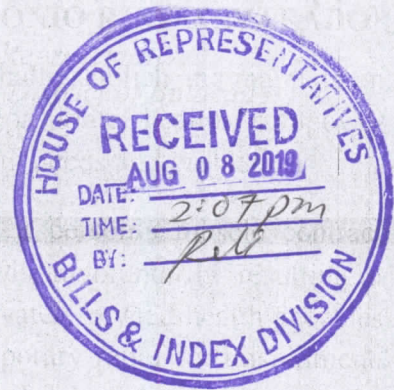


Republic of the Philippines
HOUSE OF REPRESENTATIVES
Quezon City

EIGHTEENTH CONGRESS
First Regular Session

HOUSE BILL NO. 3686



Introduced by: **“KUYA” JOSE ANTONIO R. SY-ALVARADO**

AN ACT
PROMOTING RESEARCH ON DYSTONIA

EXPLANATORY NOTE

Art. 13 Sec. 12 of the Constitution provides that the State shall establish and maintain an effective food and drug regulatory system and undertake appropriate health, manpower development and research which is responsive to the country's health needs and problems.

Dystonia is a neurological movement disorder in which a person's muscle contract uncontrollably. The contraction causes the affected body part to twist involuntarily, resulting in repetitive movements or abnormal postures. In other countries, privately owned health agencies provide a research program in order to find cure or at least a temporary relief for this ailment. There are numerous cases of Filipinos who are afflicted with this kind of disease and yet the Government's program for this ailment is minimal or even close to none.

This bill seeks to provide research program for dystonia in order to provide cure, relief or even prevention for this disease.

Hence, this proposal is submitted for consideration.

“KUYA” JOSE ANTONIO R. SY-ALVARADO ✓
Representative
First District of Bulacan

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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 the "Dystonia Research and Information Act."

SEC 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 of dystonia.

SEC 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 neurological 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.

SEC 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.

SEC 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 a committee established, 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.

SEC 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.

SEC 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 Committee at each meeting concerning the activities conducted by such member.

SEC 8. **Term of Office.** Members shall be appointed by the Secretary for a term of three 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.

SEC 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.

SEC 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.

SEC 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.

SEC 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.

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

Approved