

**GOVERNMENT OF INDIA
MINISTRY OF HEALTH AND FAMILY WELFARE
DEPARTMENT OF HEALTH AND FAMILY WELFARE**

**RAJYA SABHA
UNSTARRED QUESTION No. 2330
TO BE ANSWERED ON 21st MARCH, 2023**

ASSISTANCE UNDER NATIONAL RARE DISEASE POLICY, 2021

2330. SHRI SANJAY SINGH:

Will the Minister of **HEALTH AND FAMILY WELFARE** be pleased to state:

- (a) the number of people affected by rare diseases in the country, the percentage of children among patients afflicted with the said diseases;
- (b) the number of people died due to rare diseases during the last five years; and
- (c) the number of people suffering from rare diseases having been provided with a financial assistance of ₹ 50 lakh by Government during the said period?

**ANSWER
THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY
WELFARE
(DR. BHARATI PRAVIN PAWAR)**

(a) & (b): As per the data available with Indian Council of Medical Research (ICMR) National Registry for Rare and Other Inherited Disorders (NRROID), a total of 9076 patients have been enrolled since November, 2019. Out of these, age-wise data of 5107 patients afflicted with rare diseases have been reported which includes 66.59% children with less than 12 years of age. A total of 348 patients have died as on date.

(c): The Government has launched National Policy for Rare Diseases (NPRD), 2021 in March, 2021 for the treatment of rare disease patients. As per the amended provisions issued on 19.05.2022, financial support upto Rs. 50 lakhs is provided to the patients suffering from any category of the rare diseases and getting treatment in any of the Centres of Excellence (CoEs) identified under NPRD, 2021. Eleven CoEs have been identified as on date. Financial assistance has been released to the CoEs for the treatment of 150 patients in accordance with the provisions of the NPRD, 2021. Out of these 150 patients, Rs. 50 lakhs each in respect of 41 patients has been released to the CoEs.
