

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

'04 JUN 30 P1:39

SENATE  
S. B. No. 147

RECEIVED BY: 

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Introduced by Senator LUISA "LOI" P. EJERCITO ESTRADA

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### EXPLANATORY NOTE

The Constitution, Article 13, Section 12 provides:

"The State shall establish and maintain an effective food and drug regulatory system and undertake appropriate health manpower development and research, responsive to the country's health needs and problems."

In the United States and other countries, a number of privately funded voluntary health agencies continue to research on possible treatment of dystonia. However, research on dystonia in our country remains minimal, or even negligible.

The fact that it has afflicted hundreds of Filipinos, and that the neurological disorder is genetic, is a cause of concern. The government must help curb the growing cases of dystonia.

Not a single treatment has been found to be universally effective, and doctors would normally resort to therapies to reduce or eliminate the muscle spasms and pain that patients suffer.

This bill seeks to aid and promote research on the causes of dystonia so that they can be prevented, and that effective treatment can be found.

Hence, the early passage of this proposed measure is highly recommended.

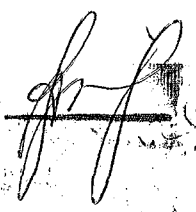


**LUISA "LOI" P. EJERCITO ESTRADA**  
Senator

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**AN ACT  
PROMOTING RESEARCH ON DYSTONIA**

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

Section 1. **Short Title.** – This Act shall be known as the “Dystonia Research and Information Act.”

Section 2. **Declaration of Policy.** – The Constitution, Article 13, Section 12 mandates the State to undertake appropriate health manpower development and research responsive to the country’s health needs and problems. Taking into account this mandate, the State shall promote research for the prevention and treatment on dystonia.

Section 3. **Definition of Terms.** – For purposes of this Act, the term:

- (A) “Secretary” shall refer to the Secretary of the Department of Health;
- (B) “Dystonia” shall refer to the movement disorder in which sustained muscle contractions cause twisting and repetitive movements or abnormal postures. The movements, which are involuntary and sometimes painful, may affect a single muscle, a group of muscles such as those in the arms, legs, or neck, or the entire body;
- (C) “Committee” refers to the Committee on Dystonia Research.

Section 4. *Dystonia Research.* – The Secretary shall conduct or support research to expand the understanding of dystonia. Such research shall:

- (A) if determined to be scientifically appropriate, include a multidisciplinary, clinical, case-controlled study of dystonia patients;
- (B) involve families of persons who suffer from dystonia, focus on atypical disease presentation, neurological dysfunction, diminished intelligence and emotional imbalance;
- (C) evaluate to what extent, if any, their health differs from other patients with neurological disorders.

Section 5. *Committee on Dystonia Research.* – To assist the Secretary in receiving accurate and complete information about dystonia, its symptoms, origin, classification, prevention and treatment, there shall be established a committee, to be known as the Committee on Dystonia Research, to ensure the strategic management, communication, and oversight of the policy formation, research, and activities of the government regarding dystonia.

Section 6. *Composition.* –

- (1) The Committee shall be composed of nine (9) members:
  - (A) Two (2) representatives from the Department
  - (B) One (1) representative of any other agencies necessary to accomplish the purpose of the Committee
  - (C) Four (4) physicians or practitioners with established credentials in the area of neurological disorders; and
  - (D) Two (2) immediate relatives of dystonia patients to be appointed by the Secretary.
- (2) The Secretary shall act as the chair of the Committee. He shall convene meetings of the Committee, not less than twice each year, and compile information for the consideration of the full Committee at such meetings.

Section 7. *Meetings.* – The meetings of the Committee shall be open to the public and public witnesses shall be given the opportunity to speak and make presentations at such meetings. Each member shall make a presentation to the full Committee at each meeting concerning the activities conducted by such member.

Section 8. *Term of Office.* – Members shall be appointed by the Secretary for a term of three (3) years. Of those first appointed, three (3) members shall serve for three (3) years, three (3) members for two (2) years, and the last three (3) members for one (1) year.

Any vacancy in the membership of the Committee shall be filled in the same manner as the original appointment.

Any member of the Committee may be removed for cause in accordance with procedures established by the Committee.

Section 9. *Functions.* – The Committee shall have the following functions:

- (A) Advise the Secretary on appropriate research activities to be undertaken by the Office with respect to research on dystonia, its prevention and treatment;
- (B) Report to the Secretary on such research;
- (C) Provide recommendations to the Secretary regarding activities of the Committee;
- (D) Prepare a report regarding the activities of the Committee; and
- (E) Ensure that materials concerning dystonia are available, up to date, and responsive to reports of problems with dystonia, and that timely aggregate data concerning such reports shall be made available to the public upon request and consistent with existing confidentiality standards.

Section 10. *Appropriations.* – To carry out the provisions of this Act, such amount as may be necessary is hereby authorized to be appropriated from the National

Treasury. Thereafter, the amount necessary for the continuous operation of the research shall be included in the annual appropriation of the Department of Health.

Section 11. *Separability Clause* – If any provision or part hereof is held invalid or unconstitutional, the remainder of the law or the provision not otherwise affected shall remain valid and subsisting.

Section 12. *Repealing Clause*. – Any law, presidential decree or issuance, executive order, letter of instruction, administrative order, rule or regulation contrary to or inconsistent with the provision of this act is hereby repealed, modified or amended accordingly.

Section 13. *Effectivity Clause*. – This Act shall take effect fifteen (15) days after its publication in at least two (2) newspapers of general circulation.

*Approved,*