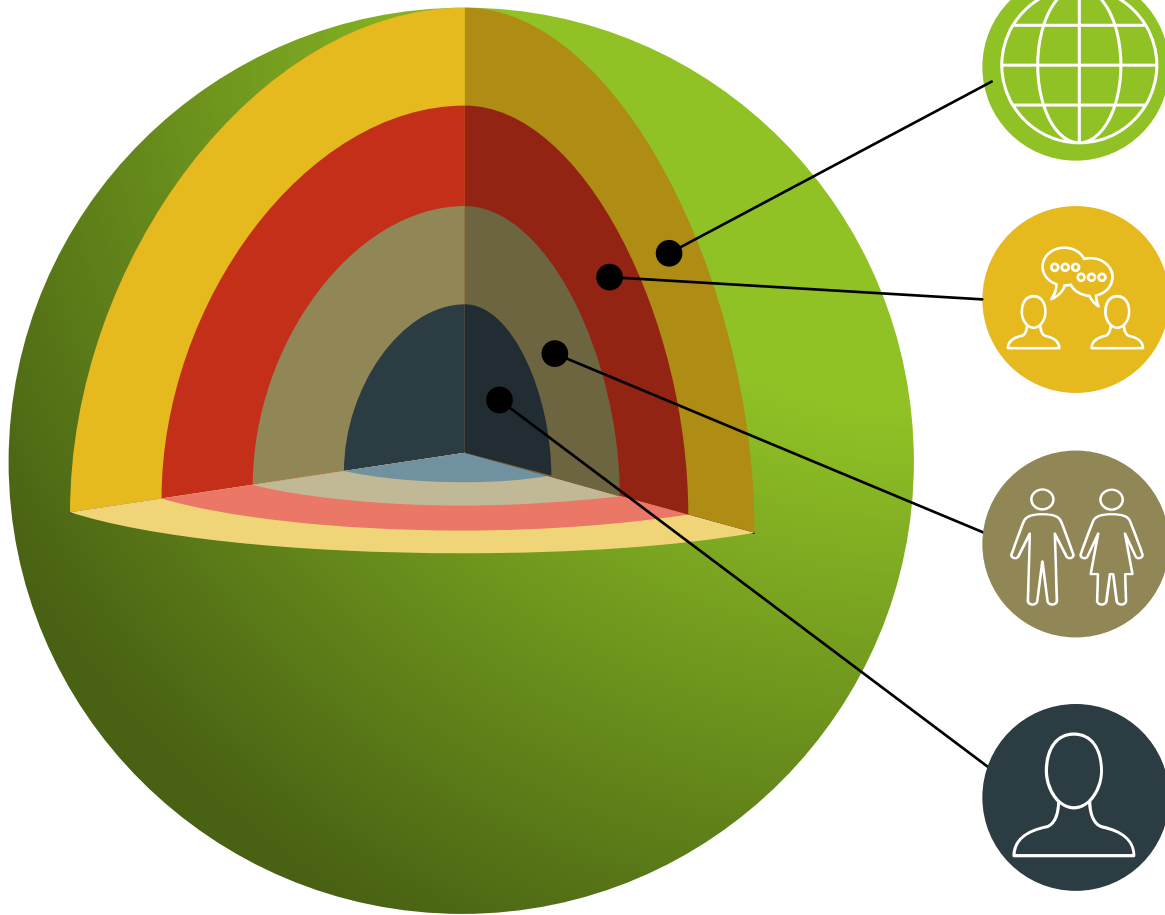




Proposal of INPDA

RDI Membership Meeting, Barcelona, June 4th 2017

International Health Organization Involvement is Critical



UN/WHO Involvement

The worldwide issues of rare diseases should be under the umbrella of a UN organisation

RDI

RDI represent all rare disease international alliances and the role of RDI should be defined by mandates from the international disease alliances

Rare Disease International Alliances

Rare disease patient communities to organize themselves into international alliances according to rare disease types

Rare Disease Patients

remain in any cases always free of conflicts of interest. Thi is not the case with other players within the rare disease field.

