

Republic of the Philippines
HOUSE OF REPRESENTATIVE
Quezon City

SEVENTEENTH (17th) CONGRESS
First Regular Session

House Bill No. 2716

HOUSE OF REPRESENTATIVES	
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Introduced by: REP. ELISA T. KHO

EXPLANATORY NOTE

Our Constitution expressly provides under Article 2, Section 15 that:

“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.

Elisa T. Kho
ELISA T. KHO, M.D., FPCCP

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AN ACT
MANDATING THE NATIONAL INSTITUTES OF HEALTH TO
CONDUCT RESEARCH ON RARE PEDIATRIC DISEASES AND
CONDITIONS

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

SECTION 1. *Short Title* — This Act shall be known as "Rare Pediatric Diseases and Conditions Research Act."

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

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

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

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

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

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letter of instruction, administrative order, rule or regulation contrary, to or inconsistent with this Act is hereby repealed, modified, or amended accordingly.

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

Adopted.