

No. J.11011/14/2017-HFW (TRD)/163-164  
GOVERNMENT OF MIZORAM  
HEALTH & FAMILY WELFARE DEPARTMENT  
MIZORAM SECRETARIAT, MINECO, AIZAWL-796001

Aizawl, the 24<sup>th</sup> June, 2022

**OFFICE MEMORANDUM**

Govt. of India, Ministry of Health & Family Welfare, Department of Health & Family Welfare in a lo tih chhuah National Policy for Rare Diseases (NPRD), 2021 Para 10(i) a tarlan-

*'Natna khirh leh vang (National Policy for Rare Diseases, 2021, Group 1 list a mi) veite tan vawikhat enkawlina (one time treatment) sum fai tanpuina Cheng Nuai Sawmhnih (Rs.20.00 lakh) thleng Govt. of India, Rashtriya Arogya Nidhi Scheme atangin pek an ni ang. He tanpuina hi BPL chhungkua bakah Pradhan Mantri Jan Arogya Yojona hnuaia tanpuina dawng theite, a ram mipui 40% chin, Sorkar damdawiin (Govt. Health Facility) a enkawlte tan a huam ang.'*

tih chu Ministry of Health & Family Welfare Office Memorandum, No.W.11037/40/2022-Grants(RD) dt.19.05.2022 a chhuah angin a hnuaia tarlan ang hian thlak a ni-

*'Natna khirh leh vang (Rare Diseases category hnuaia awm) veite chu National Policy for Rare Diseases (NPRD) 2021 hnuaiah sum fai tanpuina Cheng Nuai Sawmnga (Rs.50.00 Lakh) thleng pek theih an ni ang. Sumfai a tanpuina hi natna khirh leh vang vei mekte, Umbrella Scheme of Rashtriya Arogya Nidhi pawn a mite NPRD, 2021 hnuaia Centre of Excellence (CoE) hmuna enkawl te tan pek theih a ni ang.'*

National Policy for Rare Diseases (NPRD), 2021 hnuaia policy dangte chu a ngai anga chhiar tur an ni.

Heng thu siam danglam te hi a chungga Ministry of Health & Family Welfare Office Memorandum chhuah ni, 19.05.2022 atanga hman tan tur a ni.

Sumfai tanpuina pek dan tur chungchang guidelines hi siamthat mek a ni a. Guidelines peihfel a nih hma chuan sumfai a tanpuina pek ngaite hnena tanpuina Cheng Nuai Sawmnga (Rs.50.00 lakh) thleng pek tur hi khaihlak a awm lohna turin Umbrella Scheme of Rashtriya Arogya Nidhi (RAN) budget head hmanlai atangin pek chhunzawm phawt tur a ni ang.

**Enclosed: O.M W.11037/40/2022-Grants(RD) dt.19.05.2022**

**Sd/-ESTHER LALRUATKIMI**  
Principal Secretary to the Govt. of Mizoram  
Health & Family Welfare Department

## National Policy for Rare Diseases, 2021

### List of Rare Diseases -

#### **Group 1: Disorders amenable to one-time curative treatment:**

##### **a) Disorders amenable to treatment with Hematopoietic Stem Cell Transplantation (HSCT) –**

- i. Such Lysosomal Storage Disorders (LSDs) for which Enzyme Replacement Therapy (ERT) is presently not available and severe form of Mucopolysaccharoidosis (MPS) type I within first 2 years of age.
- ii. Adrenoleukodystrophy (early stages), before the onset of hard neurological signs. 13
- iii. Immune deficiency disorders like Severe Combined Immunodeficiency (SCID), Chronic Granulomatous disease, Wiskot Aldrich Syndrome etc.
- iv. Osteopetrosis
- v. Fanconi Anemia

##### **b) Disorders amenable to organ transplantation**

###### **i. Liver Transplantation -Metabolic Liver diseases:**

- a. Tyrosinemia,
- b. Glycogen storage disorders (GSD) I, III and IV due to poor metabolic control, multiple liver adenomas, or high risk for Hepatocellular carcinoma or evidence of substantial cirrhosis or liver dysfunction or progressive liver failure,
- c. MSUD (Maple Syrup Urine Disease),
- d. Urea cycle disorders,
- e. Organic acidemias.

###### **ii. Renal Transplantation**

- a. Fabry disease
- b. Autosomal recessive Polycystic Kidney Disease (ARPKD),
- c. Autosomal dominant Polycystic Kidney Disease (ADPKD) etc.

**iii. Patients requiring combined liver and kidney transplants can also be considered if the same ceiling of funds is maintained. (Rarely Methyl Malonicaciduria may require combined liver & Kidney transplant) etc.**