



शरीरमाद्यं खलु धर्मसाधनम्

All India Institute of Medical Sciences, New Delhi

EMPOWERING HEALTH CARE WORKFORCE ON RARE DISEASES



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PEOPLE TO PEOPLE HEALTH FOUNDATION

Executive Summary

While “rare” by definition, rare diseases collectively affect an estimated **70-96 million people in India**. Due to low awareness and a lack of specialized referral system, patients often face a long “diagnostic odyssey,” leading to irreversible physical and cognitive damage.

This program, led by the **All India Institute of Medical Sciences (AIIMS) Delhi** and the **People-to-People Health Foundation (PPHF)**, aim to bridge this gap. By aligning with the **National Policy for Rare Diseases (NPRD) 2021**, the initiative focuses on building the capacity of healthcare providers to ensure early identification, prompt referral, and multidisciplinary care. The project will begin with **Delhi NCR, Rajasthan, Kerala** and later scaled across the country.

Goal

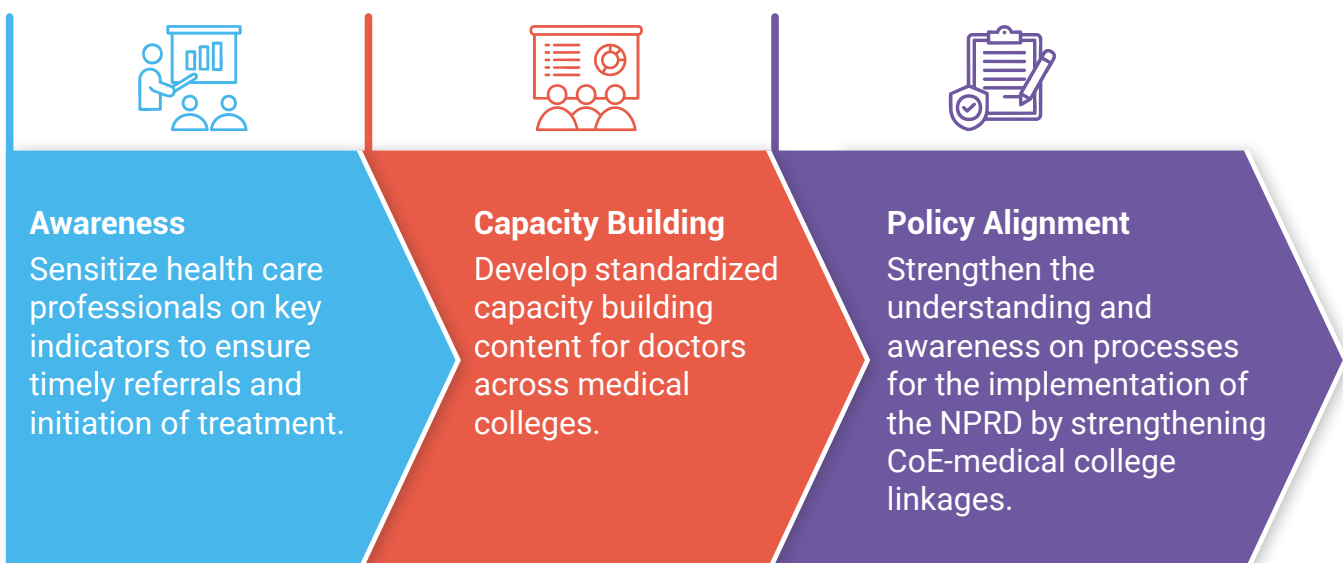
To strengthen the early identification, diagnosis, and referral of rare disease patients through targeted sensitization and capacity building across medical colleges in India.

The Three Pillars of Intervention

The project is built on a robust strategy designed to empower medical professionals across three critical areas:



Core Objectives



Strategic Implementation

Geography & Reach

- **National Leadership:** All India Institute of Medical Sciences, New Delhi.
- **Target Sites:** Medical Colleges across **Delhi NCR, Rajasthan, Kerala** and later scaled across the country.

Key Approaches

- **VIPP Methodology:** Utilizing Visual, Interactive, Participatory, and Practical methods to ensure high knowledge retention.
- **Hybrid Learning:** A blend of online modules and in-person workshops.
- **Curriculum Development:** Creation of referral algorithms, case studies, and training videos tailored to the Indian clinical context.

Project Roadmap & Interventions

Phase	Activity	Description
Mobilization	Launch & Needs Assessment	Under guidance of MoHFW and surveying CoEs to map knowledge gaps
Development	Toolkit Creation	Developing “Red-Flag” indicator guides and referral trees
Training	Master Trainer Workshops	Training nodal faculty from various colleges via a ToT model
Rollout	College-Level Sessions	Sensitizing residents and junior faculty at their home institutions
Sustenance	Refresher & Documentation	“Refresher” sessions and dissemination of project outcomes/case studies

Expected Impact & Outcomes

By the end of the intervention, the program seeks to achieve:

- **Government Medical Colleges** actively engaged in management of rare diseases.
- **Nodal Faculty** as Master Trainers.
- **Residents & Faculty** sensitized to identify early diagnostic signs and referrals across the different departments in the medical colleges.
- **Standardized Training Modules** integrated into institutional platforms for long-term sustainability.



People to People Health Foundation

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