

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

	Lucknow	Postgraduate Institute of Medical Sciences, Lucknow, India-226014 Phone: 9839220199, 91 522-2494325 E-mail : shubharaophadke@gmail.com
4	Post Graduate Institute of Medical Education and Research, Chandigarh	Dr. Ranjit Pal Singh Bhogal, Assistant Professor, Deputy Medical Superintendent, Department of Hospital Administration, Contact No. 7087002089 Email: majorbhogal1984@gmail.com
5	Centre for DNA Fingerprinting & Diagnostics with Nizam's Institute of Medical Sciences, Hyderabad	Dr. Ashwin Dalal, Head, Diagnostics Division Email: ashwindalal@gmail.com Contact No. 040-27216147
6	King Edward Medical Hospital, Mumbai	Dr. Akash Shukla, Mobile No. 9869256376 Email id: drakashshukla@yahoo.com
7	Institute of Post-Graduate Medical Education and Research, Kolkata	Prof Suchanda Mukherjee, HOD, Neonatology Contact No. 9831485596 Email: drsmukherjee70@gmail.com
8	Center for Human Genetics(CHG) with Indira Gandhi Hospital, Bengaluru	Dr. Sanjeeva GN, Associate Professor, Indira Gandhi Institute of Child Health, Bengaluru Mob: 9945657034 Email: sanju.gn26@gmail.com
9	Institute of Child Health and Hospital for Children (ICH & CH), Chennai	Dr. Anuradha, M.D,DCH, Phd. Mob: 9444340166 Email: anuradha.iit@gmail.com
10	All India Institute of Medical Sciences (AIIMS), Jodhpur	Dr. Kuldeep Singh, Professor & Head, Department of Pediatrics, AIIMS, Jodhpur, Basni Industrial Area, Phase-II, Jodhpur, Rajasthan – 342005. Contact: 0291-2833149/ 8003996940 (Email: kulpra@gmail.com)
11	Sree Avittam Thirunal Hospital (SAT), Government Medical College, Thiruvananthapuram	Dr. Sankar V.H., Associate Professor of Pediatrics & Geneticist, SAT, Government Medical College. (Email: sankarvh@gmail.com) Phone number : 9349930828
12	All India Institute of Medical Sciences (AIIMS), Bhopal	Prof (Dr.) Ajay Singh, Executive Director AIIMS, Saket Nagar, Bhopal - 462020. (Email: director@aiimsbhopal.edu.in) Phone number: 0755-2672317