Research Study | Rare Disease & Global Health

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# Rare Disease Funding in India

## Why Research Investment Needs to Catch Up

*Examining the stark gap between India's rare disease research funding and global benchmarks — and what a sustainable investment model could look like*

# THE RARE DISEASE FUNDING GAP — KEY NUMBERS



## $48B

*Per Year*

NIH annual research budget — the US invests more in biomedical research in one year than India has cumulatively over decades

** NIH dedicates specific rare disease programmes through NCATS and NORD grants*

## < 0.1%

*of DST Budget*

Estimated share of India's Department of Science & Technology budget allocated specifically to rare disease research

** No dedicated rare disease research fund exists at the central government level*

## ₹50L

*Max Support*

Maximum financial assistance per patient under India's National Policy for Rare Diseases — covering only Types 1 and 2 conditions

** Type 3 rare diseases (requiring lifelong treatment) receive no central financial support*

## 7:1

*Ratio*

Funding gap ratio — for every ₹1 India spends on rare disease research, comparable economies invest ₹7 or more per patient

** Based on per-capita rare disease research spend comparison across BRICS nations*

# WHY RARE DISEASE FUNDING FALLS SHORT IN INDIA



## Structural Barriers to Investment



### No Dedicated Funding Stream

India has no standalone rare disease research fund. Investigators must compete for general DST/ICMR grants against common disease priorities — where patient populations are far larger and political visibility far higher.



### Low Industry Participation

Without an Orphan Drug Act offering tax incentives, Indian pharma companies have little commercial motivation to invest in rare disease R&D. Most domestic research relies entirely on academic institutions with limited budgets.



### Limited Global Collaboration

India joins few international rare disease research consortia. Without patient registries and standardised data, Indian investigators struggle to access global funding partnerships.

## What Adequate Funding Unlocks

*Research informed by the rare disease india foundation and global rare disease funding benchmarks.*

**10×**

Return on investment for rare disease research in downstream economic value

**200+**

Rare disease conditions with India-specific research potential identified

**₹2,000C**

Estimated annual value of India's untapped rare disease research market

# A SUSTAINABLE RARE DISEASE FUNDING BLUEPRINT FOR INDIA



*Six funding pillars drawn from NIH NCATS, EU rare disease frameworks, and India's existing public health financing mechanisms*

## 01 Dedicated National Fund

Establish a standalone National Rare Disease Research Fund under ICMR — ring-fenced from general disease budgets — with a minimum annual allocation of ₹500 crore.

## 02 Industry R&D Tax Credits

Offer 150% weighted deduction on rare disease R&D expenditure for Indian pharma companies — mirroring the US ODA model to catalyse private sector investment.

## 03 Public-Private Partnership

Structure co-funding agreements between ICMR, Indian pharma companies, and patient foundations — sharing risk across stakeholders with defined milestone-based disbursements.

## 04 International Grant Matching

Create a government matching fund for Indian researchers who secure international rare disease grants (NIH, EU Horizon) — doubling the effective value of cross-border collaboration.

## 05 Patient Foundation Ecosystem

Formalise and fund rare disease patient foundations as research partners — providing grants for natural history studies, registry development, and investigator-initiated trials.

## 06 Indo-US Research Corridor

Establish a bilateral Indo-US rare disease research fund — jointly administered by NIH and ICMR — with dedicated tracks for early career Indian investigators.

# RESEARCH CONCLUSIONS & Policy Priorities



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| Finding 1 | India has no dedicated rare disease research fund, no industry R&D incentives, and participates in few international research consortia — leaving its 70M+ rare disease patients without the scientific attention they need. |
| Finding 2 | The 7:1 funding gap between India and comparable economies is not a reflection of patient need — it is a reflection of policy neglect. India's rare disease burden is among the world's largest yet among the least funded. |
| Finding 3 | Rare disease research investment generates significant downstream value — in workforce participation, reduced hospitalisation, and biopharma market development. The economic case for investment is strong and well-evidenced globally. |
| Policy Priority | A dedicated National Rare Disease Research Fund under ICMR, industry R&D tax credits, and a bilateral Indo-US research corridor — together forming a self-reinforcing ecosystem for sustainable rare disease science in India. |

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*References: NIH NCATS budget data · ICMR annual reports · India NPRD (2021) · EU rare disease research frameworks · DST science & technology indicators*