

SIXTEENTH CONGRESS OF THE REPUBLIC)
OF THE PHILIPPINES)
First Regular Session)



'13 OCT 21 P4:44

SENATE
S. No. 1868

RECEIVED BY: *ji*

Introduced by Senator Miriam Defensor Santiago

EXPLANATORY NOTE

The Constitution, Article 2, Section 15 provides:

The State shall protect and promote the right to health of the people and instill health consciousness among them.

Knowledge is the first step towards cure. While we focus our attention on the prevention and cure of the more common diseases, we must not be totally blind as to the rare diseases and conditions suffered by many of our countrymen. Most vulnerable to these rare afflictions are our children. In order to be able to establish means to fight these afflictions, we must commission a study that will aid us in making sound policies that can produce lasting solutions to our problem.

This bill mandates the University of the Philippines National Institutes of Health, as the primary health research arm of the government, to conduct a research that focuses on pediatric rare diseases to aid in their diagnosis, prevention, and cure.

Miriam Defensor Santiago
MIRIAM DEFENSOR SANTIAGO
all

*13 OCT 21 P 4 :44

SENATE
S. No. 1868

RECEIVED BY *ji*

Introduced by Senator Miriam Defensor Santiago

1 AN ACT
2 MANDATING THE UNIVERSITY OF THE PHILIPPINES
3 NATIONAL INSTITUTES OF HEALTH TO CONDUCT RESEARCH
4 ON PEDIATRIC RARE DISEASES AND CONDITIONS

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

5 SECTION 1. *Short Title* – This Act shall be known as “Pediatric Rare Diseases and
6 Conditions Research Act.”

7 SECTION 2. *Research* – Within two (2) years from the effectivity of this Act, the
8 University of the Philippines National Institutes of Health (UP-NIH) shall:

9 A. conduct a research that focuses primarily on pediatric rare diseases or conditions,
10 including any such diseases or conditions that are genetic disorders (such as spinal muscular
11 atrophy and Duchenne muscular dystrophy) or are related to birth defects (such as Down
12 syndrome and fragile X); and

13 B. conduct or coordinate one or more multisite clinical trials of therapies for, or
14 approaches to, the prevention, diagnosis, or treatment of one or more pediatric rare diseases or
15 conditions.

16 SECTION 3. *Registry*. – The Department of Health (DOH), in consultation with the UP-
17 NIH, shall identify which Pediatric Rare Diseases and Conditions shall be covered by this Act.
18 The DOH shall establish a registry of all Pediatric Rare Diseases and Condition, which shall be
19 accessible to the UP-NIH.

1 SECTION 4. *Report.* -- Within one (1) year from completion of the research, as provided
2 by this Act, the UP-NIH shall submit its findings to the DOH and the appropriate committees in
3 the Senate and the House of Representatives.

4 SECTION 5. *Separability Clause.* - If any provision or part thereof is held invalid or
5 unconstitutional, the remainder of the Act or the provision not otherwise affected shall remain
6 valid and subsisting.

7 SECTION 6. *Repealing Clause.* -- Any law, presidential decree or issuance, executive
8 order, letter of instruction, administrative order, rule or regulation contrary to or inconsistent
9 with this Act is hereby repealed, modified, or amended accordingly.

10 SECTION 7. *Effectivity Clause.* -- This Act shall take effect fifteen (15) days after its
11 publication in at least two (2) newspapers of general circulation.

Adopted,