

SENATE AMENDMENT NO. _____

Offered by _____ Of _____

Amend SS/SCS/HCS/House Bill No. 2372, Page 5, Section 96.196, Line 18,

2 by inserting after all of said line the following:

3 "103.190. 1. As used in this section, the terms "Lyme
 4 disease" and "posttreatment Lyme disease syndrome" shall
 5 have the same meaning as given to the terms under section
 6 192.026.

7 2. The Missouri consolidated health care plan shall,
 8 at a minimum, provide coverage for diagnostic testing,
 9 treatment, and management of Lyme disease and posttreatment
 10 Lyme disease syndrome for participants who receive a
 11 diagnosis from a licensed health care provider, acting
 12 within the scope of his or her practice, after making a
 13 thorough evaluation of the participant's symptoms,
 14 diagnostic test results, or response to treatment,
 15 including, but not limited to, necessary office visits and
 16 ongoing testing. An experimental drug shall be covered as a
 17 long-term antibiotic therapy if it is approved for an
 18 indication by the U.S. Food and Drug Administration. A
 19 drug, including, but not limited to, an experimental drug,
 20 shall be covered for an off-label use in the treatment of a
 21 tick-borne disease if the drug has been approved by the U.S.
 22 Food and Drug Administration."; and

23 Further amend said bill, page 28, section 192.021, line
 24 18, by inserting after all of said line the following:

25 "192.026. 1. Sections 103.190 and 192.026 to 192.029
26 shall be known and may be cited as the "Missouri Lyme
27 Disease Eradication Act".

28 2. As used in sections 103.190 and 192.026 to 192.029,
29 the following terms shall mean:

30 (1) "Department", the department of health and senior
31 services;

32 (2) "Lyme disease", a condition caused by an infection
33 of the bacterium *Borrelia burgdorferi*, *Borrelia mayonii*,
34 *Borrelia afzelii*, *Borrelia garinii*, *Borrelia valaisiana*,
35 *Borrelia lusitaniae*, *Bartonella*, *Babesia*, *Ehrlichia*, or
36 related species, transmitted to humans through the bite of
37 infected blacklegged ticks (*Ixodes scapularis*) or other
38 ticks, as diagnosed by the two-tier serologic testing
39 recommended by the federal Centers for Disease Control and
40 Prevention (CDC) or by a similar blood test ordered by a
41 treating health care provider or by clinical evaluation;

42 (3) "Medically necessary", health care services or
43 products that a treating health care provider exercising
44 prudent clinical judgment would provide to a patient for the
45 purpose of preventing, evaluating, diagnosing, or treating
46 an illness, injury, disease, or symptoms of such, and that
47 are:

48 (a) Clinically appropriate in terms of type,
49 frequency, extent, site, and duration for the specific
50 circumstances; and

51 (b) Not primarily for the mere convenience of the
52 patient, health care provider, or as determined by the
53 provider based on the patient's specific circumstances;

54 (4) "Posttreatment Lyme disease syndrome", a condition
55 characterized by persistent symptoms, including, but not
56 limited to, fatigue, pain, respiratory impairment,
57 neurological impairment, or other cognitive impairment

58 following standard antibiotic or other treatment for Lyme
59 disease.

60 3. Health care providers, laboratories, and local
61 health departments shall report to the department all
62 confirmed or suspected cases of Lyme disease within seven
63 days of diagnosis using standardized surveillance case
64 definitions developed by the CDC. Any patient who receives
65 a positive or suspected diagnosis of Lyme disease shall be
66 given the option to opt out of having their identifiable
67 information shared with the department, local public health
68 officials, or the CDC.

69 4. The department shall compile an annual report on
70 the incidence and prevalence of Lyme disease in Missouri,
71 including, but not limited to, demographic data, geographic
72 distribution, treatment outcomes, and barriers to care. The
73 department shall submit the report to the CDC and the
74 general assembly and make such report available to the
75 public on the department's website by no later than December
76 thirty-first of each year.

77 5. The department shall collaborate with the
78 University of Missouri or any public four-year institution
79 of higher education to integrate Lyme disease surveillance
80 data into existing tick-borne disease monitoring programs.

81 6. Any information collected or reported under this
82 section shall be done in a manner that protects individually
83 identifiable or potentially identifiable information and
84 that is consistent with state and federal privacy laws.

85 7. The department may promulgate any rules and
86 regulations necessary to implement the provisions of
87 sections 192.026 to 192.028. Any rule or portion of a rule,
88 as that term is defined in section 536.010, that is created
89 under the authority delegated in this section shall become
90 effective only if it complies with and is subject to all of

91 the provisions of chapter 536 and, if applicable, section
92 536.028. This section and chapter 536 are nonseverable and
93 if any of the powers vested with the general assembly
94 pursuant to chapter 536 to review, to delay the effective
95 date, or to disapprove and annul a rule are subsequently
96 held unconstitutional, then the grant of rulemaking
97 authority and any rule proposed or adopted after August 28,
98 2026, shall be invalid and void.

