

New insurance policy gives relief to spinal muscular atrophy patients

Hu Min

It is the best New Year's gift for spinal muscular atrophy patients, and a ray of hope for their families.

SMA, is a rare neuro-muscular disease which seriously impacts life quality. There are nearly 30,000 SMA patients in China, with about 1,500 new cases each year.

Children with the disease usually die between 2 and 10 years of age. Even children with relatively mild cases can experience problems with their bones, muscles, lungs and heart as they grow.

Almost all patients with SMA have curved spines and the condition typically worsens after patients enter puberty. The curved spine can press the chest and many people die due to respiratory complications.

Chinese doctors only began paying serious attention to the disease in 2018. Because of limited medical knowledge in more remote areas of the country, some children were treated with useless therapies that had serious side effects.

Nusinersen sodium injection is a medication used to treat the disease. Approved in the

United States in 2016 and introduced into China in 2019, it was also the first modified therapeutic drug for treating SMA disease.

It can effectively curb the development of the disease, and improve patients' physical and breathing functions.

But its price was sky-high and not affordable for many families as it cost 700,000 yuan (US\$109,760) per injection. However, in December, it was included in China's medical insurance category of 2021, bringing hope to SMA patients' families.

Now, patients of SMA only need to pay 30,000 yuan per shot.

On January 1, more than 20 patients in 11 provinces and municipalities such as Beijing, Shanghai, Zhejiang, Guangdong, Fujian and Sichuan took the shot under the new policy.

Two Shanghai children were among them.

Xiao Yueyue, a grade-four student, has had four shots since 2019. The price used to be 700,000 yuan per shot.

There was a significant effect after the four shots, but the family could not afford

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We were very surprised, excited, and more importantly, moved when we learnt about the decrease in the price in November. The drug price was sky-high in the past. It is a surprising delight and I feel like I am dreaming.

The mother of Xiao Songguo, 7

further treatment.

Under the new policy, the family paid about 10,000 yuan and their various insurances 20,000 yuan, for a shot.

“We were in darkness in the past, but now, there is light,” said the mother. “Our confidence in the future is ignited and I think my son can receive timely and effective treatment now.

“In the past, we lived in worries and were helpless all the time as the treatment would stop any time due to financial difficulty, and I felt sorry for my son often.”

Xiao Songguo, 7, did not have any shots previously due to financial difficulty. He could not stand or walk without assistance and received rehabilitation at home to slow movement function degradation.



A boy with SMA does rehabilitation exercises. — Ti Gong



A boy with SMA undergoes rehabilitation exercises at home. — Ti Gong