

DISQUIET OVER POLICY FOR RARE DISEASES

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Caregivers to patients with 'rare diseases' and affiliated organisations are dissatisfied with the National Policy for Rare Diseases, 2021 announced on Wednesday. Though the document specifies increasing the government support for treating patients with a 'rare disease'— from Rs. 15 lakh to Rs. 20 lakh — caregivers say this doesn't reflect actual costs of treatment.

"The new policy offers no support to patients awaiting treatment since the earlier National Policy for Treatment of Rare Diseases 2017 was kept in abeyance. In the absence of any funding support, close to 130 patients are left with no option but to wait for the inevitable. Several patients have already lost their lives in the interim period. Unlike conditions under Group 1 and Group 2, patients with Group 3 disorders require sustainable treatment support," said Manjit Singh, National President, Lysosomal Storage Disorders Support Society.

"Looking at the number of rare disease patients diagnosed and considered eligible for treatment by the respective State technical committees, the immediate requirement of funds to support the immediate treatment needs of the diagnosed patients shouldn't have exceeded Rs. 80 crore to Rs. 100 crore annually. The Centre's contribution would work out to Rs. 40 to Rs. 50 crore — if it is able to convince the State(s) for a load-sharing model, as a few States like Kerala, Tamil Nadu and Karnataka have already indicated," said health economist Prof. Viswanath Pingali.

"It is alarming that the Union government has left patients with Group 3 rare diseases to fend for themselves. The new policy has absolutely no consideration for Group 3 patients, who require lifelong treatment support," said Prasanna Shirol, co-founder and executive director, Organisation for Rare Diseases India, an umbrella organisation.

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