

# CHINESE DAD MAKING MEDICINE TO TREAT HIS DYING SON



Photo shows Xu Wei feeding his son Xu Haoyang, who was diagnosed with Menkes syndrome, with honey water at home in Kunming in southwestern China's Yunnan province. —AFP photos



Xu Wei holding his son Xu Haoyang, after extracting urine from his bladder for testing at a hospital.



Xu Wei holding his son Xu Haoyang.



Xu Haoyang lying on his grandmother's shoulder.



Xu Wei pouring liquid nitrogen at his home laboratory in Kunming in southwestern China's Yunnan province.

Two-year-old Haoyang has likely just months to live—but the only medicine that can help his rare genetic condition is not found anywhere in China and closed borders due to the COVID-19 pandemic mean he cannot travel for treatment. Instead, his desperate father, Xu Wei, has created a home laboratory to create a remedy for the boy himself. "I didn't really have time to think about whether to do it or not. It had to be done," the 30-year-old told AFP from his DIY lab in a high-rise apartment building in southwestern Kunming. Haoyang has Menkes Syndrome, a genetic disorder that impacts how copper—which is crucial for brain and nervous system development—is processed in the body.

Sufferers rarely survive beyond the age of three. But Xu, who has only high school education and ran a small online business before his son became ill, is determined to give him a fighting chance. "Even though he cannot move or speak, he has a soul and feels emotions," he said, holding Haoyang in his lap to give him honey mixed in water. After being told the disease was incurable and the only medication that could help ease symptoms was not available in China, he began researching and teaching himself pharmaceuticals. "My friends and family were against it. They said it was impossible", he remembers.

Most online documents on Menkes Syndrome were in English, but undeterred Xu used translation software to understand them, before setting up a home lab in his father's gym. On discovering copper histidine could help, he set up the equipment to create it himself, mixing copper chloride dihydrate with histidine, sodium hydroxide and water.

#### Blocked by COVID

Xu now gives Haoyang a daily dose of home-made medicine, which gives the child some of the copper his body is missing. The amateur chemist claims that a few of the blood tests returned to nor-



Xu Wei moving medical equipment at his home laboratory.

mal two weeks after beginning the treatment. The toddler can't talk, but he gives a smile of recognition when his father runs a gentle hand over his head. His wife, who didn't want to give her name, cares for their five-year-old daughter in another part of the city. Menkes Syndrome is more prevalent in boys than girls, and it is estimated one in 100,000 babies are born with the disease globally according to organization Rare Diseases.

There is little information or data available but Xu said pharmaceutical companies have shown little interest as the treatment "does not have commercial value and its user group is small." Under normal circumstances, he would have travelled abroad to bring back treatments for Haoyang from specialist centers overseas, but China has largely closed its borders since the start of the COVID-19 pandemic. Xu felt he had no choice but to make it himself. "At first, I thought it was a joke," said Haoyang's grandfather Xu Jianhong. "(I thought) it was an impossible mission for him." But six weeks after throwing himself into the project, Xu produced his first vial of copper histidine.

To test it he first experimented with rabbits and



Xu Haoyang smiling as his father Xu Wei plays with him at home.

then injected the treatment into his own body. "The rabbits were fine, I was fine, so then I tried it on my son," he said. Reassured, he then started gradually increasing the dosage. But the medicine is not a cure. Professor Annick Toutain, specialist of rare diseases at the Tours University Hospital in France, said the copper treatment "is only efficient against certain genetic anomalies and if it is administered very early on, in the first three weeks of life." She said that after that the treatment will alleviate symptoms, "without leading to recovery." Xu has accepted that it can "only slow down the disease".

#### Gene therapy

His work has led to interest from VectorBuilder, an international biotech lab, who are now launching gene therapy research with Xu into Menkes syndrome. The company's chief scientist Bruce Lahn described it as "a rare disease among rare diseases" and said they were inspired after learning about Xu's family. Clinical trials and tests on animals are planned for the next few months. Xu has even been contacted by other parents whose children have



Xu Wei pouring liquid nitrogen at his home laboratory.

been diagnosed with Menkes, asking him to make treatment for their relatives too—something he has refused. "I can only be responsible for my child," he told AFP, while health authorities have said they will not intervene as long as he only makes the treatment for home use.

Huang Yu of the Medical Genetics Department at Peking University told AFP that as a doctor he was "ashamed" to hear of Xu's case. He said he hoped that "as a developing country, we can improve our medical system to better help such families." With a full-time role as an amateur chemist, Xu has little income and relies mainly on his parents. Friends tried to talk him out of his medical efforts but undeterred, the young father is planning to study molecular biology at university and do everything he can to protect his son. "I don't want him to wait desperately for death. Even if we fail, I want my son to have hope." —AFP

## Doomed 'Dune' storyboards sell for 2.7million euros

The storyboards for the doomed 1970s film version of sci-fi classic "Dune" sold for 2.66 million euros (\$3 million) at auction on Monday, around 100 times the expected price. Long considered a mythical object by sci-fi fans, the notebook of drawings for the film by Franco-Chilean director Alejandro Jodorowsky triggered a bidding war at Christie's in Paris. The film project was supposed to bring together some major stars of the period including Salvador Dali, Mick Jagger and Pink Floyd—but fell apart after four years of preparation due to lack of funding.

The auction went down to two determined bidders, with an American eventually emerging victorious. Christie's admitted their initial valuation for the drawings—between 25,000 and 35,000 euros—had failed to account for the spike in interest

triggered by the new version of the film starring Timothee Chalamet, that has topped box offices around the world in recent months. The drawings are collected in one large notebook, and were made by celebrated French graphic novelist Moebius (alias Jean Giraud, who died in 2012) and Swiss illustrator Giger, who went on to design the movie "Alien" in 1979 and died in 2014.

As well as Dali and Jagger, the tumultuous Dune project was also due to feature veteran Hollywood legends Orson Welles and Gloria Swanson in the cast, with Pink Floyd among the bands approached for the soundtrack. Its infamous collapse was retold in the 2013 documentary "Jodorowsky's Dune". The brainchild of author Frank Herbert, the novel "Dune" was first published in 1965 and became a six-volume space opera of

massive influence, not least on the "Star Wars" franchise. Following the latter's blockbuster box office success, Hollywood took renewed interest in "Dune" in the early 1980s.

That led to David Lynch's version, released in 1984 with a cast including British musician Sting and Patrick Stewart of "Star Trek: Next Generation". But that Dune movie had its own troubles and became one of the decade's biggest flops. Jodorowsky's storyboards were said to have influenced later hits of the genre including "Blade Runner". "We know of several other copies: one was offered for auction several years ago, another is in Jodorowsky's possession... A third has been partially reproduced online," said Christie's. It said around 10 to 20 copies were produced, though it was hard to be certain. —AFP



One of the ten Alejandro Jodorowsky's epic 1970 Dune storyboard copies is displayed to the public three days before an auction at Christie's Paris gallery. —AFP