



Ohio Legislative Service Commission

Bill Analysis

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H.B. 100

129th General Assembly
(As Introduced)

Reps. Williams, Szollosi, Antonio, Yuko, Reece, Letson, Milkovich, Winburn, Foley, Heard, Hagan, Murray, Weddington, Fedor, Mallory

BILL SUMMARY

- Requires the Commission on Minority Health to establish, maintain, and promote a Lupus Education and Awareness Program and to establish both an intergovernmental council and an advisory panel to oversee the program.
 - Authorizes the Commission to accept donations and grants from organizations, medical schools, and the federal government for fulfilling the obligations of the program.
 - Requires the Commission to establish a grant program to support nonprofit health organizations with expertise in lupus.
 - Requires the Commission to establish a grant program to educate and train health care professionals and service providers and requires that the grants be awarded to applicants who are affiliated with the Lupus Foundation of America.
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CONTENT AND OPERATION

Lupus Education and Awareness Program

The bill requires the Commission on Minority Health to establish, promote, and maintain a Lupus Education and Awareness Program that focuses on minority populations and communities at risk for contracting lupus. Lupus is an autoimmune disease that causes a person's immune system to attack otherwise healthy tissues and organs, resulting in chronic inflammation and tissue damage. Some of the most common symptoms are extreme fatigue, painful or swollen joints, unexplained fever, skin rashes, and kidney problems. The cause of lupus is unknown, although scientists believe that it is caused by a combination of genetic and environmental factors. Lupus

tends to affect certain groups of individuals more than others. More women than men have lupus, and lupus is two to three times more common in African American women than in Caucasian women. Lupus is also more common in women of Hispanic, Asian, and Native American descent.¹

In creating and implementing the program, the Commission is required to do all of the following:

- (1) Provide sufficient staff and appropriate training to carry out the program;
- (2) Create a grant program to support nonprofit health organizations with expertise in lupus to increase public awareness and improve health professional education and understanding of the disease;
- (3) Establish an intergovernmental council and advisory panel to oversee the program's implementation;
- (4) Identify appropriate entities to carry out the program;
- (5) Base the program on the most up-to-date scientific information and findings;
- (6) Coordinate efforts with government entities, community leaders and organizations, health and human services providers, and national, state, and local lupus organizations, such as the Lupus Foundation of America, to maximize state resources in the areas of lupus awareness and education;
- (7) Identify and use other successful lupus education and awareness programs and obtain related materials and services from organizations with expertise and knowledge of lupus.²

Program funding

The bill creates the Lupus Education and Awareness Fund in the state treasury. The bill does not contain an appropriation.

Under the bill, the Commission is authorized to accept grants, donations, and gifts from foundations, organizations, medical schools, and other entities for fulfilling the program's requirements. The Commission may also accept grants from the federal government. The Commission must seek any federal waiver necessary to maximize

¹ National Institute of Arthritis and Musculoskeletal and Skin Diseases, *Lupus*, available at <http://www.niams.nih.gov/Health_Info/Lupus/default.asp>.

² R.C. 3701.781(A) and (B).

funds from the federal government. Money collected from any of these entities must be credited to the Lupus Education and Awareness Fund, which must be used to administer the program.³

Intergovernmental council

As part of establishing the Lupus Education and Awareness Program, the bill requires the Commission to create an intergovernmental council to oversee the program's implementation. In establishing the council, the Commission must seek to ensure coordination of lupus education and awareness efforts and efforts to address health conditions that disproportionately affect women and communities of color.

The council must include representatives from appropriate state agencies, including entities with responsibility for Medicaid, health disparities, public health programs, women's health programs, education, and public welfare. The Commission's chairperson is to serve as the chair of the council.

The bill requires the council to do all of the following:

(1) Provide oversight for the program and other lupus programs conducted by the Commission;

(2) Develop and issue grant applications and policies and procedures for programs aimed at health professionals and the public;

(3) Establish a mechanism for sharing lupus information among those involved in implementing lupus-related programs;

(4) Assist the Commission and other offices in developing and coordinating plans for lupus education and health promotion and ensure that lupus-related issues are integrated into other statewide plans.

The council must prepare an annual report describing state-sponsored lupus education initiatives and the council's recommendations for new lupus education initiatives. The report must be transmitted to the General Assembly and made available to the public.⁴

³ R.C. 3701.781(C) and (D) and 3701.786.

⁴ R.C. 3701.784.

Advisory panel

The bill requires the Commission to establish an advisory panel to advise the Commission and the intergovernmental council on the implementation of the Lupus Education and Awareness Program. The Commission must consult with the panel on a regular basis.

The panel members are to be appointed by the Commission. Each member must have familiarity with lupus and lupus-related issues. Individuals and organizations may submit nominations for appointment to the panel. The membership must include (1) at least three individuals with lupus (at least one of whom is a member of a minority group), (2) not more than two representatives from the Commission, (3) at least five individuals from lupus nonprofit health organizations, with preference given to individuals from the Lupus Foundation of America, and (4) at least five scientists or clinicians with experience in lupus who practice in a variety of scientific fields.

The Commission must select one of the panel members to serve as the panel's chairperson. The panel must meet at the call of the chairperson, but not fewer than four times per year. Panel members' terms are for a period of two years, and a panel member may serve no more than two terms. Members are to serve without compensation but may be reimbursed for actual and necessary expenses.⁵

Needs assessment and program administration

The bill requires the Commission to conduct a needs assessment to identify all of the following:

- (1) The level of lupus awareness in Ohio among health professionals and the public;
- (2) The existence, in Ohio and nationwide, of lupus education, awareness, and treatment programs and related technical assistance;
- (3) The educational and support service needs of health care providers in Ohio as the needs relate to lupus;
- (4) The needs of people with lupus, as well as their families and caregivers;
- (5) The services available to people with lupus.

