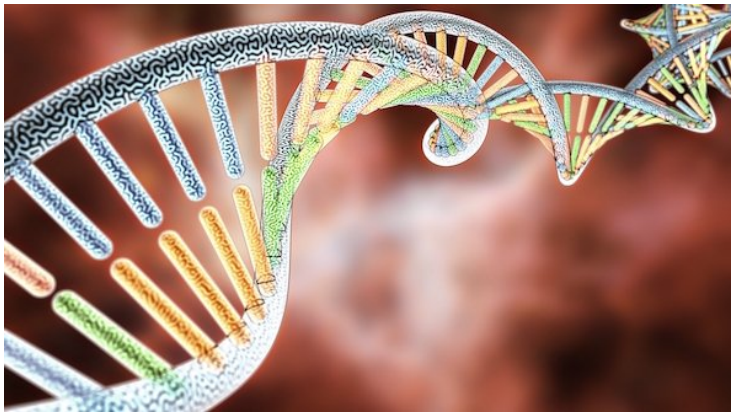
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Rainbow Childrenâ??s Hospital performs rare gene therapy

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A three-year-old was administered ZOLGENSMA, a single dose intravenous injection gene therapy



Hyderabad-based Rainbow Children's Hospital has performed a rare gene therapy for the third time in the last 14 months. Three-year-old Ayaansh Gupta, suffering from Spinal Muscular Atrophy (SMA) was administered ZOLGENSMA at Rainbow Children's Hospital, Secunderabad, under the supervision of Dr Ramesh Konanki, Consultant Pediatric Neurologist.

ZOLGENSMA costs Rs 16 crore and has been imported from the US.

ZOLGENSMA is a single dose intravenous injection gene therapy, in which the defective SMN1 gene is replaced through an adenoviral vector. Earlier, two children have been given ZOLGENSMA at Rainbow Children's Hospital, Secunderabad, in August 2020 and April 2021, and the medicine was provided by Novartis free of cost, on compassionate grounds. Both these children are recovering quite well and making progress in their physical growth and development.

Elaborating details, Dr Konanki stated that currently, there are three proven treatments for children suffering from SMA. He said, "They have to be given either of ZOLGENSMA, SPINRAZA and RISDIPLAM and unfortunately none of these medicines is currently available in India, and all are hugely expensive. SPINRAZA and RISDIPLAM need to be taken life-long, and costs around Rs 40-70 Lakh per year. Many children affected with SMA do not have access to any of these treatments due to the mammoth costs involved for treatment," Dr Ramesh said.

The Consultant Pediatric Neurologist, on behalf of the medical community and the SMA community (CureSMA group) request Central and State governments to negotiate with respective pharma companies and make these medicines available at an affordable price. Further, Dr Ramesh Konanki desired policymakers to encourage research into treatments for rare diseases through the provision of research funding and also provision of medical insurance for frequent hospitalisation and surgeries.

"The parents were able to arrange the amount after going through crowdfunding by ImpactGuru.com, and the union finance ministry has waived off the tax worth around Rs 6 crores. I would like to request the Indian government to make this injection available in India for a price that can be afforded by every parent," said Dr Preetham Kumar, Consultant - Pediatrician & Pediatric Intensive Care, Rainbow Children's Hospital Secunderabad.