99 192.027. 1. There is hereby created in the state
100 treasury the "Lyme Research and Eradication Fund", which
101 shall consist of moneys appropriated to it by the general
102 assembly, as well as any grants, bequests, gifts, or
103 donations. The state treasurer shall be custodian of the
104 fund. In accordance with sections 30.170 and 30.180, the
105 state treasurer may approve disbursements. The fund shall
106 be a dedicated fund and money in the fund shall be used
107 solely by the department for the purposes of implementing
108 the provisions of this section. Notwithstanding the
109 provisions of section 33.080 to the contrary, any moneys
110 remaining in the fund at the end of the biennium shall not
111 revert to the credit of the general revenue fund. The state
112 treasurer shall invest moneys in the fund in the same manner
113 as other funds are invested. Any interest and moneys earned
114 on such investments shall be credited to the fund.

115 2. The department shall use the moneys in the fund to
116 distribute grants to public four-year institutions of higher
117 education, research institutions, and nonprofit
118 organizations for Lyme disease research, including, but not
119 limited to, the following:

120 (1) Development of improved diagnostics, therapies,
121 and treatments;

122 (2) Studies on novel therapies, such as those inspired
123 by natural host immunity; and

124 (3) Eradication strategies, including, but not limited
125 to, tick population control through acaricides, deer
126 management programs, and environmental interventions.

127 3. No less than twenty percent of the funds shall be
128 utilized to support eradication efforts in rural counties.

129 4. The department shall submit a report to the general
130 assembly no later than March first of each year detailing
131 fund expenditures, research outcomes, and progress toward
132 Lyme disease eradication in the state.

133 192.028. 1. There shall be established within the
134 department the "Lyme Disease Task Force" to advise the
135 department on disease prevention and surveillance, as well
136 as education relating to the disease for health care
137 providers and the public. The task force shall consist of
138 the following members:

139 (1) The director of the department, or his or her
140 designee, who shall serve as the chairman; and

141 (2) As appointed by the director of the department:

142 (a) Two physicians licensed to practice in this state
143 who are members of a statewide organization representing
144 physicians, one of whom represents a medical school faculty
145 and one of whom has experience treating Lyme disease or
146 posttreatment Lyme disease syndrome;

147 (b) Two advanced practice registered nurses licensed
148 to practice in this state who are selected from the
149 recommendations of one or more professional nursing
150 associations and who have experience treating Lyme disease
151 or posttreatment Lyme disease syndrome;

152 (c) One local public health administrator; and

153 (d) One veterinarian who is licensed to practice in
154 this state; and

155 (3) Two residents of this state appointed by the
156 governor, with the advice and consent of the senate, who
157 have or have had a diagnosis of Lyme disease.

158 2. The terms of office for each member aside from the
159 director, or his or her designee, shall be three years.
160 Members may continue to serve after the expiration of a term
161 until a new member is appointed. Each member appointed to
162 fill a vacancy occurring prior to the expiration of the term
163 for which his or her predecessor was appointed shall be
164 appointed for the remainder of such term. The task force
165 shall meet as frequently as the chairman deems necessary,
166 but not less than two times each year. Members of the task
167 force shall receive no compensation for their service, but
168 shall, subject to appropriation, be reimbursed for their
169 actual and necessary expenses incurred in the performance of
170 their duties.

171 3. The task force shall have the following duties and
172 responsibilities:

173 (1) Monitor the implementation of the "Missouri Lyme
174 Disease Eradication Act", established under sections 103.190
175 and 192.026 to 192.029, and provide feedback and input to
176 the department for necessary additions or modifications;

177 (2) Review relevant literature and guidelines
178 pertaining to accurate diagnoses of Lyme disease and
179 posttreatment Lyme disease syndrome with the purpose of
180 creating cohesive and consistent guidelines for the
181 diagnosis of Lyme disease and posttreatment Lyme disease
182 syndrome across all counties in this state and with the
183 intent of providing accurate and relevant data to the
184 Centers for Disease Control and Prevention;

185 (3) Provide recommendations on professional continuing
186 education materials and opportunities that emphasize Lyme
187 disease prevention, protection, and treatment; and

188 (4) Assist the department in establishing policies,
189 procedures, techniques, and criteria for the collection,
190 maintenance, exchange, and sharing of medical information
191 pertaining to Lyme disease and posttreatment Lyme disease
192 syndrome and identifying persons or entities with expertise
193 in Lyme disease to collaborate with the department in the
194 diagnosis, prevention, and treatment of Lyme disease and
195 posttreatment Lyme disease syndrome.

196 192.029. Notwithstanding any provision of law to the
197 contrary, a health care provider shall not be subject to any
198 discipline, suspension or revocation of a license, or denial
199 of a license renewal solely for, within such provider's
200 scope of practice, prescribing, administering, or dispensing
201 treatments or therapies for Lyme disease or posttreatment
202 Lyme disease syndrome, including, but not limited to,
203 extended antibiotic therapy or similar treatment deemed
204 medically necessary."; and

205 Further amend the title and enacting clause accordingly.