

Republic of the Philippines
HOUSE OF REPRESENTATIVES
Quezon City, Metro Manila

SIXTEENTH CONGRESS
Second Regular Session

House Bill No. 5106



Introduced by HON. LINABELLE RUTH R. VILLARICA
4TH DISTRICT, BULACAN

EXPLANATORY NOTE

Updating the medical field of pediatrics through the conduct of research on rare diseases will breathe life into the constitutional provision on the right to health of our young population. The State must regularly support this initiative for the benefit of our children.

Presently, however, our health institutions are either left to their own devices in the area of research or they are focused on the preventive and cure of the more common diseases. With our varied lifestyles, the occurrence of rare diseases afflicting our children is not a farfetched reality. For the guidance of our pediatricians, the other allied medical practitioners and health workers tasked in the physical care and nurturing of our children, an extensive study on rare diseases must be supported.

This bill mandates the State to fund a comprehensive study and research of rare diseases by the University of the Philippines National Institutes of Health.

Support for the enactment of this measure is earnestly requested.

REP. LINABELLE RUTH R. VILLARICA

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AN ACT MANDATING THE UNIVERSITY OF THE PHILIPPINES NATIONAL
INSTITUTES OF HEALTH TO CONDUCT RESEARCH ON PEDIATRIC RARE DISEASES
AND APPROPRIATING FUNDS THEREFOR

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

SECTION 1. *Declaration of Policy.* - It shall be the policy of the State to guarantee a healthy and strong population and promote the well-being of every Filipino.

SEC. 2. *Research on Pediatric Rare Diseases.* - The University of the Philippines National Institutes of Health (UP-NIH) shall conduct researches on:

- a.) 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.) 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.

SEC. 3. *Registry of Pediatric Rare Diseases and Conditions.* - The Department of Health (DOH), in consultation with the UP-NIH shall identify which Pediatric Rare Diseases and Conditions shall be covered by this Act. The DOH shall establish a registry of all pediatric rare diseases and conditions, which shall be subject to the guidelines issued by the UP-NIH to protect the privacy of patients afflicted with rare diseases.

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

SEC. 5. *Appropriations.* – The amount necessary for the initial implementation of this Act shall be charged against the existing appropriation of the DOH. Thereafter, the amounts needed for the full implementation of this Act shall be included in the budget of the DOH in the succeeding General Appropriations Act.

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

SEC. 7. *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.

SEC. 8. *Effectivity Clause.* – This Act shall take effect fifteen (15) days after its publication in at least two (2) newspapers of general circulation.

Adopted,