

Ministry of Health & Family Welfare
Directorate General of Health Services
(Emergency Medical Relief Cell)

Nirman Bhawan, New Delhi.

Dated: 21/02/2022.

OFFICE MEMORANDUM

Sub: Regarding uploading National Policy for Rare Diseases (NPRD 2022) on the respective official website and put on the notice board of the Hospitals/Institutes.

Dear Sir/Madam,

The undersigned is directed to refer to the Ministry's O.M. dated 30.03.2021 (copy enclosed) and O.M. dated 16/02/2022 (copy enclosed) on the subject mentioned above.

In order to give the policy a wide publicity and to emphasize the provisions envisaged in the policy, all the Centre of Excellences are requested to upload the policy on their respective official website and put on the notice board of the Hospitals/Institutes.

Dr. L. Swasticharan,
Addl. DDG and Director (EMR),
011-23063537
swasticharan.l@nic.in

To,

1. Dr. Madulika Kabra, All India Institute of Medical Sciences
2. Dr. Seema Kapoor, Maulana Azad Medical College
3. Dr. Shubha Phadke, Sanjay Gandhi Post Graduate Institute of Medical Sciences
4. Dr. Sujit Singh, Post Graduate Institute of Medical Education and Research
5. Dr. Ashwin Dalal, CDFD with Nizam Institute of Medical Sciences
6. Dr. Mamta Muranjan, King Edward Memorial Hospital
7. Dr. Suchandra Mukherjee, Institute of Post- Graduate Medical Education and Research
8. Dr. Meenakshi Bhatt, Center For Human Genetics (CHG) with Indira Gandhi Hospital

2536703
18.2.2022

No. W.12914/153/2020-Grants
Government of India
Ministry of Health and Family Welfare
Department of Health and Family Welfare

Nirman Bhawan, New Delhi
Dated 16/02/2022

OFFICE MEMORANDUM

Subject: **National Policy for Rare Diseases**-regarding.

The undersigned is directed to refer to this Ministry's O.M. of even number dated 30.03.2021(copy enclosed) on the subject mentioned above and to say that Ministry of Health and Family Welfare had finalized a National Policy for Rare Diseases(NPRD), 2021 on 30.03.2021. The policy was circulated to all stakeholders and published on the website of this Ministry on the same day. The policy may be accessed at <https://main.mohfw.gov.in/documents/policy>.

2. In order to give the policy a wide publicity and to emphasize the provisions envisaged in the policy, it is once again circulated to all stakeholders including States/UTs.
3. Centres of Excellence (CoEs) are requested to upload the policy on their respective official website and put on the notice board of the Hospitals/Institutes.
4. This issues with the approval of the Competent Authority.

Digitally Signed by Manish
Raj
Date: 16-02-2022 10:35:03
Reason: Approved
(Manish Raj)

Under Secretary to the Government of India
Email: manish.raj@nic.in

To, (LS)

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, Shashtri Bhawan, New Delhi;
5. The Secretary, Department for 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 Center 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);

2528619/2022/GRANT

F. No. W.12014/108/2020-Grants
 Government of India
 Ministry of Health and Family Welfare
 (Department of Health and Family Welfare)

Nirman Bhawan, New Delhi
 Dated 30th March, 2021

OFFICE MEMORANDUM

Subject: National Policy for Rare Diseases-regarding.

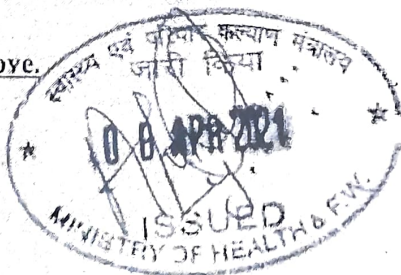
The undersigned is directed to refer to this Ministry's Public Notice No. W.11037/1/2020-Grants(RD) dated 13.01.2020 on the subject mentioned above and to say that Ministry of Health and Family Welfare had formulated a National Policy for Treatment of Rare Diseases(NPTRD) in July, 2017.

2. However, owing to implementation challenges, the said policy was kept in abeyance till the revised policy was issued or till further orders, whichever was earlier. A gazette notification informing the general public to this effect was also issued on 18.12.2018. Given the challenges in implementing the policy, the need for wider consultation and recommendations, a decision was taken to reframe the National Policy for Rare Diseases. Accordingly, an Expert Committee was constituted by Ministry of Health and Family Welfare in November, 2018 to review the NPTRD, 2017 and draft Policy for Rare Diseases.

3. Based on the report of the Expert Committee and with the approval of the Competent Authority, a draft of the National Policy for Rare Diseases had been finalized and placed in the public domain vide this Ministry's Public Notice No. W.11037/1/2020-Grants(RD) dated 13.01.2020, with a view to elicit comments/views of the stakeholders, including the general public.

4. In view of the comments/views received and with the approval of the Competent Authority, National Policy for Rare Diseases, 2021 has been finalized and is available on the website of this Ministry (URL: <https://main.mohfw.gov.in/documents/policy> and <https://main.mohfw.gov.in/media/news-and-highlights>). A copy of the said policy is enclosed herewith for ready reference.

Encl: As above.



Rajeev Kumar
 30/03/2021

(Rajeev Kumar)

Under Secretary to the Government of India
 Tele: 011-23063019

To,

1. The Secretary, Department of Biotechnology, Ministry of Science and Technology, Government of India;
2. The Secretary, Department of Health Research/Director General, Indian Council for Medical Research, New Delhi;

Contd...