

Drug firms look away while my children die

One of Shekeela Ahmed's teenage children has died. Her other two will soon follow, as regulations deter research, writes Lois Rogers

A MOTHER has been told that her three teenage children will die before reaching adulthood — and there is nothing doctors can do to save them.

Shekeela Ahmed, 45, a businesswoman, has already lost her eldest daughter, Sonam, 17, to Lafora disease, a rare aggressive form of epilepsy.

Her son, Shamoan, 18, fell ill at 15 with the symptoms and does not have long to live. He can no longer walk, talk or eat.

Her youngest child, Amarah, 14, has also suffered the first symptoms. She is one of a handful of teenage victims in the UK waiting for a cure to be found before it is too late.

However, the small number of sufferers of Lafora and labyrinthine drug-trials bureaucracy mean that trials are not financially worthwhile for pharmaceutical companies.

Amarah's situation is particularly painful because she has seen her siblings suffer from progressive dementia and loss of body function.

Her mother, a divorcee from Beeston, Nottingham, who receives no support from the children's father, said: "Amarah just holds on to the hope that treatment will be found, and so do I, otherwise I

William Whitehouse, a paediatric neurologist at Nottingham University, who is caring for the family, said: "All we can do at the moment is help them get the most out of the time available."

He believes it may be possible to overcome the defective brain enzyme with a pump that delivers drugs to the brain via the spinal cord. He says, however, that getting drug trials started when there are virtually no participants has become increasingly difficult. "We have an industry of people meant to help researchers get through the red tape, but because everyone is terrified of getting into trouble they over-interpret regulations so nothing gets done."

About 3.5m Britons suffer from "rare diseases", which, collectively, are now more common than conditions such as heart disease and cancer.

Affected families from around the world can contact each other through the internet and lobby for research. Although Lafora was first identified 100 years ago, its real incidence is unknown. So far about 200 teenagers have been diagnosed globally, though there are believed to be thousands.

Research funds for treatment come only from affected families. Alice Morgan, a single mother from St Helier in Jersey, has raised more than £200,000 from charity events. Her son John became ill with Lafora aged 15. He suffered rapid and severe brain damage and died last year, aged 21.

"Within six weeks of his diagnosis he couldn't lace his shoes," said Morgan, 55, an education support worker. "Every time he collapsed with a fit he would dislocate both his shoulders. Sometimes he had three fits a day. It was horrible."

She is now renewing her fundraising. "Although it's too late for John, we can't give up on these children. I would have tried any medication if there was a chance of saving him."

There are several Lafora research groups around the world. Much of the parents' money is being sent to Berge Minassian, a neurologist at Toronto's Hospital for Sick Children, who has spent decades researching the condition.

