

Republic of the Philippines
HOUSE OF REPRESENTATIVES
Quezon City
SIXTEENTH CONGRESS
First Regular Session
House Bill No. **3258**



Introduced by **Hon. Sol Aragones**

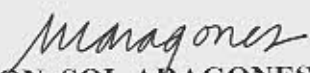
EXPLANATORY NOTE

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 any kind of 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.


HON. SOL ARAGONES
Representative, 3rd District of Laguna

1 B. conduct or coordinate one or more multisite clinical trials of
2 therapies for, or approaches to, the prevention, diagnosis, or treatment
3 of one or more pediatric rare diseases or conditions.
4

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

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

12 SECTION 5. *Repealing Clause.* – Any law, presidential decree or
13 issuance, executive order, letter of instruction, administrative order, rule or
14 regulation contrary to or inconsistent with this Act is hereby repealed, modified,
15 or amended accordingly.

16 SECTION 6. *Effectivity Clause.* – This Act shall take effect fifteen (15)
17 days after its publication in at least two (2) newspapers of general circulation.

18 Adopted,