⁵ R.C. 3701.785.

The bill requires the Commission to develop and maintain a directory of lupus-related services and health care providers that specialize in diagnosing and treating lupus. The Commission must distribute the directory to all stakeholders, including individuals with lupus, families, representatives from voluntary organizations, health professionals, health plans, and state and local health agencies.

The bill requires the Commission to undertake activities to raise public awareness about lupus symptoms, risk factors, diagnosis, and treatment options, with a focus on elevated-risk populations. The activities must include (1) implementing a statewide campaign to educate the general public about lupus through public service announcements, advertisements, posters, and other materials, (2) distributing health information and conducting risk assessments at public events, and (3) distributing information through local health departments, schools, area agencies on aging, employer wellness programs, health professionals, hospitals and health plans, community-based and other organizations, and regional offices of the Ohio Department of Health.⁶

Grant programs

The bill requires the Commission to establish two grant programs related to lupus awareness and education. One grant program is for educating health professionals and other service providers affiliated with the Lupus Foundation of America. The other grant program is for supporting nonprofit organizations in promoting public awareness and increasing education of health professionals. As discussed above, the bill does not contain an appropriation (see "**Program funding**").

Grant program for health professionals and service providers

Under one of the bill's grant programs, the Commission is to award grants to educate and train physicians, health professionals, and other service providers in the most current scientific and medical information on lupus. This includes education on lupus diagnosis, treatment, medical best practices for dealing with lupus in special populations, and the risks and benefits of medications.

The bill requires that grant awards be allocated in amounts proportionate to the populations of areas served by the Ohio chapters of the Lupus Foundation of America. Only applicants who are affiliated with the Foundation are eligible to receive grants.

The bill requires each grant recipient to do all of the following:

⁶ R.C. 3701.782.

(1) Develop health professional educational materials with the latest scientific and medical information;

(2) Work to increase knowledge among health and human services professionals about the importance of lupus diagnosis, treatment, and rehabilitation;

(3) Use available curricula for training community leaders and health and human services providers on lupus detection and treatment;

(4) Support continuing medical education programs in Ohio presented by leading state academic institutions;

(5) Provide seminars and workshops for the professional development of lupus care providers;

(6) Conduct statewide conferences on lupus. Each grant recipient is to prepare and submit an annual report to the Commission that describes the use of the grant money.⁷

Grant program for nonprofit organizations

Under the other grant program that must be established, the Commission is to support nonprofit health organizations with expertise in lupus. The purpose of the grant program is to aid these organizations in increasing public awareness and enhancing health professional education and understanding of the symptoms and consequences of lupus and the populations most at risk of contracting the disease.⁸

Legislative findings

Under the bill, the General Assembly's findings regarding lupus are specified as including the following:

- Lupus is a serious, complex, and debilitating autoimmune disease that can cause inflammation and tissue damage to virtually any organ system in the body, including the skin, joints, other connective tissue, blood and blood vessels, heart, lungs, kidneys, and brain.
- The Lupus Foundation of America estimates that approximately 1.5 to 2 million Americans live with lupus; lupus affects women nine times more

⁷ R.C. 3701.783.

⁸ R.C. 3701.781(B)(2).

often than men and 80% of newly diagnosed cases of lupus develop among women of childbearing age.

- Lupus disproportionately affects women of color; it is two to three times more common among African Americans, Hispanics, Asians, and Native Americans and is generally more prevalent in minority populations.
- According to the Centers for Disease Control and Prevention, the rate of lupus mortality has increased since the late 1970s and is higher among older African-American women.
- No new drugs have been approved by the U.S. Food and Drug Administration specifically for lupus in nearly 40 years and while current treatments for the disease can be effective, they can cause damaging side effects.
- The pain and fatigue associated with lupus can threaten the ability to live independently, maintain employment, and lead a normal life. One in five individuals 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.
- The estimated average annual cost of medical treatment for an individual with lupus is between \$10,000 and \$30,000; for individuals with 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.
- More than half of individuals with lupus suffer four or more years and visit three or more physicians before obtaining a diagnosis of lupus. Early diagnosis of and treatment for lupus can prevent or reduce serious organ damage, disability, and death.
- Despite the magnitude of lupus, health professional and public understanding of lupus remains low. Only one in five Americans can provide basic information about lupus, and awareness of lupus is lowest among adults 18 to 34 years of age--the age group most likely to develop lupus.
- Lupus is a significant national health issue that deserves a comprehensive and coordinated response by state and federal governments with

involvement of the health care provider, patient, and public health communities.⁹

Legislative intent

The bill specifies that its purpose is to create a multi-pronged, statewide program to promote public and health professional awareness and increase knowledge concerning the causes and consequences of lupus, the importance of early diagnosis and appropriate management, and effective treatment and management strategies. The following activities are identified to implement the bill's purpose:

- Conducting educational and training programs for health professionals on lupus diagnosis and management;
- Developing and disseminating educational materials and information to patients and health professionals on lupus research results and health care services available;
- Designing and implementing a statewide public education campaign aimed at heightening public awareness of lupus;
- Leveraging educational and training resources and services previously developed by organizations with appropriate expertise and knowledge of lupus.¹⁰

HISTORY

ACTION	DATE
Introduced	02-15-11

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⁹ Section 2.

¹⁰ Section 3.