Kerala: Rare surgery changes this tribal boy's life

Encephlocele is a condition the brain matter oozes out of gap present in the skull and forms a sac-like structure.

Manikandan, a 13-year-old tribal boy hailing from Parambikulam, Palakkad was diagnosed with a rare medical condition – encephlocele – because of which he got a bizarre appearance.

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In this condition the brain matter oozes out of gap present in the skull and forms a sac-like structure. In Manikandan's case, the structure was fist-sized and it hung from his nose.

His vision got hindered because of the structure which had also deformed his face. His horrible condition bettered after a team of 10 surgeons at Amrita Institute of Medical Sciences (AIMS) removed the structure after conducted an 11-hour-long surgery.

As Manikanda's parents -- Selvan and Ramata -- are poor plantation workers, Kerala Government agencies aided them by funding this operation.
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It was a complex surgery. Manikandan's encephalocele was very large which had pushed the bone of his right eye outwards. For surgery, his skull was opened and the normal brain isolated from the sac of non-functioning brain matter hanging from his face. The removal of the deformity left a defect in the skull, a portion of which had to be reconstructed," said Dr Subramania Iyer, Head, Plastic & Reconstructive Surgery, Amrita Institute of Medical Sciences (Amrita Hospital).

The patient's eye sockets were repositioned to remove the deformity in the right eye, and the nose was also remodeled. All these were huge surgical challenges. Manikandan has recovered fully from the surgery and is ready for discharge. He will now be able to attend school and participate in all social activities like any other child of his age. The surgery was carried out by the combined efforts of the paediatric craniofacial department consisting of more than 12 surgeons and anesthetists," Iyer added.

The surgical team that operated on Manikandan consisted of paediatric neurosurgeons, cranio maxillofacial surgeons and plastic surgeons, assisted by neuro anaesthetists and a paediatric neuro ICU nursing team. It was led by Dr. Suhas Udaykumar, Dr. Pramod Subhash and Dr. Subramania Iyer, helped by the anesthetic team led by Dr. Gokuldas and Dr. Mathew.

"We belong to the Marasar tribe and work in a plantation. I have five children, who are all normal and healthy, except Manikandan who was born with a swelling on the nose which kept growing. Because of the huge deformity on his face, he never went to school or mingled with other children, as people used to make fun of his appearance," said Selvan, Manikandan's father.

After surgery, he is eager to go back home, start school and make friends. I thank the doctors of Amrita Hospital from the bottom of my heart for enabling my son to lead a normal life," Selvan said further.

The district administration of Palakkad and the tribal welfare department stepped in to fund Manikandan's surgery. Mr. Suresh, District Tribal Welfare Officer, Palakkad, brought the plight of the boy to the attention of Dr P Pugazhenthi (IFS), Director, Scheduled Tribes Development Department, Kerala. He, in turn, escalated the issue to Mr AK Balan, Hon. Minister for Welfare of Scheduled Castes, Scheduled Tribes and Backward Classes, Govt. of Kerala. The Minister took keen interest in the matter and sanctioned funds for Manikandan's surgery. Ms P Marykutty (IAS), District Collector, Palakkad, provided logistical support to liaison between the various Government departments and visited Manikandan at Amrita Hospital to monitor his progress.

Encephalocele is a rare congenital disorder – found in 1 in 5,000 births – in which bones
of a baby's skull do not close completely in the mother's uterus. This creates an opening through which brain tissue and cerebro-spinal fluid protrude out of the head in a sac-like structure. The condition can be fatal if the encephalocele hampers brain development. Once past infancy, patients usually live an isolated life, ashamed to show their face in public.