

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



Senate
Office of the Secretary

'13 AUG 29 P5:11

SENATE
Senate Bill No. 1443

RECEIVED BY: *ji*

Introduced by Senator Miriam Defensor Santiago

EXPLANATORY NOTE

The Constitution, Article 2, Section 15 provides:

The State shall protect and promote the right to health of the people and instill health consciousness among them.

In the United States, it is estimated that 300,000 people suffer from scleroderma, 80 percent of whom are women often diagnosed during their child bearing years. Scleroderma is a chronic, disabling and often fatal autoimmune disease in which the body's soft tissues contract and harden due to an over production of collagen. It causes damage to one or more of the body's organ systems, including the skin, heart, lungs, kidneys, gastrointestinal tract, and blood vessels.¹

Based on a study conducted by some UP-PGH doctors,² there seems to be also a female predominance (97.5%) in the case of scleroderma in the Philippines, with a mean age of onset at 34 years and a mean duration of 4 years prior to consult.

¹ <http://www.gpo.gov/fdsys/pkg/BILLS-113s1239is/pdf/BILLS-113s1239is.pdf>.

² International Journal of Rheumatic Diseases (Vol. 15, September 2012) entitled "Clinical Profile of Filipino Patients with Scleroderma (Systemic sclerosis): An 11-year retrospective review of 40 cases" by UP-PGH Doctors Lo, Racaza and Penserga

The study shows that limited type was most commonly observed, and some of the manifestations noted were skin tightness, joint complaints, weight loss, Raynaud's, hyperpigmentation and reduced oral aperture.

The study also suggests that disease features involving Raynaud's phenomenon, skin, joints, heart and lungs, are common among Filipinos and other racial groups. But renal involvement appears to be less common among Filipinos and its Asian counterparts compared with Caucasians and Africans.

Scleroderma is reportedly very hard to diagnose due to different combination of symptoms; thus, there should be more research on the disease. This bill aims to expand the research and awareness activities of the Department of Health with respect to scleroderma.

Miriam Defensor Santiago
MIRIAM DEFENSOR SANTIAGO

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1 AN ACT
2 EXPANDING THE RESEARCH AND AWARENESS ON SCLERODERMA OF
3 THE DEPARTMENT OF HEALTH

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

4 SECTION 1. *Short Title.* – This Act shall be known as the “Scleroderma
5 Research and Awareness Act”.

6 SECTION 2. *Research on Scleroderma.* – The Department of Health shall
7 expand and intensify its activities with respect to scleroderma, with particular
8 emphasis on the following areas:

9 (1) Research focused on the etiology of scleroderma and the development
10 of new treatment options.

11 (2) Clinical research to evaluate new treatments options.

12 (3) Basic research on the relationship between scleroderma and secondary
13 conditions such as pulmonary hypertension, gastroparesis, Raynaud’s
14 phenomenon, Sjogren’s Syndrome, and other diseases as determined by the
15 Department of Health.

16 (4) Establishment of scleroderma patient registries, including family and
17 childhood onset registries.

1 (5) Support for training of new clinicians and investigators with expertise
2 in scleroderma.

3 SECTION 3. *Promoting Public Awareness of Scleroderma.* – The
4 Department of Health shall carry out an educational campaign to increase public
5 awareness of scleroderma. Print, video, and web-based materials distributed may
6 include:

- 7 (1) basic information on scleroderma and its symptoms;
8 (2) information on the incidence and prevalence of scleroderma;
9 (3) diseases and conditions affiliated with scleroderma; or
10 (4) the importance of early diagnosis and treatment.

11 SECTION 4. *Report to Congress.* – The Secretary of Health shall report to
12 the Committee on Health and Demography of the Senate and the House of
13 Representatives on the status of activities under this Act.

14 SECTION 5. *Appropriations.* – There are authorized to be appropriated to
15 carry out this Act such sums as may be necessary for each of fiscal years starting
16 2014 through 2016.

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

20 SECTION 7. *Repealing Clause.* – Any law, presidential decree or issuance,
21 executive order, letter of instruction, administrative order, rule or regulation

1 contrary to, or inconsistent with the provisions of this Act is hereby repealed,
2 modified or amended accordingly.

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

Approved,