



**Ikramul Khan, Ali Husain and Rehana, who suffer from progeria, a rare disorder, at S.B. Devi Charity Home in Kolkata.** PHOTO: PTI

**Ikramul Khan and his brother Ali Hussain live at a charity home in Kolkata, where their caretakers hide them from the painful and uncomfortable stares of onlookers.**

IF YOU WANT to know about the medical condition progeria, you should either see Amitabh Bachchan in the film Paa, or meet Ikramul Khan and his brother Ali Hussain. The brothers live at a charity home in Kolkata, where their caretakers hide them from the painful and uncomfortable stares of onlookers.

People think they are some kind of aliens, their father Bisul Khan says. Progeria is a rare disorder passed to a child at birth by parents carrying the defective gene. One in about eight million people suffers from it. The affected child develops the look of a bird with an oversized bald head on a dwarfed body.

The child also ages three times faster than does a normal human being. Ikramul and Ali are probably the only example in the world where more than one member of a family suffers from the disorder, also called the rapid ageing or HutchinsonGilford progeria syndrome.

Ikramul and Ali were born to Bisul Khan and Razia Khatoon from Bihar. They were seven siblings in all, five of whom had the fullblown condition. Of them Guriya, Rehana and Robina died when they turned 17, 24 and 13 respectively. Ikramul and Ali lived on.

In fact, Ikramul's resilience has surprised even his doctor. Ikramul is 23 now. His paediatrician Dr Chandan Chattopadhyay says those affected by progeria usually do not live beyond 17.

The two brothers are, however, full of life. They probably do not know of Amitabh Bachchan yet, and the bond that he has struck with them through Paa.

They, however, have got to know and adore Salman Khan from his film Wanted, which they went to see at an upmarket theatre in Kolkata. It was their first outing to a cinema hall -- their finest hour, and they were immediately star-struck. Ali, in fact, convinced himself that he would be an action hero one day.

Needless to say, life has not been easy for them. "We lived through hell when we were in Bihar," their father says.

"We were frustrated... Had no money, no support... We just did not want to live."

Then in 2003, S.B. Devi Charity Home in Kolkata opened its door to them.

"We made sure that they did not feel alienated when they were in our company. We treated them like human beings...", says Sekhar Chattopadhyay, general manager of the Trust which runs the home.

"They got to wear good clothes. They got to see Shah Rukh and Salman on television. They got a lot of our love, care and affection. Ikramul even learnt to spell his name in Hindi."

These are probably the small, meaningful gestures that have helped them live beyond the years that doctors had otherwise ruled for them.

"The disorder cannot be corrected. We can only make sure that they are well fed and well supported. It is about their mental, social and psychological wellbeing," Chattopadhyay says.

Ikramul and Ali, of course, know what ails them. They probably also realise they do not have long to live. "It is sad that we are suffering from such a disease. But we do not want anybody else to suffer from it," Ikramul says for both of them.

"We have, therefore, told Dr Saab to use us for his research and find a solution soon," he adds.