



E.S.I.C.

कर्मचारी राज्य बीमा निगम

(श्रम और रोजगार मंत्रालय, भारत सरकार)
EMPLOYEES' STATE INSURANCE CORPORATION
(Ministry of Labour & Employment, Government of India)



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संख्या: U-16/30/632 (ERT)/17/SST

दिनांक: 21/01/2022

सेवा मे,

- निदेशक(चि.)/दिल्ली/निदेशक(चि.)नोएडा,
- चिकित्सा अधीक्षक – सभी क.रा.बी.निगम अस्पताल,
- क्षेत्रीय निदेशक/रा.चि.अ.(एसएमओ) – सभी राज्य
- डीन – सभी क.रा.बी. – पीजीआईएमएसआर चिकित्सा महाविद्यालय
- डिम्स- सभी राज्य [क्षेत्रीय निदेशक/रा.चि.अ.(एसएमओ) द्वारा]

विषय: ESIC guidelines for rare diseases-reg

संदर्भ: Hqrs. Office webupload on the cited subject dated 12.03.2021

महोदय/महोदया,

With reference to the subject cited above, I am to convey that the teaching and training material prepared by rare diseases committee for spreading awareness about rare diseases to all ESIC/ESI field locations including health care workers, ESI Beneficiaries and general public are being circulated shortly from Hqrs. Office.

This is for your information, compliance and necessary action/adherence

This is issued with the approval of Competent Authority.

संलग्न: यथोपरि

भवदीय
अनीता सेठी

(डॉ. अनीता सेठी)

डीएमसी (एसएसटी)

प्रतिलिपि:

PR 0042ranch, Hqrs. Office.



U-16/30/632/2017-SST/ERT

Dated: 12/03/2021.

To,

Dean/Medical Superintendent ESIC Hospitals & Medical Colleges,	RDs & SMOs, Regional Office, ESI Corporation,	DIMS (Through RD)	Director (Medical) Delhi & Noida.
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Sub: ESIC guidelines for Rare Diseases-reg

Ref: National Draft Policy for Rare Disease, 2020 and Enzyme Replacement Therapy for ESI Beneficiaries.

Madam/Sir,

Rare diseases are health conditions that affect a very small number of people and in spite of their low prevalence they are a major public health problem. This requires a multipronged, multisectoral approach to screen, diagnose, treat and rehabilitate patients suffering from it. Further lack of effective treatment which is exorbitantly costly and may not lead to "cure", prevention needs to be focused by increasing awareness among the health care workers and population at large.


In order to deal with rare diseases ESIC has:

- A. Compiled a booklet "Operational Guidelines for Rare Diseases" (32 pages, copy enclosed) which include:
 - 1) Organizational Structures for:
 - Overall Management
 - Data Collection
 - Training
 - 2) Protocols for:
 - Optimal Screening,
 - Early Diagnosis
 - Management of confirmed or suspected cases
- B. Prepared a Teaching & Training module for health care workers and IEC material for general public, which will be circulated shortly after a pilot run.
- C. A Dashboard is being created at ESIC Hqrs for collection and compilation of data of rare diseases. Till the time it is made functional the field locations are required to collect and compile the data and forward to ESIC Hqrs. as per the above guidelines.

This is for your information, compliance and necessary action/adherence. Monthly compliance of the same be forwarded as per above guidelines.

This issues with the approval of Director General.

Yours faithfully


(Dr. Anita Sethi)
Dy. MC (SST)

Copy to:

WCM is requested to web upload.