a couple of months.

There are many families like that of Jakobi and Jamal who are unaware of consanguineous marriages, feeding cleft children and knowing where to get free treatment. This is one of the reasons, we initiated the Awareness Program.