

Exclusive First stem cell brain surgery

7-yr-old gets transplant for rare disorder

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AS AADITYA watches a cartoon show on television, his right hand wavering to caress soft toys (SpongeBob SquarePants and Noddy) tucked next to him in bed, the boy has no clue that researchers and doctors across the world are watching his recovery with bated breath.

That's because this frail boy, who is set to turn eight next month, is the first ever to receive a stem cell transplant for a rare and destructive illness — called Childhood Alzheimer's (medical term: Niemann-Pick Type C or NPC), which causes neurological degeneration and seizures — for which there is no conventional treatment. Stem cells are cells that can, when provided the right stimulus, change themselves into specialised cells and, thus, develop into and replace malfunctioning or damaged body organs. **Continued on Page 8**



Aaditya suffers from childhood Alzheimer's

HOW IT HAPPENED

- Two burr-holes were made in the crown region of Aaditya's head using a high-speed drilling instrument used in brain surgery.
- About 40 million stem cells were lodged in six locations of the brain. A 'Stealth Station', helped in navigation.
- The treatment costs were Rs 4.25 lakh.

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The operation was carried out at the BGS Global Hospital, Bangalore, on December 18 by Dr N.K. Venkataramana, Vice Chairman & Chief Neurosurgeon of the hospital.

Aaditya has recovered significantly after the stem cell transplant therapy. Now, his gaze shifts when people move in his bedroom, his head does not droop and the fingers of his right hand move to touch soft toys placed next to him. He could not do any of these earlier.

"The child's deterioration has stopped and there's some improvement (following the surgery). Next, he has to be-

come active, but we cannot say how long it will take (for him to recover completely)," said Dr Venkataramana.

His recovery will bring cheer not only to his kin, but also to those in various corners of the world suffering from this disease.

Aaditya's affliction has spawned a global network of researchers, parents and philanthropists who are not only exchanging information on this ailment but are also raising \$200,000 to support research on NPC and to evolve an effective treatment for children struck by it.

This group, led by Aaditya's aunt, Duriya Lakdawala, a banker based in

Detroit, US, has already raised \$10,000 during Christmas 2008. "We would like to see more kids benefit from this treatment," says Tasneem, the boy's mother.

Looking back, Tasneem says it took doctors nearly two years to accurately diagnose Aaditya's affliction. The family got to know about NPC only after doctors at Gangaram Hospital, New Delhi, requested a skin biopsy in a laboratory in The Netherlands. Next, it was another journey to find treatment, but none existed, not even in the United States. Her sister Duriya learnt about the Stem Cell transplant approach from Dr Marc Patterson, an

expert on NPC, and later on got to know about Stempenetics, a Stem Cells bank in Manipal Hospital, Bangalore. Subsequently, they met Dr Venkataramana at BGS Global Hospital, who agreed to carry out the procedure.

According to Dr Venkataramana, his team had to get an approval from the local ethics committee (at his hospital) according to guidelines set by the Indian Council for Medical Research (ICMR). "I had to submit the entire protocol involved and make a presentation to the committee prior to the transplant. The entire process took about two months," he said.

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