

W.11037/48/2024-RD  
Government of India  
Ministry of Health & Family Welfare  
Department of Health & Family Welfare  
(Rare Disease Cell)

Room No.501-D Wing  
Nirman Bhawan, New Delhi  
Dated: 02.04.2024

**OFFICE MEMORANDUM**

Subject: Inclusion of 04 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, the following 04 (four) 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:**

- a) **Congenital Hyperinsulinemic Hypoglycemia (CHI)**
- b) **Familial Homozygous Hypercholesterolemia**
- c) **Mannosidosis**
- d) **XY Disorder of Sex Development due to 5 alpha reductase deficiency, partial androgen insensitivity syndrome**

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 Secretary (Health & FW).

Signed by

Swarnendu Singha

Date: 02-04-2024 11:28:20  
(Swarnendu Singha)

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, 3 rd /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 and Chairman of CTCRD, Nirman Bhawan, New Delhi;
10. Additional Chief Secretaries/Principal Secretaries/Commissioner (Health) of all State Governments/UT Administration
11. Director/In charge, Centres of Excellence (as per list attached);
12. The Nodal Officer, all the 12 CoEs (as per list attached).

Copy for information to:

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

(Swarnendu Singha)  
Under Secretary to the Government of India

**list of 12 (twelve) Centres of Excellence**

S. No.	Name of Centre of Excellence	Name of Nodal Officer/ Email id/contact No.
1	All India Institute of Medical Sciences, New Delhi	Dr. Neerja Gupta, Associate Professor Division of Genetics, Department of Pediatrics, AIIMS, New Delhi, Email: neerja17@gmail.com, Contact No. 9868397529
2	Maulana Azad Medical College, New Delhi	Dr. Meenakshi Bothra Assistant Professor, Division of Genetics, Department of Pediatrics, MAMC, New Delhi Email: meenakshibothra@gmail.com Contact No. 8700509704
3	Sanjay Gandhi Post Graduate Institute of Medical Sciences,	Dr. Shubha Phadke M D Professor & Head, Department of Medical Genetics, Sanjay Gandhi