



Integration of Rare Diseases in the Philippine National Health System

Second High Level Event of the NGO Committee for Rare Diseases
21 February 2019
United Nations, New York

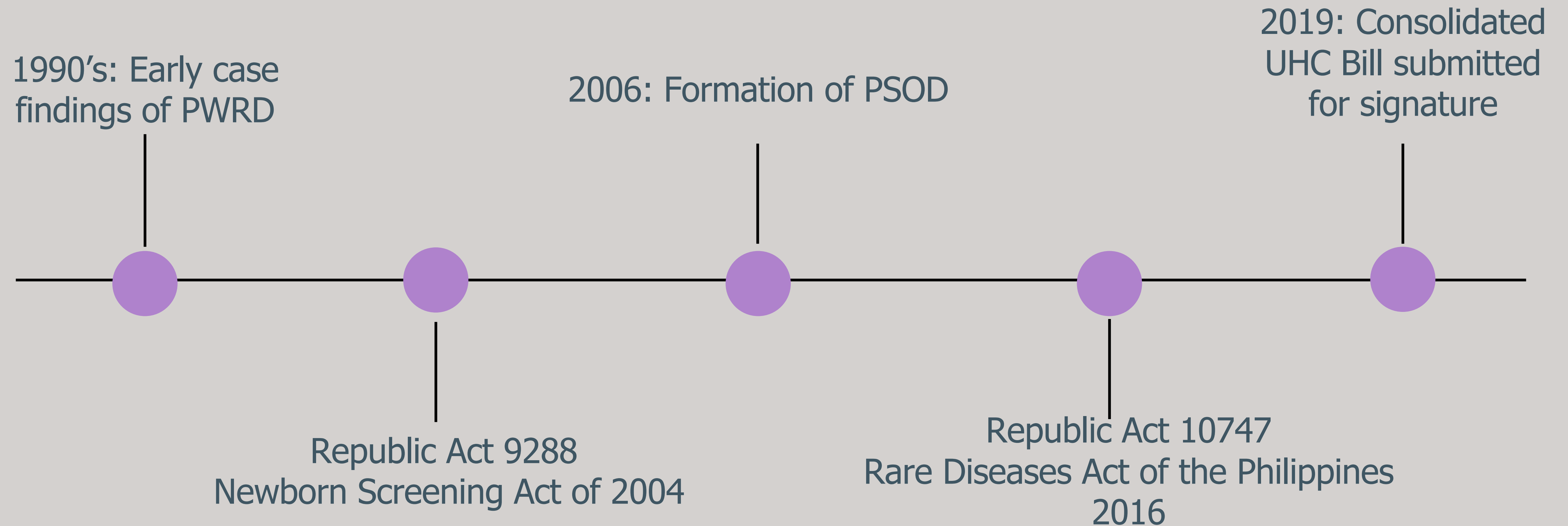
Cynthia K. Magdaraog
President
Philippine Society for Orphan Disorders, Inc.



Topic Coverage

- Milestones
- PSOD's contribution to the passage of the Rare Diseases Act
- Salient features of the Rare Diseases Act
- Provisions on the pending Universal Health Care Act impacting implementation of the RDA
- Persons With Rare Diseases Claim: Our to Right to Life

Milestones



PSOD's Contribution to the Passage of the RDA



Rare Disease Medicine Access
Program
2011, 2013 and 2018



Ground level lobbying for the
passage of RDA



Member of the
Technical Working Group

Salient Features of the Rare Diseases Act

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

- NBS continuity care nationwide
- Telegenetics
- Rare Disease Registry
- Rare Disease Management Program

INTEGRATED

- Public Educational and Information campaign by the DOH
- Committed collaboration among stakeholders
 - NIH
 - FDA
 - DILG/DePED
 - DOST

SUSTAINABLE

- PhilHealth Benefit Package for RD
 - Fiscal Incentive
- Exemption from all taxes and customs duties of donations for:
- Rare Disease Research
 - Maintenance of Registry
 - Purchase of Orphan Drugs & Orphan Products

