As Introduced

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H. B. No. 100

Representative Williams

Cosponsors: Representatives Szollosi, Antonio, Yuko, Reece, Letson, Milkovich, Winburn, Foley, Heard, Hagan, Murray, Weddington, Fedor, Mallory

A BILL

To enact sections 3701.781, 3701.782, 3701.783, 3701.784, 3701.785, and 3701.786 of the Revised Code to create the Lupus Education and Awareness Program.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF OHIO:

Section 1. That sections 3701.781, 3701.782, 3701.783, 3701.784, 3701.785, and 3701.786 of the Revised Code be enacted to read as follows:

Sec. 3701.781. (A) The commission on minority health shall establish, promote, and maintain a lupus education and awareness program with an emphasis on minority populations and at-risk communities to raise public awareness, educate consumers, and educate and train health professionals, human services providers, and other audiences.

(B) The commission, in creating and implementing the program, shall do all of the following:

(1) Provide sufficient staff and appropriate training to

implement the program;

(2) Establish a grant program to support nonprofit voluntary health organizations with expertise in lupus to increase public awareness and enhance health professional education and understanding of the symptoms and consequences of lupus and the populations most at risk;

(3) Establish an intergovernmental council and advisory panel to oversee the implementation of the program;

(4) Identify the appropriate entities to carry out the program;

(5) Base the program on the most current scientific information and findings;

(6) Work with government entities, community and business leaders, community organizations, health and human services providers, and national, state, and local lupus organizations, such as the lupus foundation of America, inc., to coordinate efforts to maximize state resources in the areas of lupus education and awareness;

(7) Identify and use other successful lupus education and awareness programs and procure related materials and services from organizations with appropriate expertise and knowledge of lupus.

(C) The commission may accept gifts, grants, and donations from the federal government, foundations, organizations, medical schools, and other entities for fulfilling the obligations of the program.

(D) The commission shall seek any federal waiver that may be necessary to maximize funds from the federal government to implement the program.

Sec. 3701.782. (A)(1) The commission on minority health shall conduct a needs assessment to identify all of the following:

(a) The level of statewide health professional and public awareness about lupus;

(b) The existence of lupus education, awareness, and treatment programs and related technical assistance available in the state and nationwide;

(c) The lupus-related educational and support service needs of health care providers in the state, including physicians, nurses, health plans, and other health professionals and health care entities;

(d) The needs of people with lupus, their families, and caregivers, including health care providers, physicians, nurses, health plans, and other health professionals and health care entities;

(e) The services available to individuals with lupus, including the existence and availability of lupus treatment and specialty care, lupus support groups, and other related care and management services.

(2) Based on the needs assessment, the commission shall develop and maintain a directory of lupus-related services and health care providers with specialization in services to diagnose and treat lupus. The commission shall disseminate the directory to all stakeholders, including individuals with lupus, families, representatives from voluntary organizations, health professionals, health plans, and state and local health agencies.

(B) The commission shall undertake activities to raise public awareness about the symptoms 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. Such activities shall include but not be limited to the following:

(1) Implementing a statewide campaign to educate the general

public about lupus by utilizing print, radio, and television public service announcements, advertisements, posters, and other materials;

(2) Disseminating health information and conducting individual risk assessments at public events, such as health fairs and community forums sponsored by the Ohio department of health;

(3) Distributing information through local health departments; schools; area agencies on aging; employer wellness programs; physicians and other health professionals; hospitals and health plans; women's, health, nonprofit, and community-based organizations; and regional offices of the Ohio department of health.

Sec. 3701.783. (A) The commission on minority health shall establish a program to award grants to educate and train physicians, health professionals, and other service providers on the most current, accurate scientific and medical information on lupus diagnosis, treatment, and therapeutic decision-making, including medical best practices for detecting and treating the disease in special populations, risks and benefits of medications, and research advances. In awarding grants, the commission shall allocate the total amount available for the grants in amounts that are proportionate to the populations of the areas served by the Ohio chapters of the lupus foundation of America, inc.

To be eligible for a grant, an applicant must be affiliated with the foundation.

