

As Introduced

**128th General Assembly
Regular Session
2009-2010**

H. B. No. 105

Representative Williams, S.

**Cosponsors: Representatives Boyd, Mallory, Dyer, Amstutz, Brown, Yuko,
Skindell, DeBose, Letson, Chandler, Patten, Slesnick, Evans, Fende, Luckie,
Harwood, Murray, Miller**

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A B I L L

To enact sections 3701.781, 3701.782, 3701.783, 1
3701.784, 3701.785, and 3701.786 of the Revised 2
Code to create the Lupus Education and Awareness 3
Program and to make an appropriation. 4

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

Section 1. That sections 3701.781, 3701.782, 3701.783, 5
3701.784, 3701.785, and 3701.786 of the Revised Code be enacted to 6
read as follows: 7

Sec. 3701.781. (A) The commission on minority health shall 8
establish, promote, and maintain a lupus education and awareness 9
program with an emphasis on minority populations and at-risk 10
communities to raise public awareness, educate consumers, and 11
educate and train health professionals, human services providers, 12
and other audiences. 13

(B) The commission, in creating and implementing the program, 14
shall do all of the following: 15

(1) Provide sufficient staff and appropriate training to 16

implement the program; 17

(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; 18
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(3) Establish an intergovernmental council and advisory panel to oversee the implementation of the program; 23
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(4) Identify the appropriate entities to carry out the program; 25
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(5) Base the program on the most current scientific information and findings; 27
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(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; 29
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(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. 35
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(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. Any funds shall supplement and not supplant appropriations provided for the implementation of the program. 38
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(D) The commission shall seek any federal waiver that may be necessary to maximize funds from the federal government to implement the program. 43
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Sec. 3701.782. (A)(1) The commission on minority health shall 46

<u>conduct a needs assessment to identify all of the following:</u>	47
<u>(a) The level of statewide health professional and public awareness about lupus;</u>	48
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<u>(b) The existence of lupus education, awareness, and treatment programs and related technical assistance available in the state and nationwide;</u>	50
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<u>(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;</u>	53
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<u>(d) The needs of people with lupus, their families, and caregivers, including health care providers, physicians, nurses, health care plans, and other health professionals and health care entities;</u>	57
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<u>(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.</u>	61
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<u>(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.</u>	65
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<u>(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:</u>	72
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(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; 78
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(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; 82
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(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. 85
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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. 91
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To be eligible for a grant, an applicant must be affiliated with the foundation. 103
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(B) Each grant recipient shall do all of the following: 105

(1) Develop health professional educational materials that identify the latest scientific and medical information and 106
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<u>clinical applications;</u>	108
<u>(2) Work to increase knowledge among physicians, nurses, and health and human services professionals about the importance of lupus diagnosis, treatment, and rehabilitation;</u>	109 110 111
<u>(3) Use available curricula for training of health and human services providers and community leaders on lupus detection and treatment;</u>	112 113 114
<u>(4) Support continuing medical education programs in all geographical areas in the state presented by the leading state academic institutions by providing the most current information;</u>	115 116 117
<u>(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 care providers;</u>	118 119 120 121
<u>(6) Conduct statewide conferences on lupus at appropriate intervals;</u>	122 123
<u>(7) Prepare an annual report that describes the recipient's use of the grant and submit a copy of the report to the commission.</u>	124 125 126
Sec. 3701.784. <u>(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 people 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.</u>	127 128 129 130 131 132 133 134 135 136 137

<u>(B) The council shall do all of the following:</u>	138
<u>(1) Provide oversight to the lupus education and awareness program, as well as other lupus programs conducted by the commission;</u>	139 140 141
<u>(2) Develop and issue grant applications and policies and procedures for programs aimed at health professionals and the public;</u>	142 143 144
<u>(3) Establish a mechanism for sharing information on lupus among all officials and employees involved in carrying out lupus-related programs;</u>	145 146 147
<u>(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;</u>	148 149 150 151
<u>(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.</u>	152 153 154 155 156
Sec. 3701.785. <u>(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.</u>	157 158 159 160 161
<u>(B)(1) Individuals and organizations may submit nominations to the commission to be appointed. Each panel member shall have familiarity with lupus and issues that surround lupus.</u>	162 163 164
<u>(2) The panel shall be comprised of the following members to be appointed by the commission:</u>	165 166
<u>(a) At least three individuals with lupus, at least one of</u>	167

whom is a member of a minority group; 168

(b) Not more than two representatives from the commission; 169

(c) At least five individuals from lupus nonprofit health 170
organizations, with preference given to individuals from the lupus 171
foundation of America, inc.; 172

(d) At least five scientists or clinicians with experience in 173
lupus who participate in various fields of scientific endeavor, 174
including the fields of biomedical research, social, 175
translational, behavioral and epidemiological research, and public 176
health. 177

(3) The commission shall select from among the panel members 178
one member to serve as chairperson of the panel. 179

Members of the panel shall serve terms of two years each. 180
Members may be named to serve a total of two terms and terms may 181
be consecutive. 182

A majority of the members of the panel constitutes a quorum. 183
A majority vote of a quorum is required for any official action of 184
the panel. 185

The panel shall meet at the call of the panel chairperson, 186
but not less than four times per year. 187

All members shall serve without compensation, but may be 188
reimbursed for actual, necessary expenses incurred in the 189
performance of their duties. 190

