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Representative Williams

**Cosponsors: Representatives Szollosi, Antonio, Yuko, Reece, Letson,
Milkovich, Winburn, Foley, Heard, Hagan, R., Murray, Weddington, Fedor,
Mallory, Barnes, Carney, Garland, Ramos**

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A B I L L

To enact sections 3701.77, 3701.771, 3701.772, 1
3701.773, 3701.774, and 3701.775 of the Revised 2
Code to authorize the Department of Health to 3
create the Lupus Education and Awareness Program. 4

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

Section 1. That sections 3701.77, 3701.771, 3701.772, 5
3701.773, 3701.774, and 3701.775 of the Revised Code be enacted to 6
read as follows: 7

Sec. 3701.77. (A) The department of health may establish, 8
promote, and maintain a lupus education and awareness program with 9
an emphasis on at-risk communities to raise public awareness, 10
educate consumers, and educate and train health professionals, 11
human services providers, and other audiences. 12

(B) The department, in creating and implementing the program, 13
may do all of the following: 14

(1) Provide sufficient staff and appropriate training to 15
implement the program; 16

(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; 17
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(3) Establish an intergovernmental council and advisory panel to oversee the implementation of the program; 22
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(4) Identify the appropriate entities to carry out the program; 24
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(5) Base the program on the most current scientific information and findings; 26
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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; 28
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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. 34
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(C) The department may accept gifts, grants, and donations from the federal government, foundations, organizations, medical schools, and other entities for fulfilling the obligations of the program. 37
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(D) The department may seek any federal waiver that may be necessary to maximize funds from the federal government to implement the program. 41
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Sec. 3701.771. (A)(1) The department of health may conduct a needs assessment to identify all of the following: 44
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(a) The level of statewide health professional and public 46

awareness about lupus; 47

(b) The existence of lupus education, awareness, and 48
treatment programs and related technical assistance available in 49
the state and nationwide; 50

(c) The lupus-related educational and support service needs 51
of health care providers in the state, including physicians, 52
nurses, health plans, and other health professionals and health 53
care entities; 54

(d) The needs of people with lupus, their families, and 55
caregivers, including health care providers, physicians, nurses, 56
health plans, and other health professionals and health care 57
entities; 58

(e) The services available to individuals with lupus, 59
including the existence and availability of lupus treatment and 60
specialty care, lupus support groups, and other related care and 61
management services. 62

(2) Based on the needs assessment, the department may develop 63
and maintain a directory of lupus-related services and health care 64
providers with specialization in services to diagnose and treat 65
lupus. The department may disseminate the directory to all 66
stakeholders, including individuals with lupus, families, 67
representatives from voluntary organizations, health 68
professionals, health plans, and state and local health agencies. 69

(B) The department may undertake activities to raise public 70
awareness about the symptoms of lupus, personal risk factors, and 71
options for diagnosing and treating the disease with a particular 72
focus on populations at elevated risk for lupus. Such activities 73
may include, but are not limited to, the following: 74

(1) Implementing a statewide campaign to educate the general 75
public about lupus by utilizing print, radio, and television 76
public service announcements, advertisements, posters, and other 77

materials; 78

(2) Disseminating health information and conducting 79
individual risk assessments at public events, such as health fairs 80
and community forums sponsored by the department; 81

(3) Distributing information through local health 82
departments; schools; area agencies on aging; employer wellness 83
programs; physicians and other health professionals; hospitals and 84
health plans; health, nonprofit, and community-based 85
organizations; and regional offices of the department. 86

Sec. 3701.772. (A) The department of health may establish a 87
program to award grants to educate and train physicians, health 88
professionals, and other service providers on the most current, 89
accurate scientific and medical information on lupus diagnosis, 90
treatment, and therapeutic decision-making, including medical best 91
practices for detecting and treating the disease in special 92
populations, risks and benefits of medications, and research 93
advances. If a program to award grants is established, the 94
department shall allocate the total amount available for the 95
grants in amounts that are proportionate to the populations of the 96
areas served by the Ohio chapters of the lupus foundation of 97
America, inc. 98

To be eligible for a grant, an applicant must be affiliated 99
with the foundation. 100

(B) Each grant recipient shall do all of the following: 101

(1) Develop health professional educational materials that 102
identify the latest scientific and medical information and 103
clinical applications; 104

(2) Work to increase knowledge among physicians, nurses, and 105
other health and human services professionals about the importance 106
of lupus diagnosis, treatment, and rehabilitation; 107

(3) Use available curricula for training of health and human services providers and community leaders on lupus detection and treatment; 108
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(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; 111
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(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; 114
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(6) Conduct statewide conferences on lupus at appropriate intervals; 118
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(7) Prepare an annual report that describes the recipient's use of the grant and submit a copy of the report to the department. 120
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Sec. 3701.773. (A) If the department of health establishes the intergovernmental council as permitted by division (B)(3) of section 3701.77 of the Revised Code, the department shall seek to ensure coordination of lupus education and awareness efforts. The director of health 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, and public welfare. 123
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(B) The council shall do all of the following: 132

