

 YELLOW
ELEPHANT

EVERY LIFE IS PRECIOUS

Rare Diseases Awareness campaign

Brief

In India, healthcare priority is mostly given to diseases which affect a larger number of people. Rare diseases as a health issue have always been ignored. Rare disorders, being rare, are the 'orphan' of health systems and government schemes. While a consensus on the need for health reforms was emerging, it was important to build a narrative that would also help drive a change to make rare diseases a part of the national agenda.

Given this scenario, it was important to engage with the policymakers and to make them aware of the various issues and challenges that rare disease patients face. Through continuous and consistent engagement, it is hoped that longstanding guiding principles would be developed which would ultimately benefit the patients.

Objective

The fundamental right to health is the right for all people to have equal opportunities for access to quality healthcare, irrespective of disease condition. Taking this as the premise, a strategic campaign on rare diseases (specifically Lysosomal Storage Disorders (LSDs)) was driven run emphasising on the fact that every human life is important, and that rare diseases deserve equality of health status.



Tackle government ignorance

- Build communication to manage lack of fundamental awareness amongst policy and decision makers
- Advocate for more government spends on healthcare and priority for Rare Diseases
- Build a consensus between state & center

01



Delay in diagnosis

Build awareness against late diagnosis of rare diseases which becomes a long and arduous journey for patients

02



Insurance cover

- No insurance cover for genetic disorders, treatment/ procedures
- No reimbursements thus leading to out-of-pocket expenses

03

Outcome

National

The Indian Ministry of Health (MoH) finally committed to modify the NPTRD* in consultation with wider stakeholders at Federal & state level

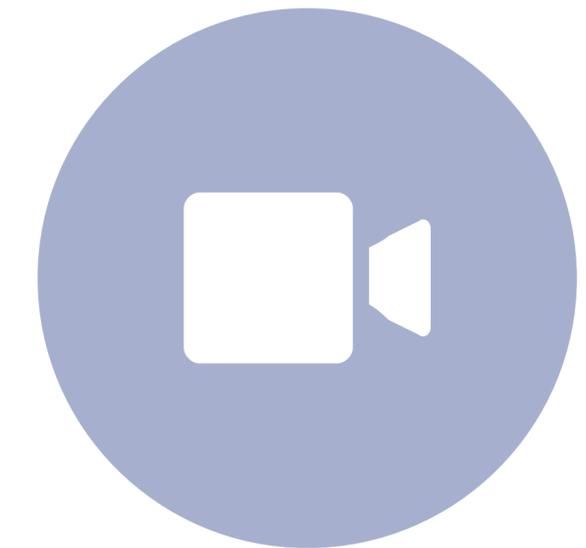


Action

The MoH agreed to a time-bound plan for policy formulation & implementation and next action steps

Progress

The first consultative meeting involved the Union Government, stakeholders, PAGs and Sanofi India as the lone industry partner



Outreach & engagement

The campaign managed to generate a media reach of over 290 mn, over 160K organic impressions on Twitter and captured stories of over 30 Rare Disease patients

* National Policy for Treatment of Rare Diseases