

Govt to extend all support to patients suffering from rare diseases: Rathore

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Health minister Rajendra Rathore has said the government would extend complete support to patients suffering with rare diseases like Lysosomal Storage Disorders (LSDs).

Speaking during 1st Stakeholders' Roundtable Meeting (RTM) on Welfare of Rare Disease patients in state, Rathore said, "I am deeply hurt to see the plight of rare disease patients. The state government will provide all ground assistance to ensure such patients get all possible support from government in the future. We propose to undertake number of welfare initiatives for such patients including setting up a committee, making treatment available under National Health Mission and ensuring availability of drugs under

MEET TO ADDRESS RARE DISEASE PATIENTS' ISSUES

The Roundtable Meeting (RTM) on Welfare of Rare Disease patients was 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. On the occasion, parents of rare disease patients met key genetic experts and health officials to discuss their plight and access to treatment.

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undertaken by the Lysosomal Storage Disorders Support Society of India (LSDSS) to address concerns of rare disease patients with various stakeholders in the city.

Speakers present at the RTM included Dr SD Sharma, Superintendent of JK Lon Hospital, Dr Lalit Bharadwaj from Fortis Hospital, Dr Munish Kukkar from MGMC, Manjit Singh, President of LSDSS, Ministry officials, patients and their families.

"For most families, time and money are of the essence. The longer they wait for enzyme injections, disease will progress to a stage where it cannot be arrested. If the health ministry could take some steps to make treatment available at a subsidised cost, many patients can be benefitted and live close to normal life," said Manjit Singh, president, LSDSS, during his address.