Rare Diseases Cell
Public Health Division
Ministry of Health & Family Welfare
Room No.540-A, Nirman Bhawan,
New Delhi-110011, Tel:23061117

Procedure to apply for financial assistance for treatment of rare diseases.

The procedure to apply for financial assistance for rare diseases as per the National Policy for Treatment of Rare Diseases is as under:

i. The patient/caregiver may contact the State Health and Family Welfare Department to know the details of the hospital from where treatment for rare diseases can be had. The contact address of the State Technical Committee (STC) to which application for financial assistance is to be submitted may also be obtained from the concerned State Health Department.

ii. The patient/caregiver may then send his/her application to the STC, including details of the patient, copy of complete medical records, name and contact details of the treating hospital and doctor etc. Additional mandatory details, as attached to this letter, should also be provided.

iii. After receipt of the application from the patient, the STC need to examine the case. If the STC approves the eligibility of the patient for financial assistance, it may send its detailed recommendation to the Central Technical Committee (CTC) in the Ministry of Health & Family Welfare, New Delhi.

iv. The CTC will then consider the case and the decision of the CTC will be conveyed to the STC. The State can then claim 60% of the approved cost of treatment from the Centre through the State PIP proposals under the National Health Mission. As per the National Policy, patients belonging to BPL category are eligible for free treatment for rare diseases and the cost will be borne between the Centre and the State in a 60:40 ratio.

2. It may be noted that the central share of treatment cost will be released only to the States, as per NHM guidelines. Unless the application is considered and recommended by the STC as per the National Policy for Treatment of Rare Diseases, it cannot be considered by the CTC. Recommendation of the STC is mandatory.

3. A web based application is being developed to make the entire process online. Once the online mechanism is put in place, the patients/caregivers, STC and CTC will apply/interact through this web application only. Till such time the online portal is not ready, patients/ caregivers/STC may submit their physical applications as per the procedure mentioned above.

The address of the rare diseases cell in the Ministry of Health & Family Welfare is as under:

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Additional Mandatory information to be attached with the application

Annexure I

Name of the Disease / Syndrome: MPS I & MPS II ★ (Information Mandatory)

★ i. Demographic information

- Name
- Parents' Name (Mother & Father both)
- DOB/Age
- Sex
- Consanguinity -Yes/ No
- Complete Residential Address with District and State
- Parents' / Guardian's Occupation
- Annual Income
- Is the patient a beneficiary of any health insurance / reimbursement scheme (E.g. CGHS, EIS or any other Government or private scheme) : Yes/No
- Hospital where presently being treated & since when? (Along with the details of the treating physician):
- Hospital where treatment is desired:

★ii. History/Clinical Data

- Weight
- Height
- Head Circumference
- Developmental delay/Regression
- Joint Involvement (Specify)
- Present mobility status
- Ophthalmic evaluation – Corneal clouding (For MPS I only) , Glaucoma, fundus, Vision
- Organomegaly- specify Liver & Spleen size
- Hernia – Umbilical/Inguinal
- H/O any surgery
- Snoring/Sleep apnoea
- Any treatment if taken (please specify) ERT/HSCT

iii. Investigations

- **★Confirmatory Diagnosis – Enzyme assay (mandatory) with or with out Molecular studies (Pl enclose reports)**

- IQ/DQ ★
- ECHO (Cardiac involvement) ★
- Neuroimaging (CT Head , MRI for E/O Hydrocephalous) ★
- Hearing testing ★
- PFTs (if done)
- Sleep studies (if done)
- Clinical Photograph ★

1. **Gaucher's Disease**

★iv. Demographic information

- Name
- Parents' Name (Mother & Father both)
- DOB/Age
- Sex
- Consanguinity -Yes/ No
- Complete Residential Address with District and State
- Parents' / Guardian's Occupation
- Annual Income
- Is the patient a beneficiary of any health insurance / reimbursement scheme (E.g. CGHS, EIS or any other Government or private scheme) : Yes/No
- Hospital where presently being treated & since when? (Along with the details of the treating physician):
- Hospital where treatment is desired:

i. Clinical Data★

- Weight
- Height
- Head Circumference
- IQ/DQ
- Pallor/Bleeding / H/o Blood or Platelet transfusion (specify frequency)
- Liver & Spleen Size (Clinical)
- H/o Bone pains , fracture, scoliosis
- Neurological involvement- Development delay, seizures, oculomotor apraxia Yes/No- if yes Specify
- Any treatment taken (if yes specify)

Investigations

- **Confirmatory Diagnosis – Enzyme assay(Mandatory) with or with out Molecular studies★ (Pl enclose reports)**

★ a) Hb, TLC, Platelets (at least within last 3 months)
b) USG/ MRI for organ volumes (if available)
c) DXA Scan Report (if available)
★d) Clinical photograph

2. **Spinal Muscular Atrophy I (All Information Mandatory except PFT)★**

v. Demographic information

- Name
- Parents' Name (Mother & Father both)
- DOB/Age
- Sex
- Consanguinity -Yes/ No
- Complete Residential Address with District and State

- Parents' / Guardian's Occupation
- Annual Income
- Is the patient a beneficiary of any health insurance / reimbursement scheme (E.g. CGHS, EIS or any other Government or private scheme) : Yes/No
- Hospital where presently being treated & since when? (Along with the details of the treating physician):
- Hospital where treatment is desired:

★ i. Age of onset

ii. Present motor status
   a) Can the child sit/ stand / walk
   b) Wheel chair bound (yes or no)

iii. Skeletal deformities Yes/No if present specify

iv. Any O2 / ventilation requirement Yes/No

v. Formal muscle charting report (Please enclose)

Investigations

MLPA report – Please specify number of copies of SMN2 gene (enclose report)

Pulmonary Function tests (if available)

PFT if available (Applicable for Type II)