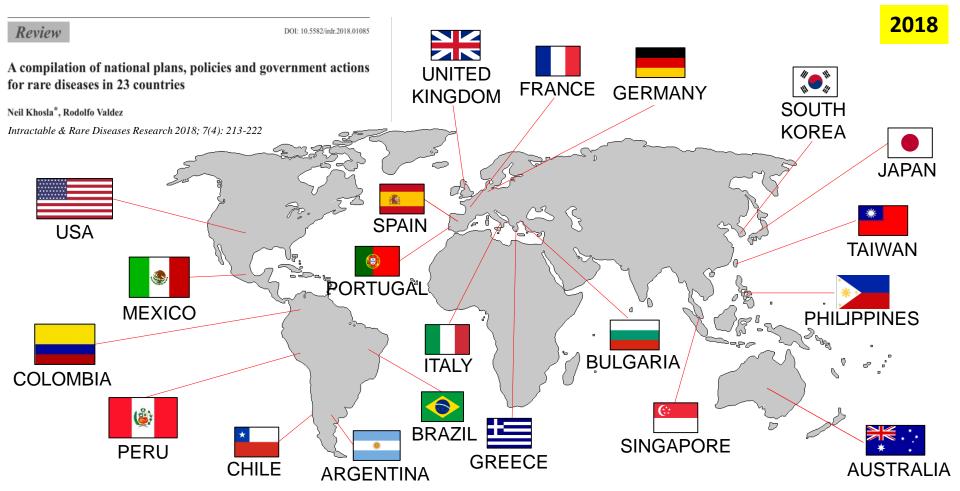
# Including rare diseases in the national health system – the case of the Philippines

### Carmencita D. Padilla, MD, MAHPS

Professor and Chancellor University of the Philippines Manila



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





# PHILIPPINES **—**

7000+ islands
Low Middle Income Country
110M population

**Challenges** that pushed for rare disease legislation

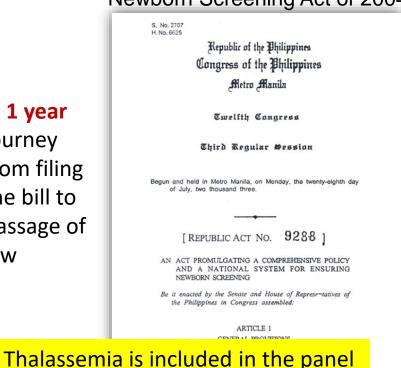
- Rare Diseases not a priority
- Rare Diseases competing with other health matters in the top 10 causes of infant mortality and morbidity

## Twin Legislation

#### **RA 9288**

Newborn Screening Act of 2004

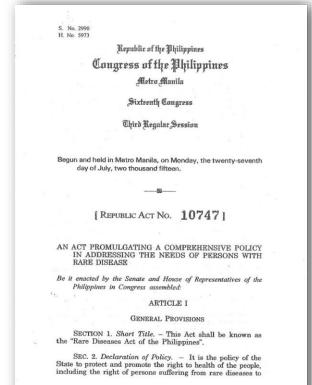
< 1 year journey from filing the bill to passage of law



of expanded newborn screening

#### **RA 10747**

Rare Diseases Act of 2016



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 Interor & 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



Patients, their families and all its donors and sponsors

## **Triplet Legislation**

### **RA 9288**

S. No. 2707 H. No. 6625

> Republic of the Philippines Congress of the Philippines Metro Manila

> > Twelfth Congress

Third Regular Bession

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

[ REPUBLIC ACT NO. 9288 1

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 1 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 neople, including the rights of children to survival and full and healthy development as

#### **RA 11223**

#### Newborn Screening Act of 2004 Universal Health Care Act of 2019

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

### **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 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:

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

# **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.

Chank 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
<a href="https://www.psod.org.ph">www.psod.org.ph</a>

https://www.facebook.com/psod.org.ph/