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Rare Disease India Foundation issues urgent demands for ensuring treatment

28 February 2022 | News

Requested the health ministry to initiate urgent measures with immediate effect

Rare Disease India Foundation (RDIF) a national patient advocacy group, has appealed to the Union Health & Family Welfare Minister Dr Mansukh Mandaviya highlighting the current gaps in providing life-saving treatment to the patients, who have been diagnosed with rare, genetic conditions for which the Drugs Controller General of India (DCGI) approved treatment is available in India for many years now.

Even after seven months of the crowdfunding platform, a meagre amount of Rs 1,15,866 has been raised so far, as a result of which not a single patient has been put on treatment.

RDIF has requested the health ministry to initiate the following measures with immediate effect:

• Extend the Umbrella Scheme of Rashtriya Arogya Nidhi (RAN) to all Group 3(a) patients with treatable conditions. Currently, the scheme only provides a one-time grant of Rs 20 lakh to Group 1 patients. There are several instances where MoHFW had in the past made exceptions to Group 3(a) patients, extending support under RAN.

• A major part of the annual budgetary allocation of Rs 25 crore under the Umbrella Scheme of Rashtriya Arogya Nidhi (RAN) for 2021-22 has remained unspent, like in most previous years. To allow utilisation of this year's allocation to provide immediate treatment support to at least the Group 3(a) patients, diagnosed with Gaucher disease, Pompe disease, Fabry disease, MPS I & MPS II.

• A National Programme on Rare Diseases with a budgetary allocation of at least Rs 150 crore be set up by the Ministry of Health and Family Welfare immediately to provide life-saving therapy of all those patients with treatable Group 3(a) disorders

like Lysosomal Storage Disorders, for which DCGI approved treatment is available, can be provided, thereby reducing any further loss of life.

• Like in the case of the PM Cares model, encourage and build support from PSUs, India’s corporate to support this cause of rare diseases