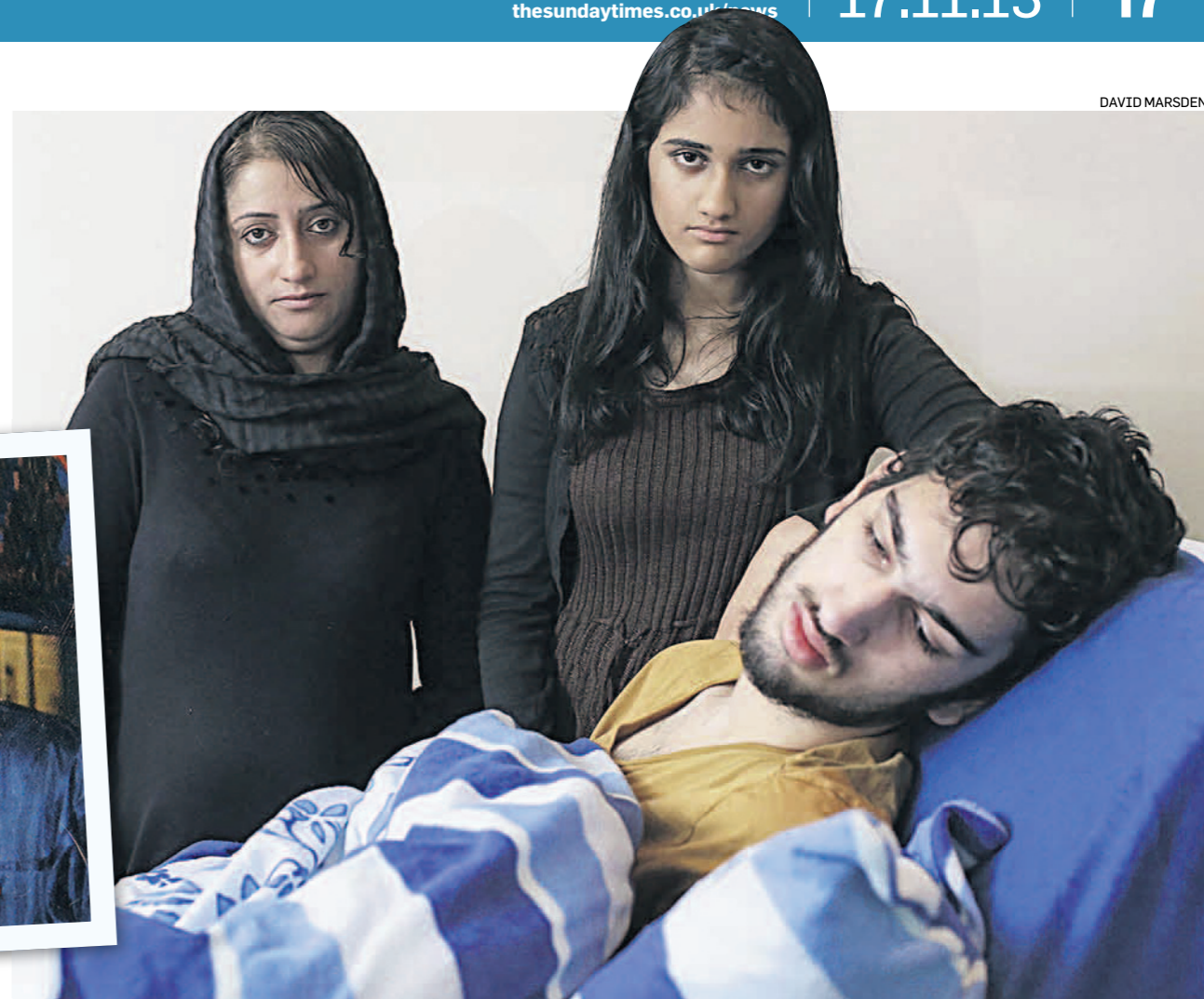
He has identified several candidate treatments that may also be effective for other rare forms of epilepsy. "We are looking at small molecules than can cross the blood-brain barrier and treat this condition," he said. "It's extremely promising, but I can't say whether it will take one year or five [to come up with a treatment]."

The Lafora families say they would willingly try experimental drugs. Empower: Access to Medicine, which is campaigning for dying people to be allowed to volunteer as drug guinea pigs, said the medical research logjam must be broken. "We are seeing promising discoveries abandoned," said a spokesman.

Last month the NHS scrapped plans for a £50m rare-disease fund but on Friday the Medicines and Healthcare Products Regulatory Agency issued a report calling for greater uptake of "existing legal flexibilities" to get experimental drugs to patients.



Sonam Ahmed, pictured with the boxer Amir Khan, died at 17. Her mother Shekeela, above left, now faces losing her seriously ill son, Shamoan, and younger daughter, Amarah



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NEWS IN BRIEF

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The children's laureate has revealed she was left "traumatised" after being sexually assaulted as a young teenager.

Malorie Blackman tells today's Desert Island Discs on Radio 4 that she was attacked by a group of men in a cinema when she was aged 13.



Seven held over body in well

Seven people have been arrested on suspicion of murder after a body was found in a garden well. The grim discovery was made by gardeners at a large home in Audley Drive, Warlingham, Surrey, on Friday.

A police marine diving team retrieved the body from the water yesterday. London's Metropolitan police said the victim was believed to have been a white adult but they were still trying to establish the gender.

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