

Health minister promises help for rare disease patients

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JAIPUR: Rajasthan health minister Rajendra Singh Rathore has promised all possible support to patients with rare diseases.

Rathore said the government would undertake a number of welfare initiatives, including setting up a committee, making treatment available under National Health Mission and making drugs available under the free medicine scheme, for such patients.

The minister was speaking at the first stakeholders' roundtable meet (RTM) on welfare of rare disease patients in the state

THE GOVERNMENT WILL MAKE DRUGS AVAILABLE UNDER THE FREE MEDICINE SCHEME

RAJENDRA RATHORE, health minister

on Tuesday evening.

The RTM was the first of its kind initiative undertaken by the Lysosomal Storage Disorders Support Society of India (LSDSS) to address concerns of rare disease patients with various stakeholders.

Experts pointed out that patients suffering from rare

diseases like Lysosomal Storage Disorders (LSDs) are facing enormous difficulties in their quest for timely diagnosis, proper information and medical help.

Owing to high cost of the medicines, they are unable to bear the cost of the treatment and have no support from either insurance firms or the government, they said. JK Lon Hospital's medical superintendent Dr S D Sharma said rare genetic diseases such as LSDs are serious and mostly prolonged and progressive in nature. "Patients are vulnerable. Therefore, there is an urgent need for support from the government and private institutions," he added.