Twin Legislation

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

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



6 Newborn screening centers

14 Continuity clinics

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

Provisions in the pending UHC Integrating the RDA Act



No one will be left behind



Health Technology Assessment

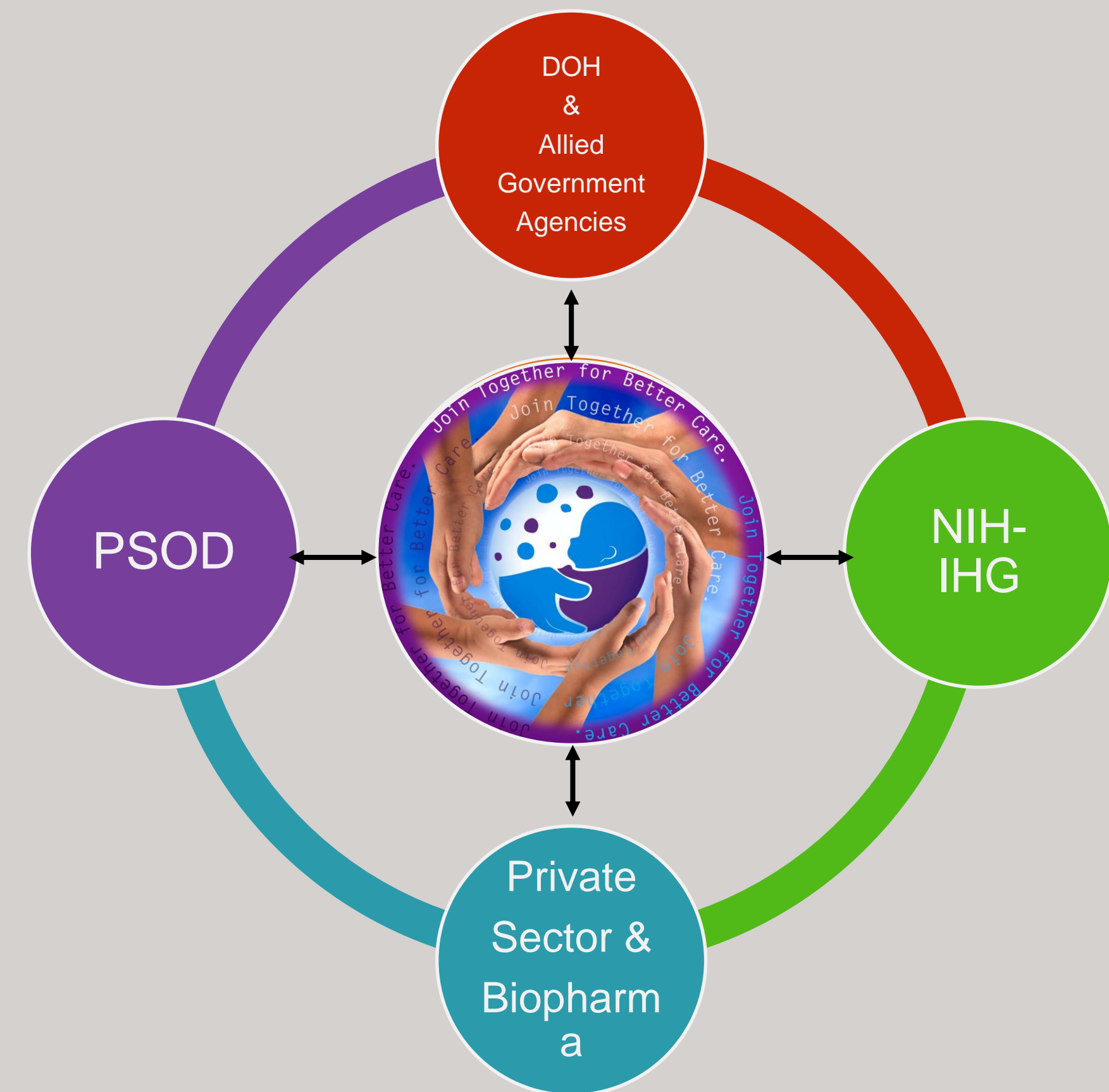


Expanded source of funding

PWRD Claim: Our Right to Life



Sustainability



Collaboration

*Someday soon, with our
collective help,
patient families can feel...
"No disease is rare for
someone you love".*



Because everyone has a right to life...
...and a right to a quality life.

Maraming Salamat Thank You

Philippine Society for Orphan Disorders, Inc.



Acknowledgement for Rare Disease Act



**Philippine Society
for Orphan Disorders**

Patients, their families and all its donors and sponsors



Institute of Human Genetics
University of the Philippines Manila

Geneticists and other health professionals

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