

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

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Countries with national plans, policies, government actions for Rare Diseases

2018

Review

DOI: 10.5582/indr.2018.01085

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

Neil Khosla*, Rodolfo Valdez

Intractable & Rare Diseases Research 2018; 7(4): 213-222





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

S. No. 2707
H. No. 6625

Republic of the Philippines
Congress of the Philippines
Metro Manila

Twelfth Congress

Third Regular Session

Begun and held in Metro Manila, on Monday, the twenty-eighth day of July, two thousand three.

[REPUBLIC ACT NO. 9288]

AN ACT PROMULGATING A COMPREHENSIVE POLICY
AND A NATIONAL SYSTEM FOR ENSURING
NEWBORN SCREENING

Be it enacted by the Senate and House of Representatives of
the Philippines in Congress assembled:

ARTICLE I

GENERAL PROVISIONS

Thalassemia is included in the panel
of expanded newborn screening

RA 10747

Rare Diseases Act of 2016

S. No. 2990
H. No. 5973

Republic of the Philippines
Congress of the Philippines
Metro Manila

Sixteenth Congress

Third Regular Session

Begun and held in Metro Manila, on Monday, the twenty-seventh day of July, two thousand fifteen.

[REPUBLIC ACT NO. 10747]

AN ACT PROMULGATING A COMPREHENSIVE POLICY
IN ADDRESSING THE NEEDS OF PERSONS WITH
RARE DISEASE

Be it enacted by the Senate and House of Representatives of the
Philippines in Congress assembled:

ARTICLE I

GENERAL PROVISIONS

SECTION 1. *Short Title.* — This Act shall be known as
the "Rare Diseases Act of the Philippines".

SEC. 2. *Declaration of Policy.* — It is the policy of the
State to protect and promote the right to health of the people,
including the right of persons suffering from rare diseases to

8 year
journey
from filing
the bill to
passage of
law

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 :

COMPREHENSIVE

- Rare Disease Registry
- Access to diagnosis through public health delivery system
- Rare Disease Management Program

INTEGRATED

- Public Educational and Information campaign by the DOH
- Committed collaboration among the stakeholders
 - National Institutes of Health
 - Food and Drug Administration
 - Dept of Interior & Local Government of Education
 - Dept of Science & Technology

SUSTAINABLE

- PHILHEALTH (natl health insurance) benefit package for rare diseases
- Fiscal Incentive (exemption from all taxes & duties of donations for:
 - Rare Disease Research
 - Maintenance of Registry
 - Purchase of Orphan Drugs & Orphan Products

Acknowledgement for Rare Disease Act



Department of Health



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



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



**Philippine Society
for Orphan Disorders**

Patients, their families and all its donors and sponsors

Triplet Legislation

RA 9288

Newborn Screening Act of 2004

RA 11223

Universal Health Care Act of 2019

RA 10747

Rare Diseases Act of 2016

S. No. 2707
H. No. 6625

Republic of the Philippines
Congress of the Philippines
Metro Manila

Twelfth Congress

Third Regular Session

Begun and held in Metro Manila, on Monday, the twenty-eighth day of July, two thousand three.

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AND A NATIONAL SYSTEM FOR ENSURING
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the Philippines in Congress assembled:*

ARTICLE I GENERAL PROVISIONS

SECTION 1. *Short Title*. - This Act shall be known as the
"Newborn Screening Act of 2004."

SEC. 2. *Declaration of Policy*. - It is the policy of the State to
protect and promote the right to health of the people, including the
rights of children to survival and full and healthy development as

S. No. 1896
H. No. 5784

Republic of the Philippines
Congress of the Philippines
Metro Manila

Seventeenth Congress

Third Regular Session

Begun and held in Metro Manila, on Monday, the twenty-third
day of July, two thousand eighteen.

[REPUBLIC ACT NO. 11223]

AN ACT INSTITUTING UNIVERSAL HEALTH CARE FOR
ALL FILIPINOS, PRESCRIBING REFORMS IN THE
HEALTH CARE SYSTEM, AND APPROPRIATING
FUNDS THEREFOR

*Be it enacted by the Senate and House of Representatives of the
Philippines in Congress assembled:*



No one will be left behind

S. No. 2990
H. No. 5973

Republic of the Philippines
Congress of the Philippines
Metro Manila

Sixteenth Congress

Third Regular Session

Begun and held in Metro Manila, on Monday, the twenty-seventh
day of July, two thousand fifteen.

[REPUBLIC ACT NO. 10747]

AN ACT PROMULGATING A COMPREHENSIVE POLICY
IN ADDRESSING THE NEEDS OF PERSONS WITH
RARE DISEASE

*Be it enacted by the Senate and House of Representatives of the
Philippines in Congress assembled:*

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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



**Asia-Pacific
Economic Cooperation**

APEC Rare Disease Action Plan

APEC LSIF Rare Disease Network

Draft Zero – 23 July 2018

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,
10. Prioritize comprehensive domestic rare disease policy integrating Pillars 1-9.

Thank you

We all have the right to quality life!

Patients and their families with rare disease advocates



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Chair
Philippine Society for Orphan Disorders, Inc
www.psod.org.ph

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