

1 AN ACT concerning public health.

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

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

6 Section 5. Legislative findings and purpose.

7 (a) The General Assembly finds the following:

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

15 (2) National data indicates that more than 1.5 million
16 Americans live with some form of lupus; lupus affects women
17 9 times more often than men, and 80% of newly diagnosed
18 cases of lupus develop among women of childbearing age. An
19 estimated 65,000 people with lupus reside in Illinois.

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

1 disparity that remains unexplained.

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

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

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

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

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

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

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

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

9 "Department" means the Department of Public Health.

10 "Director" means the Director of Public Health.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

1 plans, and State and local health agencies.

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

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

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

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

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

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

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

25 (1) at least 3 individuals with lupus;

26 (2) three representatives from relevant State agencies

1 including the Department;

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

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

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

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

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

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

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

25 All members of the panel shall serve terms of 2 years. A
26 member may be appointed to serve not more than 2 terms, whether

1 or not consecutive. A majority of the members of the panel
2 shall constitute a quorum. A majority vote of a quorum shall be
3 required for any official action of the Panel. The Panel shall
4 meet at the call of the chair, but not less than 2 times per
5 year. All members shall serve without compensation, but shall
6 be entitled to actual, necessary expenses incurred in the
7 performance of their business as members of the Panel in
8 accordance with the reimbursement policies for the State.

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

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