

File No: W-11037/40/2022- Grants (RD)
Government of India
Ministry of Health & Family Welfare
(Rare Diseases Cell)

Nirman Bhawan, New Delhi
Dated: 19/5/2022

OFFICE MEMORANDUM

The undersigned is directed to state that the following provision envisaged under Para 10(i) of National Policy for Rare Diseases (NPRD), 2021:

"Financial support upto Rs. 20 lakh under the Umbrella Scheme of Rashtriya Arogya Nidhi shall be provided by the Central Government for treatment, of those rare diseases that require a one-time treatment (diseases listed under Group 1). Beneficiaries for such financial assistance would not be limited to BPL families, but extended to about 40% of the population, who are eligible as per norms of Pradhan Mantri Jan Arogya Yojana, for their treatment in Government tertiary hospitals only."

may be treated as replaced with the following:

"Financial support upto Rs. 50 lakhs shall be provided to the patients suffering from any category of the Rare Diseases. The financial support will be provided to the patients for the treatment in any of the Centre of Excellence (CoE) mentioned in NPRD-2021, outside the Umbrella Scheme of Rashtriya Arogya Nidhi."

2. All other provisions of the policy will remain unchanged.
3. These amendments come into effect from the date of issue of this Office Memorandum.
4. The guidelines/procedure for providing financial assistance to the patients as per amended provisions are being finalized. However, till the finalization of guidelines and in order to provide uninterrupted and enhanced financial assistance i.e. upto Rs. 50 lakhs to the patients of rare diseases irrespective of category of disease, funds may continued to be granted from the current budget head of Umbrella Scheme of Rashtriya Arogya Nidhi (RAN).
5. This issues with the approval of the competent authority.

Manish

(Manish Raj)

Under Secretary to the Govt. of India
Tel. 011-23062068

To,

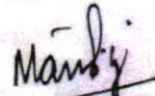
As per list attached

Copy for information and necessary action to:

1. PPS to AS (Rare Diseases);
2. PPS to AS(Grant Division);

Hindi version of the O.M. dated 19.05.2022 will 2/-
follow.

3. Under Secretary (Grants), Ministry of Health & Family Welfare, Nirman Bhawan, New Delhi with a request to make necessary provision under the Umbrella Scheme of Rashtriya Arogya Nidhi (RAN) according to the revised provisions in NPRD, 2021 mentioned in this OM till the finalization of guidelines and a separate budget head is created for providing increased financial assistance to the patients of Rare Diseases.
4. The Nodal Officer, all the 08 CoEs (as per list attached) with a request to process the cases of rare diseases as per revised provisions in NPRD, 2021 mentioned in this OM.
5. Finance Division; MoHFW;
6. Director (Budget); MoHFW;
7. The Director General and Chairman of CTCRD, Directorate General of Health Services, Nirman Bhawan, New Delhi
8. Dr. L. Swasticharan, Addl DDG, Dte.GHS, Nirman Bhawan, New Delhi.


(Manish Raj)

Under Secretary to the Govt. of India
Tel. 011-23062068

As per list attached

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, 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)