(4) The panel shall be responsible for advising the 191
commission and the intergovernmental council with respect to the 192
implementation of the lupus education and awareness program. The 193
commission shall consult with the advisory panel on a regular 194
basis. 195

Sec. 3701.786. There is hereby created in the state treasury 196

the lupus education and awareness program fund. All moneys 197
accepted under division (C) of section 3701.781 of the Revised 198
Code shall be credited to the fund. The commission shall use the 199
fund to administer the lupus education and awareness program under 200
section 3701.781 of the Revised Code. 201

Section 2. All items in this act are hereby appropriated as 202
designated out of any moneys in the state treasury to the credit 203
of the General Revenue Fund. For all appropriations made in this 204
act, those in the first column are for fiscal year 2010 and those 205
in the second column are for fiscal year 2011. The appropriations 206
made in this act are in addition to any other appropriations made 207
for the FY 2010-2011 biennium. 208

Appropriations

MIH COMMISSION ON MINORITY HEALTH 210

General Revenue Fund 211

GRF 149502 Lupus Program	\$	500,000	\$	500,000	212
TOTAL GRF General Revenue Fund	\$	500,000	\$	500,000	213
TOTAL ALL BUDGET FUND GROUPS	\$	500,000	\$	500,000	214

LUPUS PROGRAM 215

Of the foregoing appropriation item 149502, Lupus Program, 216
\$500,000 in each fiscal year shall be used for the Lupus Education 217
and Awareness Program created in section 3701.781 of the Revised 218
Code, with up to \$50,000 in each fiscal year being used by the 219
Commission for administrative costs related to the program. 220

Section 3. Within the limits set forth in this act, the 221
Director of Budget and Management shall establish accounts 222
indicating the source and amount of money for each appropriation 223
made in this act and shall determine the form and manner in which 224
the appropriation accounts shall be maintained. Expenditures from 225
appropriations contained in this act shall be accounted for as 226

though made in the main operating appropriations act of the 128th 227
General Assembly. 228

The appropriations made in this act are subject to all 229
provisions of the main operating appropriations act of the 128th 230
General Assembly that are generally applicable to such 231
appropriations. 232

Section 4. The General Assembly hereby finds the following: 233

(A) Lupus is a serious, complex, debilitating autoimmune 234
disease that can cause inflammation and tissue damage to virtually 235
any organ system in the body, including the skin, joints, other 236
connective tissue, blood and blood vessels, heart, lungs, kidney, 237
and brain. 238

(B) The Lupus Foundation of America, Inc., estimates that 239
approximately 1.5 to 2 million Americans live with lupus; lupus 240
affects women nine times more often than men and 80 per cent of 241
newly diagnosed cases of lupus develop among women of childbearing 242
age. 243

(C) Lupus disproportionately affects women of color; it is 244
two to three times more common among African Americans, Hispanics, 245
Asians, and Native Americans and is generally more prevalent in 246
minority populations. According to the Centers for Disease Control 247
and Prevention, the rate of lupus mortality has increased since 248
the late 1970's and is higher among older African-American women. 249

(D) No new drugs have been approved by the U.S. Food and Drug 250
Administration specifically for lupus in nearly 40 years and while 251
current treatments for the disease can be effective, they can 252
cause damaging side effects. 253

(E) The pain and fatigue associated with lupus can threaten 254
the ability to live independently, maintain employment, and lead a 255
normal life. One in five individuals with lupus is disabled by the 256

disease, and consequently receives support from government 257
programs, including Medicare, Medicaid, Social Security 258
Disability, and Social Security Supplemental Income. 259

(F) The estimated average annual cost of medical treatment 260
for an individual with lupus is between \$10,000 and \$30,000; for 261
individuals who have the most serious form of lupus, medical costs 262
can greatly exceed this amount, causing a significant economic, 263
emotional, and social burden to the entire family and society. 264

(G) More than half of individuals with lupus suffer four or 265
more years and visit three or more physicians before obtaining a 266
diagnosis of lupus; early diagnosis of and treatment for lupus can 267
prevent or reduce serious organ damage, disability, and death. 268

(H) Despite the magnitude of lupus and its impact on 269
individuals and families, health professional and public 270
understanding of lupus remains low; only one in five Americans can 271
provide basic information about lupus, and awareness of lupus is 272
lowest among adults 18 to 34 years of age - the age group most 273
likely to develop lupus. 274

(I) Lupus is a significant national health issue that 275
deserves a comprehensive and coordinated response by state and 276
federal governments with involvement of the health care provider, 277
patient, and public health communities. 278

Section 5. The purpose of this act is to create a 279
multi-pronged, statewide program to promote public and health 280
professional awareness and increase knowledge concerning the 281
causes and consequences of lupus, the importance of early 282
diagnosis and appropriate management, and effective treatment and 283
management strategies by all of the following: 284

(A) Conducting educational and training programs for health 285
professionals on lupus diagnosis and management; 286

(B) Developing and disseminating educational materials and information to patients and health professionals on lupus research results and health care services available;	287 288 289
(C) Designing and implementing a statewide public education campaign aimed at heightening public awareness of lupus;	290 291
(D) Leveraging educational and training resources and services previously developed by organizations with appropriate expertise and knowledge of lupus.	292 293 294
Section 6. The sections of law and the items of law of which they are composed that are contained in this act are not subject to the referendum. Therefore, under Ohio Constitution, Article II, Section 1d and section 1.471 of the Revised Code, the sections of law, and the items of which they are composed, go into immediate effect when this act becomes law.	295 296 297 298 299 300