

This braveheart teen battles rare condition with will power

17-yr-old Pune girl with Takayasu's Arteritis, which blocks blood supply to key organs, is ready to take Std XII exams starting Feb 28

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SEVENTEEN-YEAR-OLD Reena's big dream is to get past the looming Std XII board exams with marks good enough for admission into the London School of Economics. That's why, she's hit the books with a vengeance, now back at her Pune home after yet a stint at Hinduja Hospital in Mumbai.

She'll have to return to hospital soon, for Reena suffers from the uncommon disease called 'Takayasu Arteritis', an inflammatory disease that affects the aorta and its branches, cutting off blood supply to critical organs. It's almost impossible to treat, and Reena's mother Madhuri (44) knows her daughter's

future is uncertain. Still, the family is keen that she doesn't miss a year.

"My daughter has had a number of episodes of illness, but she has always bounced back. I don't know what will happen in the future. But I know for sure she has to give her HSC exams," says Madhuri.

Reena was only two-and-a-half years old when she began to show the troubling symptoms. "Reena was suffering from congenital hydro-nephrosis blockage, which affected both her kidneys. We rushed her to a nephrologist in Pune who directed us to Mumbai's Breach Candy hospital," says Madhuri from Pune. At that tender age, Reena had her first surgery on one kidney, with surgery on the

other kidney following a year later

At seven, the problems multiplied. She fared miserably in her Std III exams after a bout of diplopia (double vision). "She could not see properly. Everything, from a pencil to the words in the book, she saw everything double. Initially I thought it's the exam blues and ignored it. And it settled on its own," Madhuri says. But the diplopia bouts continued periodically. She visited her granny in Mumbai once and had an attack of vertigo. Then she lost coordination between the brain and the limbs. "We rushed her to Bombay Hospital. With medication and physiotherapy, she recovered," recollects the mother.

Despite the diplopia, Reena

Takayasu's Arteritis

- It is an inflammatory disease that affects the aorta and its branches, showing a predilection for young Asian women.
- The age of onset is typically between 15 and 30 years.
- It is also called 'pulseless disorder', because of the difficulty in detecting peripheral pulses
- Symptoms include lack of energy, weight loss, weakness and low-grade fever. As the disease progresses, the limbs may feel cool to the touch, before pain with use develops
- If the disease affects a major blood vessel carrying blood to the brain (the carotid artery) it could cause dizziness, fainting, headaches, seizures and difficulties thinking and remembering

soldiered on at her studies. "She sometimes got red marks in her report card, but kept working hard," Madhuri says. Her Std X exams bore fruit of all the hard work—she passed with 69 per cent.

But other things would simply not be as they were for other

girls. She joined a gym to reduce weight, but then experienced a numbness on the left side of her body, with a tingling sensation.

For the past two years until this January, Reena attended college as normally as possible, until things took a nasty turn. "Since the age of four she had

red patches on her legs and calf that turned black during the winter. Doctors never diagnosed it," says Madhuri. Now, her hands and legs started to swell. Also, a wound on her right ankle showed no signs of healing.

All this prompted Madhuri to consult yet more doctors and make further rounds of hospitals. Finally, at Hinduja Hospital, Reena was diagnosed as suffering from Takayasu Arteritis, after a PET/CT scan. "This disease attacks the aorta and as the disease progresses, patients lose the limb or organ that's affected since there is no blood carried to that part. Patients can have myriad symptoms—blood pressure, hypertension and inflammation of the valve," says Dr B

A Krishna, consultant and chief of Nuclear Medicine at Hinduja Hospital. "Indian patients usually show the abdominal artery affected, as in this case."

Reena is struggling to sleep at night since there is poor circulation of blood in the body.

"Sleepless nights affected her studies, but our main aim was to treat her. And, still, Reena always had her books around her," says Madhuri

This girl won't give up, says her mother, describing the tremendous positiveness and will power the 18-year-old is showing. She even took her oral exams on schedule earlier this month. "God is kind and will take care of her," says Madhuri.

(Names changed to protect identities)