(B) Each grant recipient shall do all of the following:

(1) Develop health professional educational materials that identify the latest scientific and medical information and clinical applications;

(2) Work to increase knowledge among physicians, nurses, and

other health and human services professionals about the importance of lupus diagnosis, treatment, and rehabilitation;

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

(4) Support continuing medical education programs in all geographical areas of the state presented by the leading state academic institutions by providing the most current information;

(5) Provide workshops and seminars for in-depth professional development in the field of care and management of lupus patients to bring the latest information on clinical advances to health care providers;

(6) Conduct statewide conferences on lupus at appropriate intervals;

(7) Prepare an annual report that describes the recipient's use of the grant and submit a copy of the report to the commission.

Sec. 3701.784. (A) In establishing the intergovernmental council as required by division (B)(3) of section 3701.781 of the Revised Code, the commission on minority health shall seek to ensure coordination of lupus education and awareness efforts and efforts to address health conditions disproportionately affecting women and communities of color. The chairperson of the commission shall serve as the council's chairperson. The council shall include representatives from appropriate state departments and agencies, including entities with responsibility for health disparities, medicaid, public health programs, education, public welfare, and women's health programs.

(B) The council shall do all of the following:

(1) Provide oversight to the lupus education and awareness

program, as well as 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 information on lupus among all officials and employees involved in carrying out lupus-related programs;

(4) Assist the commission and other offices in developing and coordinating plans for education and health promotion on lupus and ensure that issues related to lupus are integrated into other statewide plans;

(5) Prepare an annual report that describes educational initiatives on lupus sponsored by the state and make recommendations for new educational initiatives on lupus. The report shall be transmitted to the general assembly and be made available to the public.

Sec. 3701.785. (A) In establishing the advisory panel as required by division (B)(3) of section 3701.781 of the Revised Code, the commission on minority health shall coordinate the panel to provide input and counsel regarding the lupus education and awareness program.

(B)(1) Individuals and organizations may submit to the commission nominations for appointments to the panel. Each panel member shall have familiarity with lupus and issues that surround lupus.

(2) The panel shall be comprised of the following members to be appointed by the commission:

(a) At least three individuals with lupus, at least one of whom is a member of a minority group;

(b) Not more than two representatives from the commission;

(c) At least five individuals from lupus nonprofit health organizations, with preference given to individuals from the lupus foundation of America, inc.;

(d) At least five scientists or clinicians with experience in lupus who participate in various fields of scientific endeavor, including the fields of biomedical research, social, translational, behavioral and epidemiological research, and public health.

(3) The commission shall select from among the panel members one member to serve as chairperson of the panel.

Members of the panel shall serve terms of two years each. Members may be named to serve a total of two terms and terms may be consecutive.

A majority of the members of the panel constitutes a quorum. A majority vote of a quorum is required for any official action of the panel.

The panel shall meet at the call of the panel chairperson, but not fewer than four times per year.

All members shall serve without compensation, but may be reimbursed for actual, necessary expenses incurred in the performance of their duties.

(4) The panel shall be responsible for advising the commission and the intergovernmental council with respect to the implementation of the lupus education and awareness program. The commission shall consult with the advisory panel on a regular basis.

Sec. 3701.786. There is hereby created in the state treasury the lupus education and awareness program fund. All moneys accepted under division (C) of section 3701.781 of the Revised

<u>Code shall be credited to the fund. The commission shall use the fund to administer the lupus education and awareness program under section 3701.781 of the Revised Code.</u>

Section 2. The General Assembly hereby finds the following:

(A) 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, kidney, and brain.

(B) The Lupus Foundation of America, Inc., estimates that approximately 1.5 to 2 million Americans live with lupus; lupus affects women nine times more often than men and 80 per cent of newly diagnosed cases of lupus develop among women of childbearing age.

(C) 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 1970's and is higher among older African-American women.

(D) 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.

(E) 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.

(F) The estimated average annual cost of medical treatment for an individual with lupus is between $10,000 and $30,000; for individuals 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.

(G) 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.

(H) Despite the magnitude of lupus and its impact on individuals and families, 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.

(I) 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.

Section 3. The purpose of this act 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 by all of the following:

(A) Conducting educational and training programs for health professionals on lupus diagnosis and management;

(B) Developing and disseminating educational materials and information to patients and health professionals on lupus research results and health care services available;

(C) Designing and implementing a statewide public education campaign aimed at heightening public awareness of lupus;

(D) Leveraging educational and training resources and services previously developed by organizations with appropriate expertise and knowledge of lupus.