

**OFFICE MEMORANDUM**

**Subject: Inclusion of three (03) Diseases under Para 6.2 of National Policy for Rare Diseases (NPRD), 2021– reg.**

The undersigned is directed to say that in pursuance of paras 6.2 and 6.3 of the National Policy for Rare Diseases (NPRD), 2021, three (03) diseases have been reviewed by the Central Technical Committee for Rare Diseases (CTCRD), Directorate General of Health Services (Dte.GHS), based on updated scientific data, and included as rare diseases under the following groups of disorders, identified and categorized by experts, based on their clinical experience:

**Group 1: Disorders amenable to one-time curative treatment:**

**(b) Disorders amenable to organ transplantation**

- i. Glanzmann Thrombasthenia Disease

**Group 3: Diseases for which definitive treatment is available but challenges are to make optimal patient selection for benefit, very high cost and lifelong therapy:**

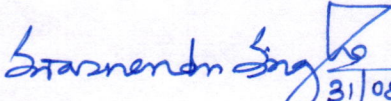
**(a) Based on the literature sufficient evidence for good long-term outcomes exists for the following disorders**

- i. Cystinosis
- ii. Hereditary Angioedema

2. The financial assistance to the patients suffering from the above mentioned rare diseases shall be provided as per the provisions of the NPRD, 2021, and guidelines and procedures issued to all Centres of Excellence (CoEs) vide this Ministry's letter dated 11.08.2022.

3. This comes into effect from the date of issue of this Office Memorandum.

4. This issues with the approval of the competent authority.

  
31/08/2023

(Swarnendu Singha)

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To

1. The Secretary, Department of Biotechnology, Ministry of Science and Technology, Government of India.
2. The Secretary, Ministry of Corporate Affairs, Government of India.