

Shunned sisters hopeful, with love from Russia

TV channel offers to fund treatment for their rare condition, document their journey to be featured on a show

Yogesh Pawar

Anita Raut yells at her daughters for disturbing the two bags kept in corner of their two-room home at Kavthe Ekhand village in Maharashtra's Sangli district. "I don't know how to stop them. They are so excited about going to Russia," says the 59-year-old mother.

Savita, 24, Manisha, 19, and Savitri, 16, rarely go out of their village. Apart from helping their mother on the fields and with running the house, they avoid stepping out for fear of being ridiculed. "We only go out with our mother as people start making nasty comments every time we step out," says the eldest daughter, Savita, who says the trip to Russia, this week seems like a dream.

Of Anita's six daughters, three suffer from Hypertrichosis lanuginosa universalis.



Manisha, Savitri and Savita Raut with their mother (second from right) at their Kavathe Ekhand residence

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Due to this condition, they have excessive body hair that covers most of their faces as well. This has led to them being shamed, shunned or "treated like a freak-show."

Mansoor Chetlu of the New Life Foundation, a Bangalore-based NGO, is coordinating between the family and a Russian state-run television channel, Rossiya 1,

which has offered to sponsor their travel and treatment at Moscow's Institute of Plastic Surgery and Cosmetology around February. According to Chetlu, the channel wants to document their entire trip and treatment, which will be presented on a special show.

While Chetlu called the channel's effort humanitarian, Anita seems unsure.

"They are spending nearly Rs2 lakh on our travel and stay and giving us Rs1 lakh. Will they not want something in return? But I can't marry these girls or do anything for them. So if this is going to help them, then why not?" she says.

Anita gets exasperated when asked if she has tried approaching anybody in the

government for help. "I've fallen at the feet of various officials several times. Aaba (as local MLA and home minister RR Patil is called here) keeps promising us land, employment and financial help every time he is here, but nothing has materialised over the last ten years."

A spokesperson for Rossiya 1 confirmed that the

WHAT THE DISEASE IS

Hypertrichosis lanuginosa universalis is a condition where one has abnormal hair growth on their body. This growth is dense and long. The disease can either be congenital or acquired, and the growth may either be confined to a particular region of the body or occur all over.

The first case was recorded in Petrus Gonsalvus' family. Their portraits found in 1648 from the Canary Islands showed members of the family with hyper hair growth.

schooling till class X. But studying further would mean travelling by bus to get to Sangli town. When Savita completed her Xth, the SSC board exam centre was in a village nearby. "I went to the bus stop and got into the bus but a huge crowd always gathered. I somehow got off and ran all the way home. I dreamt of studying till at least class XII and getting a job, but because of my looks, I've become a burden on my mother instead of helping her out."

When DNA spoke to specialists in the city, they admitted there is little research to help treat this rare disorder. Endocrinologist Deepak Chaturvedi said, "A hormonal treatment will not be expensive but can't guarantee a complete cure either. Also, cosmetic treatment costs lakhs depending on the extent of hair and is a recurrent cost."

Chaturvedi added working with the patient and their family and helping them learn to live with this non life-threatening condition would be better for them. "Only prolonged counselling and therapy can help them come to terms with the social effects," he said.

family would indeed be flying to Moscow in the next few days. "Getting them passports took time. With their visas almost in place, we are eagerly awaiting their arrival," she said, but declined to comment on the special show that the Raut sisters will be part of.

The three sisters learnt to live with jeers and pursued