Including rare diseases in the national health system – the case of the Philippines

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A compilation of national plans, policies and government actions for rare diseases in 23 countries

Neil Khosla, Rodolfo Valdez

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PHILIPPINES
7000+ islands
Low Middle Income Country
110M population

Challenges that pushed for rare disease legislation

- Rare Diseases not a priority
- Rare Diseases competing with other health matters in the top 10 causes of infant mortality and morbidity
Twin Legislation

**RA 9288**
Newborn Screening Act of 2004

< 1 year journey from filing the bill to passage of law

**RA 10747**
Rare Diseases Act of 2016

8 year journey from filing the bill to passage of law

Thalassemia is included in the panel of expanded newborn screening
# Highlights of the Rare Disease Act of 2016

Policy Declaration: The RDA mandates that persons suffering with rare disease have the right to survival and full and healthy development through access to timely health information and adequate medical care that is:

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<th><strong>COMPREHENSIVE</strong></th>
<th><strong>INTEGRATED</strong></th>
<th><strong>SUSTAINABLE</strong></th>
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<td>- Rare Disease Registry</td>
<td>- Public Educational and Information campaign by the DOH</td>
<td>- PHILHEALTH (natl health insurance) benefit package for rare diseases</td>
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<td>- Access to diagnosis through public health delivery system</td>
<td>- Committed collaboration among the stakeholders</td>
<td>- Fiscal Incentive (exemption from all taxes &amp; duties of donations for:</td>
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<td>- Rare Disease Management Program</td>
<td>- National Institutes of Health</td>
<td>- Rare Disease Research</td>
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<td></td>
<td>- Food and Drug Administration</td>
<td>- Maintenance of Registry</td>
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<td>- Dept of Interor &amp;Local Government of Education</td>
<td>- Purchase of Orphan Drugs &amp; Orphan Products</td>
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<td>- Dept of Science &amp; Technology</td>
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Acknowledgement for Rare Disease Act

Department of Health

Geneticists and other health professionals of the Institute of Human Genetics, National Institutes of Health

Senator Pia Cayetano, lead author who fought hard for the passage of the law

Patients, their families and all its donors and sponsors

Philippine Society for Orphan Disorders
Triplet Legislation

**RA 9288**
Newborn Screening Act of 2004

**RA 11223**
Universal Health Care Act of 2019

**RA 10747**
Rare Diseases Act of 2016

No one will be left behind
Continuing Challenge

Despite the Rare Disease Act of 2016 and its Implementing Rules & Regulations, we still cannot feel significant impact on patient care. We continue to struggle and compete with other health priorities.

Our Hope

The Global Community can help push for the full implementation of the Rare Disease Act of 2016. The recently passed Universal Health Care Act of 2019 will fully complement the Rare Disease Act of 2016.
Our Hope

2.3 Pillars
APEC member economies have agreed to realize 30 targets across 10 pillars:

1. Define rare diseases and orphan products with policies and processes;
2. Raise public and political awareness of rare disease issues;
3. Promote innovative research and development;
4. Build human resource capacity in medical and non-medical sectors;
5. Facilitate early, accurate, and systematic diagnosis;
6. Coordinate care across medical specialty, life course, and location;
7. Deliver new and accessible treatments to patients;
8. Support financial and social needs of patients and their families;
9. Manage pooling and usage of patient data securely and effectively; and,
Thank you

We all have the right to quality life!

Patients and their families with rare disease advocates
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