AN ACT concerning public health.

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

Section 1. Short title. This Act may be cited as the Lupus Education and Awareness Act.

Section 5. Legislative findings and purpose.

(a) The General Assembly finds the following:

(1) Lupus is an urgent national health issue. Lupus is the result of an immune system that is unbalanced and can become destructive to any organ or tissue in the body. Lupus is unpredictable and potentially fatal, yet no satisfactory treatment exists. Its health consequences include heart attacks, strokes, seizures, and organ failure.

(2) National data indicates that more than 1.5 million Americans live with some form of lupus; lupus affects women 9 times more often than men, and 80% of newly diagnosed cases of lupus develop among women of childbearing age. An estimated 65,000 people with lupus reside in Illinois.

(3) Lupus disproportionately affects women of color; it is 2 to 3 times more common among African Americans, Hispanics and Latinos, Asians, and Native Americans and is generally more prevalent in minority populations, a health

disparity that remains unexplained.

(4) No new drugs have been approved by the U.S. Food and Drug Administration specifically for lupus in 50 years and, while current treatments for the disease can be effective, they can lead to damaging side effects.

(5) The pain and fatigue associated with lupus can threaten one's ability to live independently, make it difficult to maintain employment, and lead normal lives. One in 5 people with lupus is disabled by the disease and consequently receives support from government programs, including Medicare, Medicaid, Social Security Disability, and Social Security Supplemental Income.

(6) The estimated average annual total of direct and indirect costs for an individual with lupus is $21,000; for people who have the most serious form of lupus, medical costs can greatly exceed this amount, causing a significant economic, emotional, and social burden to the entire family and society.

(b) The purpose of this Act is to create a multi-pronged, statewide program to promote public and health professional awareness among State and local health and human services officials, physicians, nurses, and other health care providers and increase knowledge concerning the causes and consequences of lupus, the importance of early diagnosis and appropriate management, and effective treatment and management strategies by taking the following actions:

(1) Conducting educational and training programs for health professionals on lupus diagnosis and management.

(2) Disseminating medically sound educational materials and information on lupus research findings to patients and health care professionals.

(3) Fostering greater public understanding and awareness of lupus statewide.

Section 10. Definitions. For the purpose of this Act:

"Department" means the Department of Public Health.

"Director" means the Director of Public Health.

"Panel" means the Interagency and Partnership Advisory Panel on Lupus.

"Program" means the Lupus Education and Awareness Program (LEAP).

Section 15. Establishment of the Lupus Education and Awareness Program.

(a) Subject to appropriation, there is created within the Department of Public Health the Lupus Education and Awareness Program (LEAP). The Program shall be composed of various components, including, but not limited to, public awareness activities and professional education programs. Subject to appropriation, the Interagency and Partnership Advisory Panel on Lupus is created to oversee LEAP and advise the Department in implementing LEAP.

(b) The Department shall establish, promote, and maintain the Lupus Education and Awareness Program with an emphasis on minority populations and at-risk communities in order to raise public awareness, educate consumers, and educate and train health professionals, human service providers, and other audiences.

The Department shall work with a national organization that deals with lupus to implement programs to raise public awareness about the symptoms and nature of lupus, personal risk factors, and options for diagnosing and treating the disease, with a particular focus on populations at elevated risk for lupus, including women and communities of color.

The Program shall include initiatives to educate and train physicians, health care professionals, and other service providers on the most up-to-date and accurate scientific and medical information regarding lupus diagnosis, treatment, risks and benefits of medications, research advances, and therapeutic decision making, including medical best practices for detecting and treating the disease in special populations. These activities shall include, but not be limited to, all of the following:

(1) Distribution of medically-sound health information produced by a national organization that deals with lupus and government agencies, including, but not limited to, the National Institutes of Health, the Centers for Disease Control and Prevention, and the Social Security

Administration, through local health departments, schools, agencies on aging, employer wellness programs, physicians and other health professionals, hospitals, health plans and health maintenance organizations, women's health programs, and nonprofit and community-based organizations.

(2) Development of educational materials for health professionals that identify the latest scientific and medical information and clinical applications.

(3) Working to increase knowledge among physicians, nurses, and health and human services professionals about the importance of lupus diagnosis, treatment, and rehabilitation.

(4) Support of continuing medical education programs presented by the leading State academic institutions by providing them with the most up-to-date information.

(5) Providing statewide workshops and seminars for in-depth professional development regarding the care and management of patients with lupus in order to bring the latest information on clinical advances to care providers.

(6) Development and maintenance of a directory of lupus-related services and lupus health care providers with specialization in services to diagnose and treat lupus. The Department shall disseminate this directory to all stakeholders, including, but not limited to, individuals with lupus, families, and representatives from voluntary organizations, health care professionals, health

plans, and State and local health agencies.

(c) The Director shall do all of the following:

(1) Designate a person in the Department to oversee the Program.

(2) Identify the appropriate entities to carry out the Program, including, but not limited to, the following: local health departments, schools, agencies on aging, employer wellness programs, physicians and other health professionals, hospitals, health plans and health maintenance organizations, women's health organizations, and nonprofit and community-based organizations.

(3) Base the Program on the most current scientific information and findings.

(4) Work with governmental entities, community and business leaders, community organizations, health care and human service providers, and national, State, and local organizations to coordinate efforts to maximize State resources in the areas of lupus education and awareness.

(5) Use public health institutions for dissemination of medically sound health materials.

(d) The Department shall establish and coordinate the Interagency and Partnership Advisory Panel on Lupus consisting of 15 members, one of whom shall be appointed by the Director as the chair. The Panel shall be composed of:

(1) at least 3 individuals with lupus;

(2) three representatives from relevant State agencies

including the Department;

(3) three scientists with experience in lupus who participate in various fields of scientific endeavor, including, but not limited to, biomedical research, social, translational, behavioral, and epidemiological research, and public health;

(4) two medical clinicians with experience in treating people with lupus; and

(5) four representatives from relevant nonprofit women's and health organizations, including one representative from a national organization that deals with the treatment of lupus.

Individuals and organizations may submit nominations to the Director to be named to the Panel. Such nominations may include the following:

(i) representatives from appropriate State departments and agencies, such as entities with responsibility for health disparities, public health programs, education, public welfare, and women's health programs;

(ii) health and medical professionals with expertise in lupus; and

(iii) individuals with lupus, and recognized experts in the provision of health services to women, lupus research, or health disparities.

All members of the panel shall serve terms of 2 years. A member may be appointed to serve not more than 2 terms, whether or not consecutive. A majority of the members of the panel shall constitute a quorum. A majority vote of a quorum shall be required for any official action of the Panel. The Panel shall meet at the call of the chair, but not less than 2 times per year. All members shall serve without compensation, but shall be entitled to actual, necessary expenses incurred in the performance of their business as members of the Panel in accordance with the reimbursement polices for the State.

Section 20. Funding. Subject to the availability of funds, the Department may make expenditures of up to $2,500 for fiscal year 2010 for use toward providing educational materials to clinics serving a high percentage of minorities in this State. The Director may accept grants, services, and property from the federal government, foundations, organizations, medical schools, and other entities as may be available for the purposes of fulfilling the obligations of this Program. Any such funds shall only supplement any appropriations made for the implementation of this Act. The Director shall seek any federal waiver or waivers that may be necessary to maximize funds from the federal government to implement the Program.

Section 25. Staffing. The Department of Public Health shall provide staffing and administrative support for the implementation of the provisions of this Act.