NGO COMMITTEE FOR
RARE DISEASES

Rare Diseases in China

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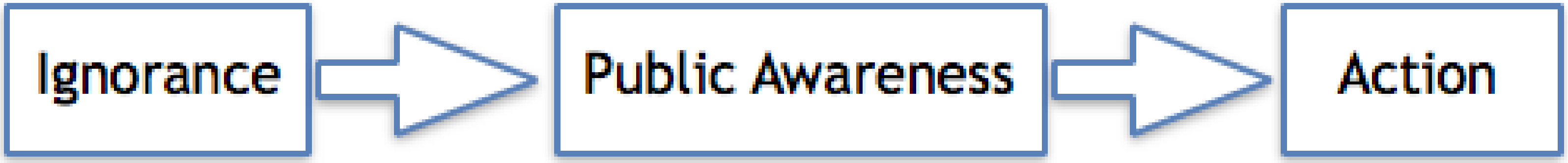
A Committee of **CoNGO**

CoNGO
The Conference of NGOs
in Consultative Relationship
with the United Nations

RD in China – Three Stages



Ignorance → Public Awareness → Action

2006之前

2006-2016

2016之后

We Made the Difference!

1. Raised public awareness, e.g. Rare Disease Day (CHINA)
2. Established China Rare Disease Organizations Network ：70+
3. Built an information platform for rare diseases in China
4. Launched China Rare Diseases Summit in 2012, became the gold standard in rare disease annual conference in China.
5. Promoted international cooperation/collaboration
6. Advocated for policy change / establishment

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Progresses on the Policy Front

1. Rare Diseases Expert Committee under Minister of Health
2. CFDA：RD priority review and separate path for submission
3. More provinces issue policies covering rare disease under social medical insurance: Zhejiang
4. Precision Medicine as China's strategic direction

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Status Quo

1. China advantage ： big patient# and huge market potentials
2. Drug research and development capability still weak, needs international collaboration
3. Only 1/4 of on-the-market orphan drugs are available in China
4. Distribution of diagnosis and treatment resources significantly unbalanced, lacking an effective referral system
5. Lack of or insufficient medical insurance coverage still remains as the biggest barrier to RD patients

Action Going Forward

1. National RD registry
   -- Ministry of Science and Technology -- a five-year, 30 Million RMB grant involving country's top 29 hospitals
   -- The very first Rare Disease Catalog in China by CORD containing 147 rare diseases
2. Non-for-profit and commercial sectors addressing different needs of rare disease patients.
3. Further international collaboration and cooperation
   -- ICORD 2017 Annual Meeting

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