

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



Senate
Office of the Secretary

'13 SEP 17 P3:54

SENATE
S. No. 1698

RECEIVED BY

ji

Introduced by Senator Miriam Defensor Santiago

EXPLANATORY NOTE

The Constitution, Article XIII, 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.

Not a single treatment has been found to be universally effective, and doctors would normally resort to therapies to reduce or eliminate 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.*

Miriam Defensor Santiago
MIRIAM DEFENSOR SANTIAGO

* This bill was originally filed during the Thirteenth Congress, First Regular Session.



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1 AN ACT
2 PROMOTING RESEARCH ON DYSTONIA

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

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

5 SECTION 2. *Declaration of Policy.* – The Constitution provides that the State shall
6 undertake appropriate health manpower development and research responsive to the country’s
7 health needs and problems. Pursuant to this policy, it shall promote research for the prevention
8 and treatment on dystonia.

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

10 (A) “Secretary” shall refer to the Secretary of Health;

11 (B) “Dystonia” shall refer to the movement disorder in which sustained muscle
12 contractions cause twisting and repetitive movements or abnormal postures. The
13 movements, which are involuntary and sometimes painful, may affect a single
14 muscle, a group of muscles, such as those in the arms, legs, or neck, or the entire
15 body; and

16 (C) “Committee” refers to the Committee on Dystonia Research.

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

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

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

13 SECTION 6. *Composition.* – The Committee shall be composed of nine (9) members:

- 14 (A) Two (2) representatives from the Department of Health;
- 15 (B) One (1) representative from any other government agency necessary to accomplish
16 the purpose of the Committee;
- 17 (C) Four (4) physicians or practitioners with established credentials in the area of
18 neurological disorders; and
- 19 (D) Two (2) immediate relatives of dystonia patients to be appointed by the Secretary.

20 The Secretary shall act as chair of the Committee. He shall convene meetings of the
21 Committee, not less than twice a year, and compile information for the consideration of the full
22 Committee at such meetings.

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

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

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

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

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

9 (A) Advise the Secretary on appropriate research activities to be undertaken by the
10 Committee with respect to research on dystonia, its prevention, and treatment;

11 (B) Report to the Secretary on such research;

12 (C) Provide recommendations to the Secretary regarding the activities of the
13 Committee;

14 (D) Prepare a report regarding the activities of the Committee;

15 (E) Ensure that materials concerning dystonia provided by the Department are
16 available, up to date, and responsive to reports of problems of dystonia, and that
17 timely aggregate data concerning such reports shall be made available to the public
18 upon request and consistent with existing confidentiality standards.

19 SECTION 10. *Appropriation.* – To carry out the provisions of this Act, such amount as
20 may be necessary is hereby authorized to be appropriated from the National Treasury.
21 Thereafter, the amount necessary for the continuous operation of the research shall be included
22 in the annual appropriation of the Department of Health.

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

1 SECTION 12. *Repealing Clause.* – Any law, presidential decree or issuance, executive
2 order, letter of instruction, administrative order, rule, or regulation contrary to or inconsistent
3 with the provisions of this Act is hereby repealed, modified, or amended accordingly.

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

Approved,