



## 96TH GENERAL ASSEMBLY

### State of Illinois

2009 and 2010

HB4587

by Rep. LaShawn K. Ford

#### SYNOPSIS AS INTRODUCED:

New Act

Creates the Lupus Education and Awareness Act. Establishes the Lupus Education and Awareness Program within the Department of Public Health. Provides that the Program shall raise public awareness, educate consumers, and educate and train health professionals, human service providers, and other audiences. Sets forth the responsibilities of the Director of the Department of Public Health concerning the Program. Provides that the Department shall establish and coordinate the Interagency and Partnership Advisory Panel on Lupus. Sets forth the membership guidelines and duties of the Panel. Provides that subject to the availability of funds, the Department may make expenditures of up to \$2,500 for the fiscal year 2010 for use toward providing educational materials to clinics.

LRB096 13256 RPM 27918 b

FISCAL NOTE ACT  
MAY APPLY

A BILL FOR

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) The Lupus Foundation of America, Inc. estimates  
16 that more than 1.5 million Americans live with some form of  
17 lupus; lupus affects women 9 times more often than men, and  
18 80% of newly diagnosed cases of lupus develop among women  
19 of childbearing age. An estimated 65,000 people with lupus  
20 reside in Illinois.

21 (3) Lupus disproportionately affects women of color;  
22 it is 2 to 3 times more common among African Americans,  
23 Hispanics and Latinos, Asians, and Native Americans and is

1 generally more prevalent in minority populations, a health  
2 disparity that remains unexplained.

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

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

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

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

1 by taking the following actions:

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

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

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

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

10 "Department" means the Department of Public Health.

11 "Director" means the Director of Public Health.

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

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

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

18 (a) There is created within the Department of Public Health  
19 the Lupus Education and Awareness Program (LEAP). The Program  
20 shall be composed of various components, including, but not  
21 limited to, public awareness activities and professional  
22 education programs. The Interagency and Partnership Advisory  
23 Panel on Lupus is created to oversee LEAP and advise the  
24 Department 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 the Lupus Foundation of  
8 America, Inc. to implement programs to raise public awareness  
9 about the symptoms and nature of lupus, personal risk factors,  
10 and options for diagnosing and treating the disease, with a  
11 particular focus on populations at elevated risk for lupus,  
12 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 the Lupus Foundation of America, Inc. and  
24 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 the Lupus Foundation of America, Inc.

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

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

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

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

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



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

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