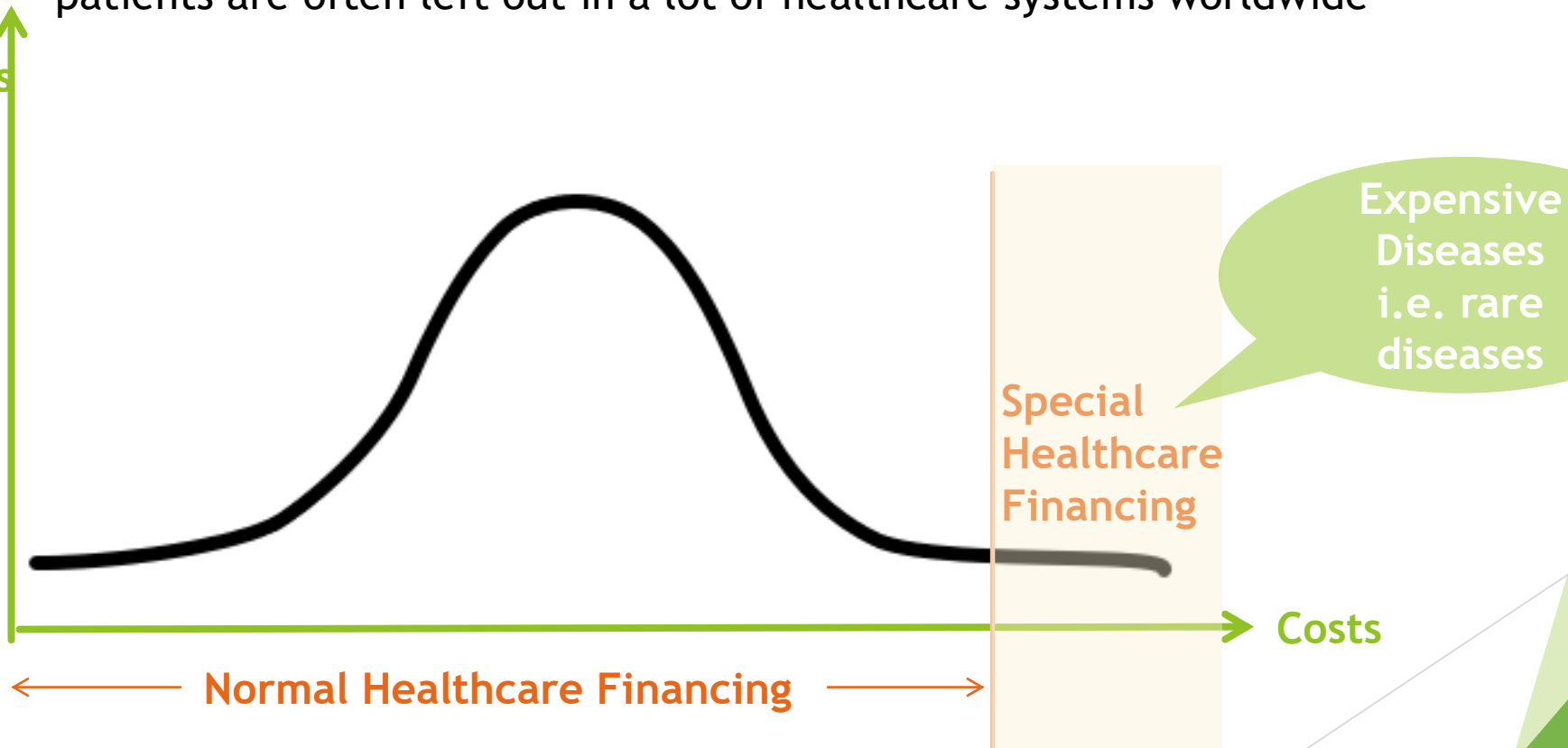
Financing of Rare Diseases is Top Priority

Financing = **1** Priority = Sustainability

The Gaussian Curve in Healthcare means Rare Disease Patients are easily left out

Because of low incidence and typically high costs, rare disease patients are often left out in a lot of healthcare systems worldwide

Number of patients



The World is Changing: Financing of Rare Diseases Needs A New Rule

Advancement in Medical and Gene Technology:

Common diseases such as cancer, Alzheimer will have many subtypes and in the future will have to be managed like rare diseases.

03



High Percentage of Carriers:

Rare disease is an issue of the human race, not of any individuals

04



Healthcare costs outpace economic growth:

