

OFFICE MEMORANDUM

Subject: Inclusion of 06 Rare Diseases with categorization under Para 6.2 of National Policy for Rare Diseases (NPRD), 2021- reg.

The undersigned is directed to refer to subject mentioned above and to say that in pursuant to Para 6.2 and 6.3 of the National Policy for Rare Diseases (NPRD), 2021, 06 (six) rare diseases, reviewed by the Central Technical Committee for Rare Diseases (CTCRD), Directorate General of Health Services (Dte.GHS) based on updated scientific data, have been included 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:

- i. Laron's Syndrome

Group 2: Diseases requiring long term / lifelong treatment having relatively lower cost of treatment and benefit has been documented in literature and annual or more frequent surveillance is required:

(b) Disorders that are amenable to other forms of therapy (hormone/ specific drugs):

- i. Wilson's Disease
- ii. Congenital Adrenal Hyperplasia (CAH)
- iii. Neonatal Onset Multisystem Inflammatory Disease (NOMID)

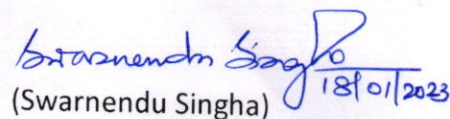
Group 3: Diseases for which definitive treatment is available but challenges are to make optimal patient selection for benefit, very high cost and lifelong therapy:

- i. Hypophosphatic Rickets
- ii. Atypical Hemolytic Uremic Syndrome (AHUS)

2. The financial assistance to the patients suffering from the above mentioned rare diseases shall be provided as per the provisions envisaged under 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.


(Swarnendu Singha) 18/01/2023

Under Secretary to the Government of India

Tel. 011-23061521

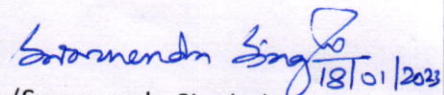
Email: swarnendu.singha@nic.in

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;
3. The Secretary, Department of Health Research/Director General, Indian Council for Medical Research, New Delhi;
4. The Secretary, Department of Pharmaceuticals, Shastri Bhawan, New Delhi;
5. The Secretary, Department of Promotion of Industry and Internal Trade, Udyog Bhawan, New Delhi;
6. The Secretary, Department of Revenue, Ministry of Finance, Government of India;
7. The Chairman, National Pharmaceutical Pricing Authority, 3rd/5th Floor, YMCA Cultural Centre Building 1, Jai Singh Road, New Delhi;
8. The Drugs Controller General of India, FDA Bhawan, New Delhi;
9. The Director General, Directorate General of Health Services & Chairman of CTCRD, Nirman Bhawan, New Delhi;
10. Additional Chief Secretaries/Principal Secretaries/Commissioner (Health) of all State Governments/UT Administration (as per list attached);
11. Director/In charge, Centres of Excellence (as per list attached);
12. The Nodal Officer, all the 11 CoEs (as per list attached).

Copy for information to:

1. PPS to Secretary (H);
2. PPS to AS (Rare Diseases);
3. IFD, MoHFW;
4. PPS to Director (EMR) & Addl. DDG, Dte.GHS, Nirman Bhawan, New Delhi.


(Swarnendu Singha)

Under Secretary to the Government of India