Kazakhstan plans to open a center for cystic fibrosis

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English doctors are ready to help in this matter

The issue of establishing a center for the study and treatment of patients with cystic fibrosis in Kazakhstan has been raised more than once. Especially often, this has been actively talked about since 2010, when the Kazakhstan association of cystic fibrosis was established at the initiative of a group of parents. They became the initiators of the arrival in Kazakhstan of a team of doctors from the UK, who these days share their knowledge and experience in the treatment of rare diseases.

Two years ago the Kazakhstan association of cystic fibrosis entered the World Organization of Cystic Fibrosis (CFW). Then our country was first visited by the president of CFW Terry Stewart and promised to come to Kazakhstan next time with a team of specialists in the field of cystic fibrosis.

Stewart kept his promise. So, on April 24 he again arrived in Almaty and this time in the company of a pulmonologist, physiotherapist, nutritionist and pediatrician. For three days, English specialists shared their knowledge in the management of patients with cystic fibrosis with their Kazakh colleagues.

By the way in the UK, some of the best indicators of successful treatment of people with rare genetic diseases. For example, among patients who have come to Kazakhstan doctors, there are those who have already over 80 years. And it should be noted a great success. In Kazakhstan, cystic fibrosis is essentially an infantile disease. In our country, such patients do not even have time to grow up.

"As much as possible, Kazakhstanis with cystic fibrosis live up to 25 years. Although, for example, in Russia, the average age has risen to 35 years, "said the head of the Kazakhstan association of cystic fibrosis, Indira Izbasarova." Our main problem is that even the doctors know too little about this disease. Two years ago this was exactly what the president of CFW noted. "

According Izbasarova British experts also embarrassed the official figure of registered patients with cystic fibrosis. But this is also understandable. The country is very weak diagnosis of this disease. In most cases, patients are identified even when the whole clinical picture is on their face.

"As the British say, 100 patients are a small indicator. Probably, we have them many times more. They simply do not come to light and die unidentified, "says Indira." It shocked foreign guests that there were only 9 doctors per 100 children with cystic fibrosis. "

By the way in the UK, since 2007, every newborn is screened for the detection of cystic fibrosis. According to their data, approximately 2500 genera account for one case of a rare genetic disease.

"This screening is expensive, but as time shows, it's still cheaper than treating a neglected form of cystic fibrosis," said CFW president Terry Stewart. "In your country it is too early to talk about the introduction of a screenshot. In Kazakhstan it is important to create a center in the near future and prepare a team of specialists who will work only with patients with cystic fibrosis who will be able to spread knowledge and experience among their colleagues. I want to note that people with this genetic disease can be useful members of society. For example, in England, 70% of our adult patients work or study in universities. "

The Kazakhstani Association of Cystic Fibrosis is hoping for attention from the Ministry of Health of the Republic of Kazakhstan.

"English doctors are ready to help us organize the Center correctly, and are ready to continue sharing our knowledge with us. Now we need to decide where this center will be based. We need support from the Ministry of Health, "Izbasarova summarized.

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