



Crowdfunding for Rare Diseases

Why in News

Recently, the Delhi **High Court** has ordered **the Ministry of Health and Family Welfare** to explore **Crowdfunding** to help two children, who are suffering from a **Rare Disease** known as **Duchenne Muscular Dystrophy**.

Key Points

▪ Constitutional Provision Involved:

- The HC held that **'Right to Health and Healthcare'** is a **fundamental right** which has been recognised by the Supreme Court to be a part of the **'Right to life'** under **Article 21** of the Constitution.

▪ Direction to the Society and Authorities:

- The **High Court** directed the **society in general and authorities in particular** to ensure that the **life of such children is not compromised**, even if there is a small window of improving their chances of survival or even providing a **better quality of life**.
- Directed **the Ministry of Health and Family Welfare** to give a specific timeline in respect of the finalisation and notification of the **Draft Health Policy for Rare Diseases, 2020**. The draft policy has a section where the **government proposed crowdfunding for treatment of high-cost Rare Diseases**.

CrowdFunding

▪ About:

- Crowdfunding is a **method of raising capital through the collective effort of a large number of individual investors**.
- This approach taps into the collective efforts of a large pool of individuals, primarily online via social media and crowdfunding platforms and leverages their networks for greater reach and exposure.

▪ Types:

- **Donation-Based Crowdfunding:** Donation-based crowdfunding is a way to source money for a project by asking a **large number of contributors to individually donate a small amount to it**. In return, the backers may receive token rewards that increase in prestige as the size of the donation increases. For the smallest sums, however, the funder may receive nothing at all.
- **Rewards-Based Crowdfunding:** Rewards-based crowdfunding involves **individuals contributing to a business in exchange for a "reward,"** typically a form of the product or service which company offers. Even though this method offers backers a reward, it's still generally considered a subset of donation-based crowdfunding since there is no financial or equity return.
- **Equity-Based Crowdfunding:** Unlike the donation-based and rewards-based methods, **equity-based crowdfunding allows contributors to become part-owners of the**

company by trading capital for equity shares. As equity owners, the contributors receive a financial return on their investment and ultimately receive a share of the profits in the form of a dividend or distribution.

▪ **Benefits:**

- **Reach** - By using a crowdfunding platform, one has **access to thousands of accredited investors** who can see, interact with, and share the fundraising campaign.
- **Presentation** - By creating a crowdfunding campaign, **one goes through the invaluable process of looking at the business from the top level**—its history, traction, offerings, addressable market, value proposition, with digestible packages.
- **PR & Marketing** - From launch to close, one can share and **promote the campaign** through social media, email newsletters, and other online marketing tactics.
- **Validation of Concept** - Presenting the concept or business to the masses affords an excellent opportunity to **validate and refine offering.**
- **Efficiency** - One of the best things about online crowdfunding is its **ability to centralize and streamline fundraising efforts.**

Rare Diseases

- A rare disease is a **health condition of low prevalence** that **affects a small number of people** compared with other prevalent diseases in the general population.
 - There is **no universally accepted definition of rare diseases** and the definitions usually vary across different countries.
- Though rare diseases are of low prevalence and individually rare, collectively they affect a considerable proportion of the population.
- **80% of rare diseases are genetic** in origin and hence disproportionately impact children.
- **In India there are 56-72 million people affected by rare diseases.**

Duchenne Muscular Dystrophy (DMD)

▪ **About:**

- It is a **genetic disorder** characterized by **progressive muscle degeneration and weakness** due to the alterations of a protein called dystrophin that helps keep muscle cells intact.

▪ **Symptoms:**

- Muscle weakness
- Enlargement of the calves
- A waddling gait
- Lumbar lordosis (an inward curve of the spine)

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