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स्वास्थ्य और परिवार कल्याण मंत्रालय

(स्वास्थ्य और परिवार कल्याण विभाग)

अधिसूचना

नई दिल्ली, 18 दिसम्बर, 2018

फा.सं. जैड-21026/52/2018-आरडी.—जबकि जून, 2017 में जारी की गई राष्ट्रीय विरल रोग उपचार नीति, 2017 प्रभावी है।

और जबकि, अब नीति में और सुधार तथा प्रभावी कार्यान्वयन हेतु उपलब्ध/प्राप्त नई सूचना एवं अद्यतन जानकारियों के आलोक में केंद्र सरकार ने इस नीति की समीक्षा करने का निर्णय लिया है।

और जबकि, केंद्र सरकार एतद्वारा यह अधिसूचित और जनता को सूचित करती है कि केंद्र सरकार द्वारा संशोधित नीति जारी होने तक या अगले आदेश तक जो भी पहले हो, उक्त राष्ट्रीय विरल रोग उपचार नीति, 2017 आस्थगित रखी जाएगी।

मनोहर अगनानी, संयुक्त सचिव

MINISTRY OF HEALTH AND FAMILY WELFARE

(Department of Health and Family Welfare)

NOTIFICATION

New Delhi, the 18th December, 2018

F.No. Z-21026/52/2018-RD.—Whereas, the National Policy for Treatment of Rare Diseases, 2017 is in force, issued in June 2017.

AND, WHEREAS, Now, the Central Government has decided to review the Policy in the light of new information and updates available/received for further improvement and effective implementation.

AND, WHEREAS, the Central Government hereby notifies and informs the public at large that the said National Policy for Treatment of Rare Diseases, 2017 shall be kept in abeyance till the revised Policy is issued by the Central Government or till further orders which is earlier.

MANOHAR AGNANI, Jt. Secy.

साधारण डाक द्वारा
ORDINARY POST



No.Z.21020/10/2018-(RD)
Government of India
Ministry of Health and Family Welfare
(Rare Disease Cell)

Nirman Bhawan, New Delhi
Dated: 16th November, 2018

OFFICE ORDER

Subject: Constitution of an Expert Committee to revise National Policy on rare Disease.

The Ministry of Health and Family Welfare has decided to constitute an Expert Committee to review the National Policy for Treatment of Rare Diseases, 2017.

2. The constitution of the Expert Committee is as under:

S. No.	Name & Designation	
1	Dr.S.Venkesh, DGHS	Chairperson
2	Shri Manohar Agnani, Joint Secretary (Rare Disease)	Member
3.	Smt.Vandana Gurnani, Joint Secretary (RBSK)	Member
4	Shri Nilambhuj Sharan, Economic Advisor	Member
5.	Dr.Mohd. Shaukat, Advisor,NCD, DGHS	Member
6.	Dr.I.C.Verma, Sir Gangaram Hospital, New Delhi	Member
7	Dr.Madhulika Kabra, Dept. of Paediatrics, AIIMS Delhi	Member
8	Dr.Harish Chellani, Dept. of Paediatrics, Safdarjung Hospital	Member
9	FSSAI representative for diets for Rare diseases.	Member
10	Dr Prabha Arora,DDG,DGHS	Member Secretary

Terms of Reference

- i. To review the National Policy for Treatment of Rare Diseases, 2017 and to suggest amendments/changes as may be required.
 - ii. To define Rare Diseases for India
 - iii. To draft revised National Policy on Rare Diseases
 - iv. To suggest vision and strategy in country's context
3. Additional members/Special Invitees may be co-opted by the Expert Committee, as and when deemed necessary.
4. The Committee will submit its report to the Ministry within 8 weeks from the date of constitution.
5. This issues with the approval of Secretary (H&FW).

(Ajaya Kumar K.P)

Under Secretary to the Government of India
Tel:23061342,
Email:ajaya59@gmail.com

To,

- i. Chairperson and all members of expert committee of National Policy for Treatment of Rare Disease.

Cont. page 2...

Copy to:

- i. PPS to AS(H)
- ii. PA to Dir.(LY)

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