Many technologies and medicines compete for the healthcare resources

01

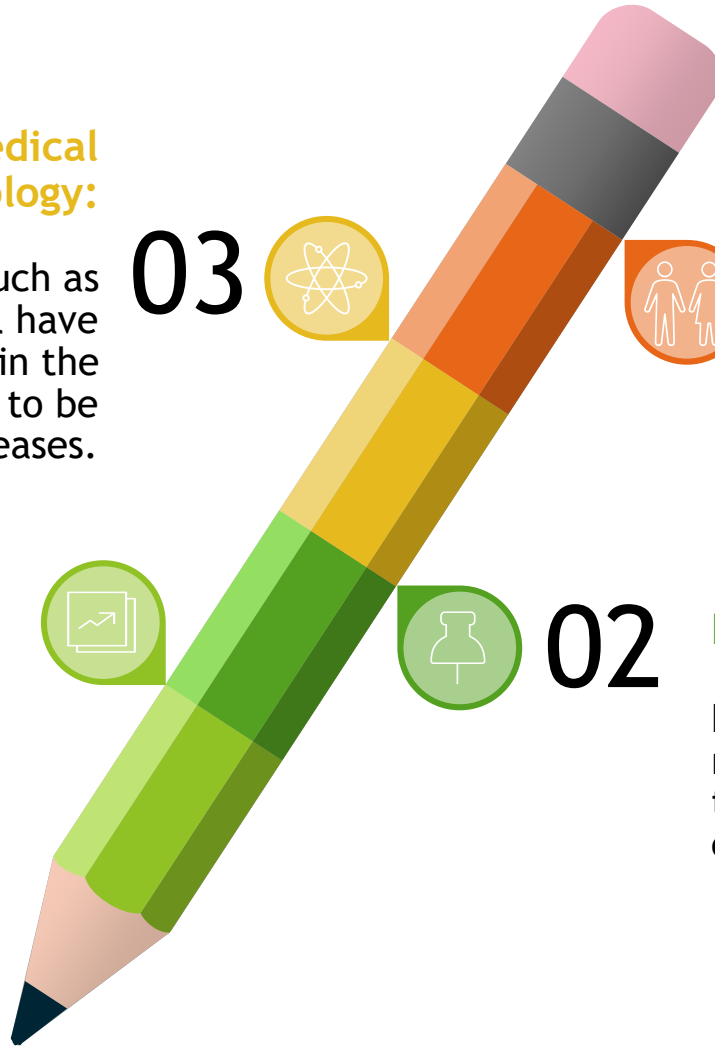


02

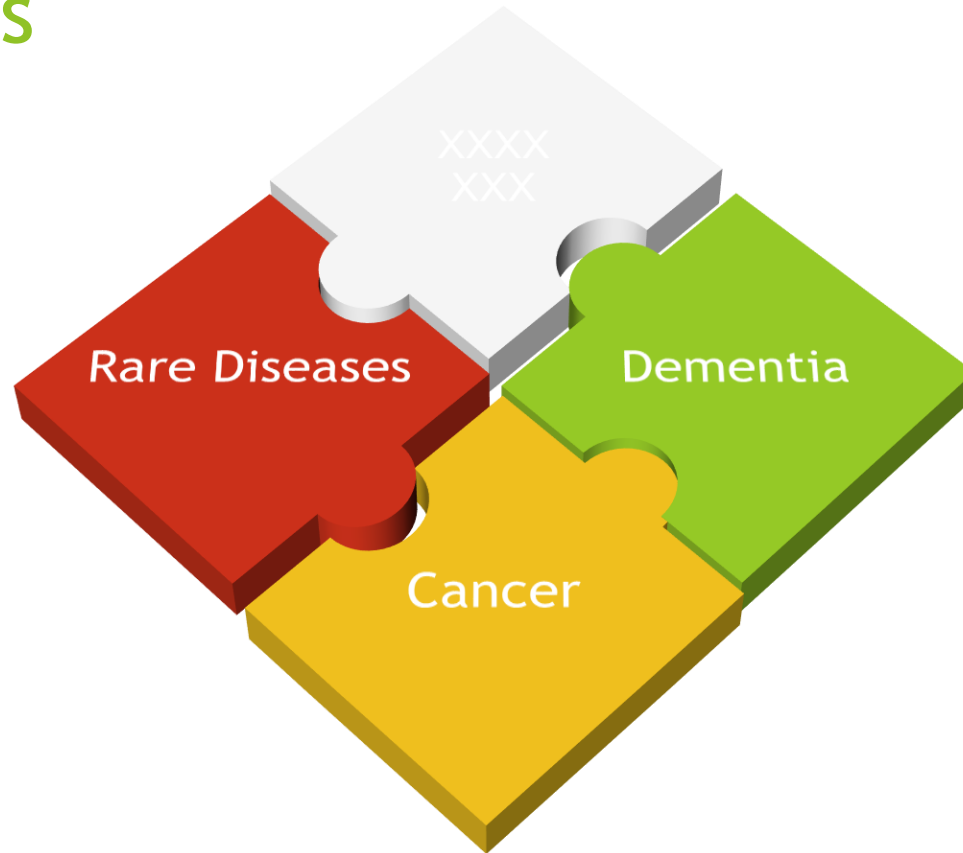


Precision Medicine:

Learning the mechanism of rare disease will facilitate the research of many common diseases



Call for A New Financing Rule: Combine Rare Expensive Diseases With Other Expensive Treatments Facing Similar Economical Problems



Proposed Mandates for RDI

- ▶ **To be recognised as one of the stakeholders within the rare diseases players in front of an international health organisation.**
- ▶ **To agree with an international health organisation about special financing tools for expensive rare disease treatments to be taken over by national economies.**

Next Step: Your Support for this Proposal
is Needed!

