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SENATE

S. No. 989

RECEIVED BY: 

Introduced by Senator Manuel "Lito" M. Lapid

EXPLANATORY NOTE

Every day, more than 5 million people worldwide struggle with the often debilitating health consequences of lupus, a potentially fatal autoimmune disease capable of damaging virtually any part of the body, including the skin, heart, lungs, kidneys, and brain. Nine out of ten people with lupus are women. Eighty percent of new lupus cases are diagnosed among women ages 15 to 44, striking at the peak of their reproductive and career potential. A merciless predator, lupus permanently disables many young women.

Systemic lupus erythematosus (lupus) is a chronic autoimmune disease that can be fatal, though with recent medical advances, fatalities are becoming increasingly rare. As with other autoimmune diseases, the immune system attacks the body's cells and tissue, resulting in inflammation and tissue damage. Lupus can affect any part of the body, but most often harms the heart, joints, skin, lungs, blood vessels, liver, kidneys, and nervous system. The course of the disease is unpredictable, with periods of illness (called flares) alternating with remissions. Lupus can occur at any age, and is most common in women. Lupus is treatable symptomatically, mainly with corticosteroids and immunosuppressants, though there is currently no cure.

Clinically, lupus can affect multiple organ systems, including the heart, skin, joints, kidneys, and nervous system. Generally, when the word "lupus" alone is used, it refers to systemic lupus erythematosus or SLE. SLE is one of several diseases known as "the great imitators" because its symptoms vary so widely, it often mimics or is mistaken for other illnesses because the symptoms come and go unpredictably. Diagnosis can be elusive, with patients sometimes suffering unexplained symptoms and untreated SLE for years. Common initial and chronic complaints are fever, malaise, joint pains, myalgias, fatigue and temporary loss of cognitive abilities. Because they are so often seen with other diseases, these signs and symptoms are not part of the diagnostic criteria for SLE.

As lupus erythematosus is a chronic disease with no known cure, treatment is restricted to dealing with the symptoms. Essentially, this involves preventing flares and reducing their severity and duration when they occur. There are several means of preventing and dealing with flares, including drugs, alternative medicine, and lifestyle changes. Due to the variety of symptoms and organ system involvement with lupus patients, the severity of the SLE in a particular patient must be assessed in order to successfully treat SLE. Mild or remittent disease can sometimes be safely left untreated. If required, nonsteroidal anti-inflammatory drugs and antimalarials may be used.

Many people with lupus are unable to maintain employment or attend school because of extended lupus-related absences and hospitalizations. A majority of those affected must live with debilitating pain and profound fatigue which greatly affects their quality of life. For some, memory and mental processing may be impaired, rendering

simple tasks such as recalling names or balancing a checkbook, as significant challenges. There is always the ever-present threat of a flare -- the sudden onset of more serious symptoms.

Despite its enormous public health implications, lupus remains a dangerously under-recognized and under-appreciated health issue.

This proposed measure seeks to increase public awareness about this disease and provide proactive government support for lupus disease research and treatment. By creating a national program for health providers about lupus, it is hoped that this proposed measure will help more people recognize the disease. This will lead to early identification and intervention, which is critical for afflicted persons.

By passing this landmark piece of legislation, our government recognizes the daily plight of our thousands of families struggling every day with lupus disease, and once and for all acknowledge lupus disease as a health issue in the country.

In view of the foregoing, early passage of this bill is earnestly sought.



MANUEL "LITO" M. LAPID
Senator

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Introduced by Senator Manuel "Lito" M. Lapid

AN ACT
INSTITUTING A COMPREHENSIVE NATIONAL HEALTH PROGRAM TO
COMBAT SYSTEMIC LUPUS ERYTHEMATOSUS (LUPUS) DISEASE,
IMPLEMENTING A NATIONWIDE AWARENESS PROGRAM,
APPROPRIATING FUNDS THEREFOR AND FOR OTHER PURPOSES

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 "**Comprehensive Systemic Lupus Erythematosus (Lupus) Disease Prevention Act of 2010**".

SEC. 2. Declaration of Policy. - It is hereby declared the policy of the State to protect and promote the right to health of the people, including the rights of persons with systemic lupus erythematosus (lupus) disease to full, healthy and holistic development and the right to self-determination. As such, the State shall promote an environment conducive to the development of persons with SLE (lupus) disease to become, to the best of their potentials, independent, self-reliant and productive members of society.

Towards this end, the State commits itself to the establishment of institutional and social mechanisms to support persons with systemic lupus erythematosus (lupus) disease and their families. As such, the State shall institutionalize a holistic program for persons with lupus disease for purposes of empowering and providing them quality of life.

