

REHAB BUDDY CDC
Child Development Centre, Jaipur

Centres of Excellence (CoE) for Rare Diseases in India

A Parent & Caregiver Guide to the National Policy for Rare Diseases (NPRD), 2021 — List of Centres, Financial Support & Step-by-Step Enrollment Process

What Is the National Policy for Rare Diseases (NPRD)?

The Ministry of Health & Family Welfare (MoHFW), Government of India, launched the National Policy for Rare Diseases in March 2021 to support the prevention, early detection, and treatment of rare diseases — including several genetic and metabolic conditions that intersect with paediatric developmental care.

As of 2026, 63 rare diseases are notified under the NPRD on the recommendation of the Central Technical Committee for Rare Diseases (CTCRD). Patients diagnosed with a notified condition can access treatment support through designated hospitals called Centres of Excellence (CoEs).

Financial Support Available

- Financial assistance of up to ₹50 lakh per patient can be provided for treatment at a notified CoE.
- Rare diseases under NPRD are classified into three groups, which affects the type of support available:
 - Group 1** — Disorders that can be cured with one-time treatment.
 - Group 2** — Diseases needing long-term/lifelong but relatively lower-cost management (special diets, hormone/enzyme support), with documented evidence of benefit.
 - Group 3** — Diseases with definitive but very high-cost, lifelong treatment, where careful patient selection matters most.

Beneficiaries are not limited to Below Poverty Line (BPL) families — eligibility has been extended to roughly 40% of the population as per Pradhan Mantri Jan Arogya Yojana (PMJAY) norms, for treatment in government tertiary hospitals. Where treatment costs exceed the policy cap, families can also register on the government's crowdfunding portal for rare disease patients.

List of Centres of Excellence (CoE) in India

The following government tertiary hospitals are officially notified as Centres of Excellence for diagnosis, prevention, and treatment of rare diseases. Patients may approach the nearest CoE, or any CoE of their convenience.

Centre of Excellence	Location
AIIMS, New Delhi	Sri Aurobindo Marg, Ansari Nagar, New Delhi – 110029
Maulana Azad Medical College (MAMC), New Delhi	Bahadur Shah Zafar Marg, New Delhi – 110002
Sanjay Gandhi Post Graduate Institute of Medical Sciences (SGPGI), Lucknow	Raibareli Road, Lucknow, Uttar Pradesh – 226014
Post Graduate Institute of Medical Education & Research (PGIMER), Chandigarh	Madhya Marg, Sector 12, Chandigarh – 160012
Centre for DNA Fingerprinting & Diagnostics (CDFD) with Nizam's Institute of Medical Sciences (NIMS), Hyderabad	Uppal, Secunderabad, Telangana
King Edward Memorial (KEM) Hospital, Mumbai	Acharya Donde Marg, Parel, Mumbai, Maharashtra – 400012
Institute of Post Graduate Medical Education & Research	244 AJC Bose Road, Kolkata, West Bengal

Centre of Excellence	Location
(IPGMER) / SSKM Hospital, Kolkata	
Centre for Human Genetics (CHG) with Indira Gandhi Institute of Child Health, Bengaluru	Bengaluru, Karnataka
AIIMS, Jodhpur	Basni Industrial Area Phase-2, Jodhpur, Rajasthan
Institute of Child Health and Hospital for Children, Egmore, Chennai	Egmore, Chennai, Tamil Nadu
Government Medical College, Thiruvananthapuram	Thiruvananthapuram, Kerala
AIIMS, Bhopal	Saket Nagar, Bhopal, Madhya Pradesh
AIIMS, Patna	Phulwari Sharif, Patna, Bihar
Assam Medical College Hospital, Dibrugarh	Dibrugarh, Assam

Note: The number of notified CoEs has grown since the policy's 2021 launch (from an initial 8) as the government has expanded the network. Always confirm current status directly with the hospital before travelling, as designations can be updated.

Nidan Kendras — Genetic Testing & Counselling Centres

Under the Department of Biotechnology's UMMID (Unique Methods of Management and treatment of Inherited Disorders) project, the following Nidan Kendras offer genetic testing and counselling for rare and inherited disorders. These can be a useful first step for families seeking a confirmed genetic diagnosis before approaching a CoE.

Nidan Kendra	Location
Lady Hardinge Medical College (LHMC)	Delhi
Nizam's Institute of Medical Sciences (NIMS)	Hyderabad, Telangana
AIIMS, Jodhpur	Jodhpur, Rajasthan
Army Hospital Research & Referral	Delhi
Nil Ratan Sircar (NRS) Medical College and Hospital	Kolkata, West Bengal

Step-by-Step Process to Enrol at a CoE

1. Get a confirmed diagnosis. Consult a specialist (paediatrician, geneticist, or your OT/developmental team) to confirm whether your child's condition is among the 63 rare diseases notified under NPRD.
2. Gather your documents. Collect all medical reports, prescriptions, and specific rare-disease test reports (e.g., biochemical markers, genetic/exome test reports), along with identity proof and, where applicable, income proof.
3. Visit the nearest or any CoE in person. Registration under NPRD is done directly at the CoE — this cannot currently be completed only online. If the nearest CoE is very far, you may start by approaching your local hospital and requesting a referral.
4. Clinical evaluation at the CoE. The specialist team examines the patient, may order confirmatory tests, and determines which NPRD group (1, 2, or 3) the condition falls under.
5. Application for financial assistance. The CoE guides the family through the application for financial support (up to ₹50 lakh), which is processed and disbursed through the CoE rather than paid directly to the family.
6. Follow up regularly. Approval and fund disbursement can take time — maintain regular contact with the CoE's rare disease coordinator for status updates.

7. If costs exceed the policy cap. For high-cost, lifelong therapies where ₹50 lakh may not be sufficient, families can register their case on the government's rare disease crowdfunding portal, where CoEs list patient cases for public and corporate donations.

Documents Typically Required

- Confirmed diagnosis report / genetic or biochemical test report
- All prior medical records, prescriptions, and specialist referral letters
- Identity proof (Aadhaar card or equivalent) of the patient
- Income proof / BPL card, if applicable (eligibility is broader than BPL alone, so check with the CoE)
- Passport-size photographs, as requested by the CoE administration
- Any existing insurance or PMJAY (Ayushman Bharat) card details

Important Notes for Parents

- This guide is informational and does not guarantee approval of financial assistance — each case is evaluated individually by the CoE and government committee.
- Processing timelines vary by centre and case complexity; patience and regular follow-up are important.
- Always verify current CoE status, contact details, and documentation requirements directly with the hospital or the official MoHFW rare disease portal before travelling.
- Rehab Buddy CDC does not process NPRD applications directly — this resource is meant to help you navigate the process; our team is happy to guide you on next steps during an OPD consultation.

Sources

Compiled from the Ministry of Health & Family Welfare's official rare disease portal (rarediseases.mohfw.gov.in), the National Policy for Rare Diseases, 2021 (MoHFW), and PIB Government of India press releases. Information current as of August 2026 — policy details, notified disease lists, and CoE designations are subject to periodic government updates.

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