

He had his first shot recently.

"We were very surprised, excited, and more importantly, moved when we learnt about the decrease in the price in November," his mother told Shanghai Daily. "The drug price was sky-high in the past.

"It is a surprising delight and I feel like I am dreaming."

Chen Wanjin, a doctor of the First Affiliated Hospital of Fujian Medical University, added: "In the past, we often received SMA patients who had to give up treatment or halted treatment due to the financial burden from treatment fees. This time, the situation is expected to be reversed".

Xing Huanping is director of the Beijing-based Meier Advocacy and Support Center for Spinal Muscular Atrophy, the first non-profit organization of its kind in China.

"On the first day of the New Year, some SMA patients received treatment under the new policy," Xing said. "We are grateful for the efforts from the government, doctors, companies and various circles of the society behind it. It is the best New Year gift to Chinese SMA patients and their families!"

At 7am, January 1, Li Jiashu, 5, received a shot of nusinersen sodium at the Maternity and Child Health Care of Zaozhuang, Shandong Province.

He was the first beneficiary of the policy in the nation.

When the boy was under medical observation, his mother Li Xiuhua waited outside the ward.

"I am very excited and happy," said Li. "It is the child's first shot and the whole process is smooth."

"I hope my boy will recover and fulfill his long-term dream - going to school."

For Li Jiashu, it was a long wait lasting nearly four years.

When he was four months

old, parents found he had trouble in walking.

"He could only walk several steps when he was nine months, and he could not crouch down when he was 11 months, like his leg was frozen," the mother recalled.

The boy was diagnosed with SMA.

"In 2019, the drug cost 700,000 yuan, and 550,000 yuan in 2020," she said.

"I knew there was a drug to treat the disease, but it seemed too far from me. I could by no means reach it."

December 3 is the four-year birthday of the boy.

When Li Weifeng, the father, opened his mobile phone on the day, the news of "sky-high drug listed in medical insurance category" popped up.

Li read it to his wife, who burst into tears.

"It is the best birthday gift for my son, and there is finally a ray of hope," the mother said.

Another patient surnamed Du in Guangzhou, Guangdong Province, has received the shot as well.

His family was deterred by the sky-high price as well.

"The new policy ignited my hope of life," he said. "Many patients and the parents of children patients cried out when they learned the news."

"I think I am lucky," said Du. "I look forward to the future now."

SMA patients need to take six shots in the first year, and three shots from the second year.

The new policy will save several millions of yuan for patients.

It will be implemented in 20-plus provinces and municipalities across the nation gradually beginning this month.

Experts have also called on the promotion of early screening of rare diseases like SMA among new born to detect the disease early for timely treatment.



Velo, or Zou Weiluo, is a student of Shanghai Huangpu Luwan No.1 Central Primary School.  
— Ti Gong

## Going to school by wheelchair transforms life of little Velo

**Hu Min**

WHEN 7-year-old Velo drove his electric wheelchair into school, he drew the attention of classmates.

"What's this? It is so cool" they said, as they gathered around him.

"It is Transformers," Velo answered.

Velo, or Zou Weiluo, is a student of Shanghai Huangpu Luwan No.1 Central Primary School.

He was diagnosed with the genetic disease spinal muscular atrophy (SMA) when he was several months old. Children born with the disease don't have a prognosis for a long life.

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I asked him to live long, and we will attend the national college entrance examination together after 10-plus years. We cherish the school life.

**Zhang Ying**  
Velo's mother

Doctors said he could not survive three years.

But he now seven years old, under the good care of his family and enrolled at school.

It was by no means easy for Velo to enrol.

He could only move his fingers and part of his elbow.

But it was his wish to go to school like other children.

He never went to kindergarten, and longed to gain knowledge and make friends at school.

"We should not deprive any child the chance of going to school," said Xu Rongjin, the schoolmaster.

Zhang Ying, Velo's mother, said "the family had many concerns."

It is difficult for Velo to write, but he kept practising.

He was enrolled in September.

The school made a specially designed timetable for Velo and arranges half day classes for him.

It is the most joyful thing for the boy to learn with other children.

Although it is difficult for him to make any motion, he tries hard to raise a hand to answer questions.

He has refused his mother's help and tries to accomplish things independently.

Velo won the respect and praise of other children with his act. They view him as good friend.

He became accustomed to his school life gradually.

Zhang accompanies him all the time at school.

"I asked him to live long, and we will attend the national college entrance examination together after 10-plus years," said Zhang. "We cherish the school life."

The diagnosis result was a heavy blow, and his family cherishes the present life very much.

Life education started early in the family.

Zhang told her two children, Velo and her daughter, that death is quite a normal thing, the same as a leaf falling one day.

"For a family foreseeing future, we hope he is happy all the time despite the length of life," said Zhang.

Velo wants to live, walk and jump like others.

At the living room of the family, there is a photo taken in 2015. The family of four crosses the finish line together hand in hand when Velo's father participated in a triathlon.

"We will move forward together hand in hand all the time," Zhang said.