Seventeenth Loksabha

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Title: Regarding treatment of rare diseases-Laid.

DR. (PROF.) KIRIT PREMJIBHAI SOLANKI (AHMEDABAD

WEST): I request the government to provide subsidized medical care to patients from poor backgrounds who are suffering from rare diseases like Gaucher 's Disease, Hurler Syndrome, Wolman Disease etc. Though these diseases have a low prevalence and are individually rare, collectively as a whole in the country 6-8% of people are estimated to be affected. 50% of cases are children and most of these are genetic diseases. Parents and families of these children face a lot of emotional and financial drain as the cost of treatment is very high. Treatment for some of these diseases may vary from Rs 10 lakh to 1 crore and lifelong treatment may be necessary. I request the Government to promote R&D in developing affordable therapies and a corpus fund must be set up with funds from centre, state and private donors so that patients suffering from these diseases could be benefited.