(1) Provide oversight to the lupus education and awareness program, as well as other lupus programs conducted by the department; 133
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(2) Develop and issue grant applications and policies and procedures for programs aimed at health professionals and the 136
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<u>public;</u>	138
<u>(3) Establish a mechanism for sharing information on lupus</u>	139
<u>among all officials and employees involved in carrying out</u>	140
<u>lupus-related programs;</u>	141
<u>(4) Assist the department and other offices in developing and</u>	142
<u>coordinating plans for education and health promotion on lupus and</u>	143
<u>ensure that issues related to lupus are integrated into other</u>	144
<u>statewide plans;</u>	145
<u>(5) Prepare an annual report that describes educational</u>	146
<u>initiatives on lupus sponsored by the state and make</u>	147
<u>recommendations for new educational initiatives on lupus. The</u>	148
<u>report shall be transmitted to the general assembly and be made</u>	149
<u>available to the public.</u>	150
<u>Sec. 3701.774. (A) If the department of health establishes</u>	151
<u>the advisory panel as permitted by division (B)(3) of section</u>	152
<u>3701.77 of the Revised Code, the department shall coordinate the</u>	153
<u>panel to provide input and counsel regarding the lupus education</u>	154
<u>and awareness program.</u>	155
<u>(B) If the panel is established, all of the following apply:</u>	156
<u>(1) Individuals and organizations may submit to the</u>	157
<u>department nominations for appointments to the panel. Each panel</u>	158
<u>member shall have familiarity with lupus and issues that surround</u>	159
<u>lupus.</u>	160
<u>(2) The panel shall be comprised of the following members to</u>	161
<u>be appointed by the director of health:</u>	162
<u>(a) At least three individuals with lupus;</u>	163
<u>(b) Not more than two representatives from the department;</u>	164
<u>(c) At least five individuals from lupus nonprofit health</u>	165
<u>organizations, with preference given to individuals from the lupus</u>	166

foundation of America, inc.; 167

(d) At least five scientists or clinicians with experience in 168
lupus who participate in various fields of scientific endeavor, 169
including the fields of biomedical research, social, 170
translational, behavioral and epidemiological research, and public 171
health. 172

(3) The department shall select from among the panel members 173
one member to serve as chairperson of the panel. 174

Members of the panel shall serve terms of two years each. 175
Members may be named to serve a total of two terms and terms may 176
be consecutive. 177

A majority of the members of the panel constitutes a quorum. 178
A majority vote of a quorum is required for any official action of 179
the panel. 180

The panel shall meet at the call of the panel chairperson, 181
but not fewer than four times per year. 182

All members shall serve without compensation, but may be 183
reimbursed for actual, necessary expenses incurred in the 184
performance of their duties. 185

(4) The panel shall be responsible for advising the 186
department and the intergovernmental council with respect to the 187
implementation of the lupus education and awareness program. The 188
department shall consult with the advisory panel on a regular 189
basis. 190

Sec. 3701.775. There is hereby created in the state treasury 191
the lupus education and awareness program fund. If the department 192
of health establishes the lupus education and awareness program, 193
as authorized under section 3701.77 of the Revised Code, all moneys 194
accepted under division (C) of that section shall be credited to 195
the fund. Money in the fund shall be used solely to administer the 196

lupus education and awareness program. 197

Section 2. The General Assembly hereby finds the following: 198

(A) Lupus is a serious, complex, and debilitating autoimmune 199
disease that can cause inflammation and tissue damage to virtually 200
any organ system in the body, including the skin, joints, other 201
connective tissue, blood and blood vessels, heart, lungs, kidneys, 202
and brain. 203

(B) The Lupus Foundation of America, Inc., estimates that 204
approximately 1.5 to 2 million Americans live with lupus. 205

(C) According to the Centers for Disease Control and 206
Prevention, the rate of lupus mortality has increased since the 207
late 1970s. 208

(D) The pain and fatigue associated with lupus can threaten 209
the ability to live independently, maintain employment, and lead a 210
normal life. One in five individuals with lupus is disabled by the 211
disease, and consequently receives support from government 212
programs, including Medicare, Medicaid, Social Security 213
Disability, and Social Security Supplemental Income. 214

(E) The estimated average annual cost of medical treatment 215
for an individual with lupus is between \$10,000 and \$30,000; for 216
individuals who have the most serious form of lupus, medical costs 217
can greatly exceed this amount, causing a significant economic, 218
emotional, and social burden to the entire family and society. 219

(F) More than half of individuals with lupus suffer four or 220
more years and visit three or more physicians before obtaining a 221
diagnosis of lupus; early diagnosis of and treatment for lupus can 222
prevent or reduce serious organ damage, disability, and death. 223

(G) Despite the magnitude of lupus and its impact on 224
individuals and families, health professional and public 225
understanding of lupus remains low; only one in five Americans can 226

provide basic information about lupus, and awareness of lupus is 227
lowest among adults 18 to 34 years of age - the age group most 228
likely to develop lupus. 229

(H) Lupus is a significant national health issue that 230
deserves a comprehensive and coordinated response by state and 231
federal governments with involvement of the health care provider, 232
patient, and public health communities. 233

Section 3. The purpose of this act is to create a 234
multi-pronged, statewide program to promote public and health 235
professional awareness and increase knowledge concerning the 236
causes and consequences of lupus, the importance of early 237
diagnosis and appropriate management, and effective treatment and 238
management strategies by all of the following: 239

(A) Conducting educational and training programs for health 240
professionals on lupus diagnosis and management; 241

(B) Developing and disseminating educational materials and 242
information to patients and health professionals on lupus research 243
results and health care services available; 244

(C) Designing and implementing a statewide public education 245
campaign aimed at heightening public awareness of lupus; 246

(D) Leveraging educational and training resources and 247
services previously developed by organizations with appropriate 248
expertise and knowledge of lupus. 249