

W-11037/82/2023-RD(Part1)
Government of India
Ministry of Health & Family Welfare
Rare Disease Cell

Nirman Bhawan, New Delhi
Dated : 20th January, 2025

OFFICE MEMORANDUM

Subject:- Inclusion of Regional Institute of Medical Sciences (RIMS), Imphal Manipur in the list of Centres of Excellence(CoE) for Rare Diseases under National Policy for Rare Diseases (NPRD), 2021 – reg.

The undersigned is directed to refer to RIMS, Imphal letter No. 94/RIMSH/RD-NRC(OH)-22 dated 13.8.2024 on the subject mentioned above and to say that in pursuant to Para 9.1 of National Policy for Rare Diseases (NPRD), 2021; Regional Institute of Medical Sciences (RIMS), Imphal Manipur has been included in the list of Centres of Excellence (CoE) for Rare Diseases, which will be a premier Government Tertiary Hospital with facilities for diagnosis, prevention and treatment of rare diseases subject to compliance of the observations mentioned in the Report submitted by the panel of Experts (Copy enclosed), within 12 months from the date of issue of this Office Memorandum.

2. The continuation of above said Hospital as CoE for Rare Diseases will be re-examined by this Ministry upon the visit of the Technical Committee of MoHFW after 12 months for verification of compliance of the following:

- i. Efforts undertaken by the Institute towards increasing awareness about Rare Diseases in Manipur and neighboring NE states.
 - ii. Promoting and maintaining digital data for pre-natal diagnostic procedures such as amniocentesis and Chorionic Villus Sampling (CVS) as per PCPNDT Act and maintaining records of termination as per MPT Act 2021. In addition, records of post-test counseling following prenatal testing to be maintained.
 - iii. Efforts undertaken by the institute towards establishment of renal transplantation, BMT and liver transplantation for Rare Disease patients.
 - iv. Steps undertaken for promoting and initiating newborn screening; testing for inborn errors of metabolism, molecular testing at the Institute for early detection of Rare diseases.
 - v. Training of manpower or having trained a Clinical Geneticist at the Institute for efficient functioning of the CoE.
3. The responsibilities and activities of the Institute will be in accordance to the provisions mentioned under Para 9.2 of National Policy for Rare Diseases(NPRD), 2021.
4. This comes into effect from the date of issue of the Office Memorandum.
5. This issues with the approval of the Competent Authority.


(Shobhit Gupta)

Under Secretary to the Govt. Of India
Tele : 2306 1521

To,

(शोभित गुप्ता)
(SHOBHIT GUPTA)
अवर सचिव/Under Secretary
स्वास्थ्य एवं परिवार कल्याण विभाग
Ministry of Health & Family Welfare
सरकार भारत/Govt. of India
नई दिल्ली/New Delhi

The Director,
Regional Institute of Medical Sciences (RIMS),
Imphal

Copy to:

1. The Secretary, Department of Biotechnology, Ministry of Science and Technology, Government of India.
2. The Secretary, Ministry of Social Justice & Empowerment, Government of India
3. The Secretary, Ministry of Corporate Affairs, Government of India
4. The Secretary, Department of Health Research, New Delhi
5. The Secretary, Department of Pharmaceutical, Shastri Bhawan, New Delhi
6. The Secretary, Department of Promotion of Industry and Internal Trade, Udyog Bhawan, New Delhi
7. The Secretary, Department of Revenue, Ministry of Finance, Government of India
8. The Chairman, National Pharmaceutical Pricing Authority, 3rd/5th Floor, UMCA Cultural Centre Building 1, Jai Singh Road, New Delhi
9. The Drugs Controller of India, FDA Bhawan, New Delhi
10. The Director General, Dte. General of Health Services & Chairman of CTCRD, Nirman Bhawan, New Delhi
11. Chief Secretaries/Additional Chief Secretaries/Principal Secretaries/Commissioner (Health) of all State Governments/UT Administration (as per list attached)
12. Director, Centres of Excellence (as per list attached)
13. The Nodal Officer of all the 12 Centres of Excellence(as per list attached)
14. State Nodal Officer (Rare Diseases), Manipur

Copy for information to:

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