SEC. 3. Definition of Terms. - For purposes of this Act, the term below shall be construed to mean, except where explicitly indicated or where the text clearly indicates otherwise, as follows:

SYSTEMIC LUPUS ERYTHEMATOSUS (SLE - LUPUS) – It is a chronic autoimmune disease that can be fatal. As with other autoimmune diseases, the immune system attacks the body's cells and tissue, resulting in inflammation and tissue damage. Lupus can affect any part of the body, but most often harms the heart, joints, skin, lungs, blood vessels, liver, kidneys, and nervous system. The course of the disease is unpredictable, with periods of illness (called flares) alternating with remissions. Lupus can occur at any age, and is most common in women.

SEC. 4. *Epidemiological Surveillance Programs.* - The National Institute of Health (NIH) of the Department of Health (DOH) is hereby mandated to conduct an annual epidemiological survey program to determine the extent and total incidence and prevalence of persons with systemic lupus erythematosus (lupus) disease in the country in order for the government to provide the necessary health interventions to address the needs faced by persons with lupus disease.

The NIH is mandated to coordinate with the Department of Health (DOH) in the conduct of epidemiological research on the issues concerning systemic lupus erythematosus (lupus) disease. The NIH is mandated to strengthen its research focus concerning lupus, including a renewed investment into basic and clinical research, expanded research into the link between environmental factors lupus, and continued investigations into causation, diagnosis, early detection and treatment for SLE. Such factors that will be studied shall also include, among others, infection and immune function, hormones and reproductive factors, genetic factors, gastro-intestinal factors, socio-demographic factors, and others.

SEC. 5. *Prevention of Conflict of Interest in the Research Process.* - Within six (6) month from the date of effectivity of this Act, the DOH shall issue the necessary standards, guidelines and regulations in order to ensure that there is no conflict of interest between the research agenda of the researchers and the drug manufacturers or government agencies promoting the widespread usage of a particular vaccine or medicine for the treatment and rehabilitation of persons with systemic lupus erythematosus (lupus) disease.

The DOH shall ensure the timely publication and dissemination of information of these guidelines and regulations in order to ensure that the various health providers and stakeholders all over the country are adequately informed.

SEC. 6. *National Program of Lupus Prevention and Rehabilitation.* – The Department of Health (DOH) is hereby mandated to implement a comprehensive and

nationwide program on systemic lupus erythematosus (lupus) disease prevention and rehabilitation.

Towards this end, the DOH is hereby mandated to implement the following objectives:

- a) to promote public awareness, education and information on issues concerning the disease;
- b) to establish sustainable networks of support group for families of persons with the disease;
- c) to provide referral services to patients and identify appropriate educational and medical expertise and facilities suited to the needs of the patients;
- d) to combat the spectrum of disorders related to the disease through screening, education, early intervention, prompt referrals for treatment and services;
- e) to undertake research and/or collaborate with other entities on research activities regarding the disease in the Philippines;
- f) to receive donations and grants from local and international donor institutions, foundations, and multilateral and bilateral foreign donor agencies involved in the prevention, cure and rehabilitation of afflicted persons;
- g) to promote the advocacy against theoretical and psychological bias and stereo-typing against afflicted persons, eliminating discrimination and misconceptions with the end in view of opening the doors of productive economic opportunities to afflicted persons;
- h) to provide the avenue for exchange of information, exchange programs and sharing of best practices on issues relating to the early detection, prevention, cure, treatment and rehabilitation of afflicted persons; and
- i) to network with other organizations, institutions and professionals working for the promotion of legislation and public programs for afflicted persons.

SEC. 7. *Programs and Services for Systemic Lupus Erythematosus (Lupus) Disease Prevention.* - The programs and services that will be provided by the Department of Health (DOH) shall include, among others, the following:

- a) Orientation and Counseling Services for families of newly diagnosed persons;
- b) Establishment of Family Support Networks and Sibling Program for families of afflicted persons to seek psycho-social support for the various problems faced by the patients;
- c) Establishment of National and Regional Referral Services where the DOH will update a list of health care institutions concerned with the care and rehabilitation of patients;

d) Publication of reading materials, manuals and easily readable instruction materials for the disease's early detection, prevention, rehabilitation and care;

e) The conduct of continuing education, information and training programs and lectures on the proper handling of afflicted persons;

f) The establishment of a databank and information and monitoring system (IMS) on the demographic, socio-economic and incidence and prevalence of afflicted persons in the country;

g) The publication of a newsletter on current developments, resources and research on systemic lupus erythematosus (lupus) disease; and

h) The conduct of continuing education/training of families, teachers, therapists and caregivers of persons with systemic lupus erythematosus (lupus) disease through seminars, conventions and other forms of tri-media educational tools.

