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Telemedicine helps in treating 4-year-old with rare disorder

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Pune: A four-year-old boy was suffering from Dystrophic Epidermolysis Bullosa, which is a rare genetic disorder that affects the skin. The child was helped by medical experts through telemedicine as he hails from a small village in Rajasthan. In this rare disorder, the skin of the patient is as delicate and fragile as that of a butterfly.

A series of teleconferencing and video conferencing was followed that helped the doctors at Nanavati Hospital to understand the patient and his case. The patient was then flown to the hospital for further treatment under Dr Raina Nahar, Consultant Dermatologist. Dystrophic Epidermolysis Bullosa is an inherited disease affecting the skin and other organs of the body. A cure for this has not been determined yet and the only way to deal with it is through continuous treatment and care. The child came to the hospital in a critical condition with blistering and peeling skin all over the body. His hands and feet were totally contracted which hampered his day-to-day activities.

While speaking about the case, Dr Raina Nahar said that this is a rare type of genetic mutation. "Protein 'collagen 7' is missing from his gene, which makes the skin fragile and resulting in the erosion and blisters causing extreme pain. His hands and legs were contracted. Internally, the child was suffering from digestion problems, oral blisters, constipation, acid reflux and anaemia," said Dr Nahar.

Providing the first line of treatment is to stop further erosion, the hospital ordered a special air-bed, foam chair, special footwear (foam footwear) and soft clothes.

"The treatment of the baby involves special care and medicines. The child was in a critical condition when he arrived at the hospital," Dr Nahar said.

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THE CONDITION

- Dystrophic Epidermolysis Bullosa is an inherited disease affecting the skin and other organs of the body.
- A cure has not been determined. The only way to deal with it is through continuous treatment and care.
- "Butterfly child" is the colloquial name for a child born with the disease, as their skin is seen to be as delicate and fragile as that of a butterfly.
- ""Protein 'collagen 7' is missing from his gene," said Dr Nahar.

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"However, now the child is recovering with the help of advanced medical treatment," emphasised Dr Nahar.

She further added that the permanent cure for the baby is to undergo a bone marrow transplant.

"The hospital is in the process of genetic testing and HLA typing to plan for bone marrow transplant that will be remarkable in these cases. Once the child's immunity is enhanced and if the bone marrow matches with the siblings then the surgery could be performed on the baby," said Dr Nahar.

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