

‘LAX MEDICAL CENTRES PUTTING PATIENTS WITH RARE DISEASES AT RISK’

Relevant for: Developmental Issues | Topic: Health & Sanitation and related issues

Despite the Health Ministry issuing guidelines and procedures for providing financial assistance to the patients suffering from various rare diseases, only two out of the nine medical centres selected from across the country have submitted applications for receiving funds for such treatment.

The delay puts at further risk several patients who continue to battle rare diseases and are almost completely dependent on government assistance for medicines and medical care. The Ministry has now written to these medical institutes to immediately rectify the situation to ensure that no patient suffers without treatment.

“After a long delay, the National Policy for Rare Diseases was finalised in March 2021 offering monetary aid of Rs. 20 lakh to only Group 1 patients (Disorders amenable to one-time curative treatment). This was modified in May 2022, with an amendment in the policy, announcing Rs. 50 lakh monetary aid to all groups of Rare Diseases,” said Manjit Singh, president, Lysosomal Storage Disorder Support Society.

It has been several months since the Health Ministry issued guidelines to these medical centres towards the utilisation of the Rs. 50 lakh per patient grant for rare disease treatment but most of them have not initiated any steps to implement it, he pointed out.

“While the Ministry is concerned and committed to this sensitive issue, the onus is on all these centres to process the applications of eligible patients and recommend the same to the Ministry to source the funds. Some centres are not entertaining the request applications of patients who have been approaching them,” he said.

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