SEC. 8. Early Identification and Intervention for Persons with Systemic Lupus Erythematosus (Lupus) Disease. – The DOH is hereby mandated to establish a program for early identification, screening and detection of persons with systemic lupus erythematosus (lupus) disease.

SEC. 9. Lupus Early Detection and Screening Fees. – The Philippine Health Insurance Corporation (PHIC) shall include the cost of early detection and screening programs for systemic lupus erythematosus (lupus) disease as one of the available benefits to its members.

The early detection and screening tests fee shall be applied to, among others, testing costs, education, follow-up and readable overhead expenses. These early detection and screening are designed to identify persons who should receive more intensive diagnosis or assessment in order to improve the health and well-being of the patient.

SEC. 10. National Awareness Week for Systemic Lupus Erythematosus (Lupus) Disease Prevention. - In order to mainstream the issues and concerns of patients with systemic lupus erythematosus (lupus) disease, the first week of May of every year is hereby declared as the “**Systemic Lupus Erythematosus (Lupus) Awareness Week**”. This week shall be celebrated nationwide so that stakeholders all over the nation can celebrate and increase public awareness on the advantages prevalence and incidence of the dreaded disease. The week-long activity will be spearheaded by the Department of Health (DOH), in coordination with the Department of Social Welfare and Development (DSWD) and the Philippine Information Agency (PIA).

SEC. 11. *Creation of a National Website for Persons with Lupus.* – The DOH is hereby mandated to establish a national website on this National Health Prevention Program for Lupus in the Philippines. The website shall highlight the various programs, interventions, services and advocacy channels being provided by the Government on the issue so that parents and relatives of persons with SLE can avail of the information and services provided by the State.

This website shall contain all the information on the variety of medical, psychological, psycho-social and research interventions available in the Philippines.

The website shall also include information on the various DOH-accredited health service providers who can provide therapy and treatment to patients.

The website is envisioned to be an avenue where people can express their views regarding the disease and network to address the various needs and concerns of patients.

It will also be an avenue to clear misconceptions and incorrect information on the mental state of patients.

SEC. 12. *Continuing Education and Training of Health Personnel and Service Providers on Lupus Prevention and Rehabilitation.* - All DOH staff and health providers providing various health services to persons with lupus disease are mandated to undergo a mandatory continuing education and training program to sensitize and empower them to become effective frontliners in the delivery of health service to afflicted persons.

SEC. 13. *Protection Against Forcible Use of Cures and Vaccines.* – The DOH shall formulate the necessary guidelines, standards and procedures against the forcible use of cures, vaccines and therapies to afflicted persons in order to protect the rights of patients to informed consent and right to self-determination.

The DOH shall promulgate guidelines and standards to ensure that the interventions and programs being provided by the government towards patients with lupus disease do not violate their basic Constitutional, Human Rights and inalienable rights towards self-determination and self-development.

SEC. 14. *Confidentiality of Medical Information for Persons with Systemic Lupus Erythematosus (Lupus) Disease.* - To ensure that the early detection, screening tests, vaccination, medical treatment and rehabilitation of afflicted persons is implemented subject to all other rights guaranteed by the Constitution, the Department of Health (DOH), in consultation with the Department of Justice (DOJ), shall formulate the pertinent implementing rules and regulations to ensure the confidentiality

of the medical records in order to protect the unwarranted intrusion into the privacy of the patient.

SEC. 15. *Appropriation.* – The amount necessary to carry out the provisions of this Act shall be included and incorporated in the annual general appropriations of the Department of Health (DOH).

SEC. 16. *Implementing Rules and Regulations (IRR).* - Within six (6) months from the date of effectivity of this Act, the DOH shall promulgate necessary implementing rules and regulations to implement the provisions of this Act.

SEC. 17. *Repealing Clause.* - All laws, decrees, executive orders, rules and regulations or parts thereof not consistent with the provisions of this Act are hereby repealed or modified accordingly.

SEC. 18. *Separability Clause.* - If any provision or part of this Act, or the application thereof to any person or circumstance, is held unconstitutional or invalid, the remainder of this Act shall not be affected thereby.

SEC. 19. *Effectivity Clause.* - This Act shall take effect fifteen (15) days from the date of its complete publication in the Official Gazette or in at least two (2) newspapers of general circulation.

Approved,