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**KOLKATA:** Binal Khan is 48 and his wife Razia 45, but their two sons Ikramal and Ali Hussain seem as if they are between 70 and 80 years old.

The curious case of the Khans is what inspired Chansu Kamra's maker R. Balki's forthcoming film *Paa*, starring Amitabh Bachchan and son Abhishek. It was the story of Binal's progeria-affected children that was the inspiration behind *Paa*, to be released on December 4.

While progeria in itself is rare, what pains the Khans is a league of their own is that Binal and Razia had three more children suffering from the disease, all of who succumbed to it.

Balki read about the Khan siblings on the internet. Then came the Oscar-winning *The Curious Case of Benjamin Button* starring Brad Pitt in the lead role and *Paa* was born. The Bachchan-starrer is being made at a cost of Rs 15 crore with much of a going for Big B make up as a child who looks like an 80-year-old man.

The filmmaker said although he knew about the Khan children, he didn't try to get in touch with the family, it being a "sensitive issue".

Originally from Chhapra in Bihar, the young Khans were five siblings, all of them afflicted by progeria. At present, only 23-year-old Ikramal and 11-year-old Ali are alive. Their sisters — Guriya, Rehana and Rabina — were also born with progeria, a rare disease affecting one in every 40 lakh people.

Guriya and Rabina died when they were around 14 but Rehana lived till the age of 23 last year. The disease, however, spared



Progeria patients Ikramal and Ali in Kolkata.

## Old at a young age

**THEY ARE 23 & 11** but look 80. The Khan siblings suffer from progeria, a rare disease that has inspired the latest Bachchan film



their two other siblings, Saajida, 20, and eight-year-old, Chanda. Saajida, who delivered a healthy baby girl last week, was a carrier of the progeria gene but was not affected. Chanda, the youngest of the lot, isn't even a carrier.

Despite five of his children suffering from the disease, Binal came to know of progeria only after coming to Kolkata in 2001, when his eldest daughter Guriya was admitted to the Institute of Child Health (ICH). "We provided them with free treatment, including blood transfusion," said ICH director Aparna Ghosh.

The doctor said the Khans were the largest

**There are hardly any medicines to cure progeria. All we can do is to monitor their food habits, social and psychological wellbeing**

CHANDAN CHATTOPADHYAY

Paediatrician

progeria-affected family in the world. "There are hardly any medicines to cure progeria. All we can do is to keep a watch on their food habits along with their social and psychological wellbeing," said Switzerland-based paediatrician Chandan Chattopadhyay, who researched on the Khan children.

"When they were born, we

didn't understand why they looked old. It was revealed only after a few months that they had some problem when they could not bend their knees and remained standing," Binal said.

Since their skin is wrinkled, the Khans initially thought it to be some sort of leprosy. Doctors at ICH, along with Switzerland's Basel University, spotted the gene *Lamin*, which caused the rare genetic disorder.

An extremely rare, severe, genetic condition, the symptoms include ageing in the early years. Those affected by progeria typically live around 13 years although some have been known to live into their late teens and early twenties. It is a genetic condition that occurs as a mutation and is not usu-

ally inherited. "Two progeria sons prove quite a handful for Razia. "We've to help them take a bath and eat. Me and my husband always have to be on our toes to take care of them."

S.B. Devi Charity Home, a healthcare NGO has also lent a helping hand. "We have engaged them in some activities so that they can mingle with the society," said general secretary Sankar Chattopadhyay.

If the physical problems are not enough, there's also ridicule to handle. The mother reminisced how people considered her children evil and they were boycotted socially. "People used to laugh at them and they were treated like outcasts," said Binal, who works as a security guard.

## KNOWHOW

### WHAT IS PROGERIA?

Also known as Hutchinson Gilford Progeria Syndrome, it is an extremely rare, severe, genetic condition characterised by an appearance of accelerated ageing in children. Approximately one in four million people are diagnosed with this condition. Those born with progeria typically live about 13 years

### ETYMOLOGY

The name is derived from the Greek and means prematurely old

### WHAT'S THAT GENE?

Lamin A/C gene located in chromosome 1

### CAUSES

It is an inborn disease inherited from the genes of parents.

Parents, mother and father need to transmit this affected gene. If the child has the affected gene from both parents, s/he will suffer from progeria. If s/he gets only one affected gene, it may be transmitted to the next generation

### TREATMENT

Progeria cannot be cured but nutrition, social and psychological wellbeing can ensure longer life

### FIGURE IT OUT

Worldwide, there are about 48 living children suffering from progeria. But Khans are the only family-related case in the world

### SYMPTOMS

Although born looking healthy, children with progeria begin to display characteristics of ageing at 18-24 month. Signs include growth failure, loss of body fat and hair, aged-looking skin, stiffness of joints, hip dislocation

### SCREEN PRESENCE

■ **Bodyshock The 80-Year-Old Children:** The Channel 4 documentary follows the doctor who diagnosed the Khan children in 2003 and describes the race to solve the scientific riddle and ultimately cure this disease

■ **Paa:** R Balki's film to be released on December 4