National University Hospital

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Little Devdan 'doing well' after costly infusion treatment

Rush to treat S'pore boy with 'world's most expensive drug' hits a snag when he has fever, but ends well

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Little Devdan was diagnosed with spinal muscular atrophy (SMA) in 2019 when he was just a month old.

But an infusion treatment last Saturday, thanks to a stunning campaign that raised more than $2.8 million, means the toddler may be well on his way to leading a normal life.

Last month, The New Paper reported that Devdan, who is now two years old, was set to be treated with Zolgensma, a one-time gene therapy for children with SMA.

SMA is a neuromuscular disorder that affects the nerves and muscles and leads to muscle weakness that worsens over time. Devdan was confirmed to have Type 2 SMA when he was seven months old.

Devdan can stand only when supported and is unable to walk or run. If left untreated, his muscles will degenerate and lose strength, and he could face total immobility in his teens.

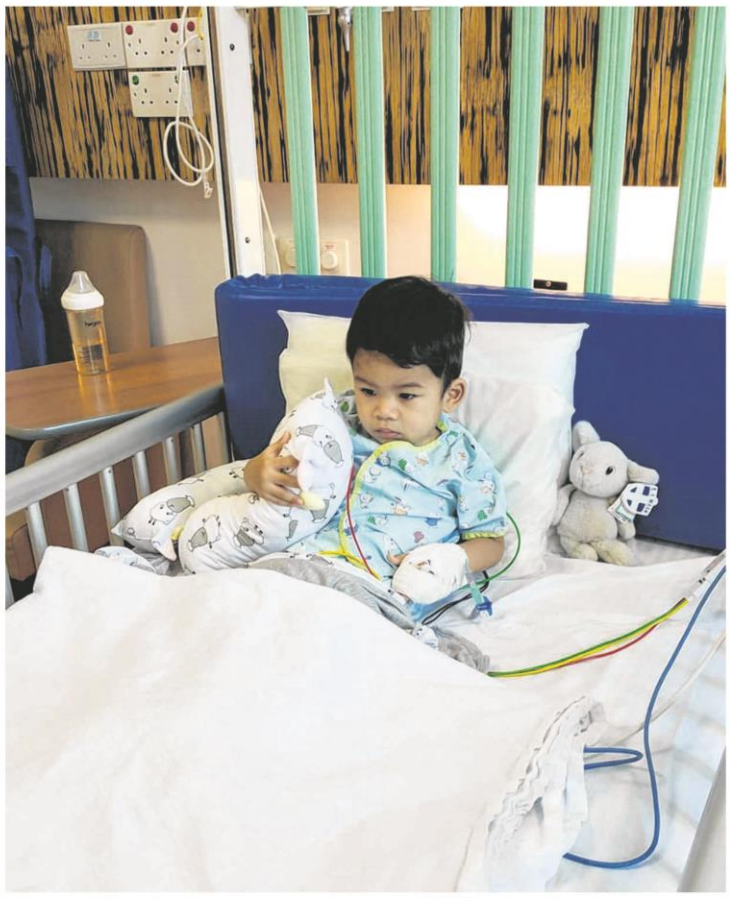
The treatment, widely touted as the most expensive drug in the world, was approved by the United States Food and Drug Administration (FDA) in 2019 and costs around $2.9 million.

Donors managed to raise $2.869 million in a campaign helmed by local charity platform Ray of Hope within 10 days of its launch in early August, ahead of its goal of $2.868 million.

Devdan is an only child and his father, Mr Dave Devaraj, 33, is a civil servant.

His mother, who wanted to be known only as Ms Shu Wen, a designer, also 33, told The New Paper yesterday: "Devdan is currently doing well and in good spirits."

She said the process of getting the treatment in time for Devdan had been an "emotional roller coaster", as the boy's treatment was originally set to take place on Sept 14.



Two-year-old Devdan after receiving the treatment at NUH last Saturday. PHOTO: **SHU WEN**

"I am just thankful that everything went smoothly... It was a stressful period for us due to the urgency to ensure Devdan received the infusion before his second birthday on Oct 2."

– Ms Shu Wen, Devdan's mother, who explained that gene-therapy drug Zolgensma is approved only for children who are younger than two years old

But his sudden fever at 4am that day meant the treatment had to be postponed.

Relieved that her son finally received the treatment last Saturday, Ms Shu Wen said: "I am just thankful everything went smoothly and that the treatment was successfully completed in about an hour.

"It was a stressful period for us due to the urgency to ensure Devdan received the infusion before his second birthday on Oct 2."

Zolgensma is approved only for children who are younger than two, before irreversible harm to the motor neurons is done.

Ms Shu Wen added: "The longer we wait, the more of Devdan's motor neurons will degenerate. It felt like we were racing against time to stop the disease."

In response to queries from TNP, a spokesman for National University Hospital (NUH), where Devdan received the treatment, said: "The patient is receiving multidisciplinary supportive care from our medical team at NUH. The infusion treatment was completed this weekend and it went well."

The spokesman added that the medical team at NUH is closely monitoring Devdan's condition and will continue to provide the necessary support to him and his family.

Said Ms Shu Wen: "We are extremely grateful for all the effort the team at NUH put in to make this a successful treatment. We could not have done it without them."

She explained that Devdan was discharged on the evening of his treatment, but will return to NUH every few days for the next one month to ensure there are no complications.

Devdan will also attend physiotherapy sessions in the coming months.

Ms Shu Wen noted that the money raised from the campaign in August is solely for the treatment, adding: "There are no grants for his condition yet, but we will be receiving subsidies for his follow-up treatments, which greatly eases our financial worries."

She said: "My husband and I were very anxious during the treatment. But Devdan was braver than we were. He did not cry or struggle much, so we were comforted that he seemed happy and lively throughout the process."

Recalling the fund-raising campaign that made this treatment possible, Ms Shu Wen added: "We are extremely thankful to all the donors and those who have helped us in any way.

"It has been a blessing to have been able to witness such overwhelming support and encouragement from everyone. Thank you for making a difference in my son's life."

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