

Government of Rajasthan
Department of Medical Education

No. F.16 (43) ME/Gr.-1/2019

Date: 16 DEC 2021

CIRCULAR

In supersession to this Department order even no. dated 3rd December 2021 following guidelines are hereby issued for the management of patients suffering from rare diseases viz Lysosomal Storage Disorder diseases in the State: -

1. The Government of Rajasthan has decided to take necessary steps for management of rare diseases viz Lysosomal Storage Disorder diseases in consonance with the 'National Policy for Rare Diseases-2021'.
2. Necessary action is under process by the State Government for developing an online platform on the basis of the national portal for crowd funding which is under process. During transition period, medical institutions are directed to get the necessary registration done for the treatment of existing patients.
3. Center of Rare Disease, Department of Pediatrics, Sir Padampat Mother & Child Health Institute (J.K. Lone), S.M.S. Medical College, Jaipur will be the State Level Nodal Agency.
4. Medical College Jaipur and Jodhpur will be the treatment center for the patients suffering from Lysosomal Storage Disorder (Gaucher) disease.
5. All such patients will also be entitled to get all the benefits admissible under State Government schemes viz MNDY MNJY and Chiranjivi Yojana.
6. All medical institutions should ensure arrangements for registration, information, health education, IEC and necessary care and giving information of the above patients to the state level nodal agency.

By Order,

(Sunil Sharma)

Joint Secretary to the Government

Copy to:

1. Principal Secretary to Chief Minister, Rajasthan
2. SA to Hon'ble Minister of Medical and Health, Medical Education.
3. PS to the Principal Secretary, Medical & Health, Medical Education.
4. PS to the Secretary, Medical and Health, Medical Education.
5. PA to the Commissioner, Medical Education/Director RajMES.
6. All Principal & Controller, Government Medical Colleges, Rajasthan.
7. ACP, Medical Education for uploading.
8. Public Relations Officer, Directorate of Medical Education.
9. OIC case CW 17098/2019 Medical College Jaipur
10. Guard- File.

(Ashok Kumar Soni)

Deputy Secretary to the Government