(Reprinted with amendments adopted on April 14, 2021) FIRST REPRINT S.B. 175

SENATE BILL NO. 175-SENATOR NEAL

MARCH 8, 2021

Referred to Committee on Health and Human Services

SUMMARY—Enacts provisions relating to lupus. (BDR 40-8)

FISCAL NOTE: Effect on Local Government: May have Fiscal Impact. Effect on the State: Yes.

EXPLANATION - Matter in bolded italics is new; matter between brackets formitted material is material to be omitted.

AN ACT relating to public health; requiring the Chief Medical Officer to establish and maintain a system for the reporting and analysis of certain information on lupus and its variants; authorizing administrative penalties for the failure to report certain information; requiring the Division of Public and Behavioral Health of the Department of Health and Human Services to report certain information on lupus and its variants; making an appropriation; and providing other matters properly relating thereto.

Legislative Counsel's Digest:

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Existing law requires the Chief Medical Officer appointed by the Director of the Department of Health and Human Services to establish and maintain systems for the reporting of information on: (1) sickle cell disease and its variants, and (2) cancer and other neoplasms. (NRS 439.4929, 457.230) Existing law requires the chief administrative officer of each health care facility in this State to make available to the Chief Medical Officer or his or her representative the records of the health care facility for each reportable incidence of sickle cell disease or a variant thereof or cancer or another neoplasm. (NRS 439.4933, 457.250) Section 5 of this bill requires the Chief Medical Officer to establish and maintain a similar system for the reporting of information on lupus and its variants. Sections 5 and 6 of this bill require hospitals, medical laboratories, certain other facilities and providers of health care to report certain information prescribed by the State Board of Health concerning each case of lupus and its variants diagnosed or treated at the facility or by the provider, as applicable. Section 7 of this bill requires the chief administrative officer of each health care facility in this State to make available to the Chief Medical Officer or his or her representative the records of the health care facility for each case of lupus and its variants for abstraction by the Division of Public and Behavioral Health of the Department of Health and Human Services. Section 7 also provides for the imposition of an administrative penalty against a





person that fails to make the records of the facility for each case of lupus and its variants available for abstraction. **Sections 8 and 9** of this bill provide for analysis, reporting and research of the reported and abstracted information concerning cases of lupus and its variants. **Section 10** of this bill requires the Division to apply for and accept gifts, grants and donations to carry out the provisions of **sections 2-12** of this bill. **Sections 6, 11 and 13** of this bill provide for the confidentiality of reported information concerning patients, physicians and facilities. **Section 12** of this bill provides immunity from liability for any person or organization who discloses information in good faith to the Division in accordance with the requirements of **sections 5-7**. **Section 14** of this bill makes an appropriation to the Department of Health and Human Services to pay for an employee to support the system for the reporting of information on lupus and its variants.

THE PEOPLE OF THE STATE OF NEVADA, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

- **Section 1.** Chapter 439 of NRS is hereby amended by adding thereto the provisions set forth as sections 2 to 12, inclusive, of this act.
 - Sec. 2. As used in sections 2 to 12, inclusive, of this act, unless context otherwise requires, the words and terms defined in sections 3 and 4 of this act have the meanings ascribed to them in those sections.
- Sec. 3. "Health care facility" has the meaning ascribed to it in NRS 162A.740.
- Sec. 4. "Lupus and its variants" means a chronic autoimmune disease that occurs when the immune system attacks tissues and organs which can cause inflammation and pain in any part of the body of the person with the disease.
- Sec. 5. 1. The Chief Medical Officer shall, pursuant to regulations adopted by the State Board of Health pursuant to section 6 of this act, establish and maintain a system for the reporting of information on lupus and its variants. The Chief Medical Officer shall coordinate with the National Lupus Patient Registry of the Centers for Disease Control and Prevention of the United States Department of Health and Human Services, when establishing and maintaining the system.
- 2. The system established pursuant to subsection 1 must include a record of the cases of lupus and its variants which occur in this State along with such information concerning the cases as may be appropriate to form the basis for:
- (a) Conducting comprehensive epidemiologic surveys of lupus and its variants in this State; and
- (b) Evaluating the appropriateness of measures for the treatment of lupus and its variants.





- 3. Hospitals, medical laboratories and other facilities that provide screening, diagnostic or therapeutic services to patients with respect to lupus and its variants shall report the information prescribed by the State Board of Health pursuant to section 6 of this act to the system established pursuant to subsection 1.
- 4. Any provider of health care who diagnoses or provides treatment for lupus and its variants, except for cases directly referred to the provider or cases that have been previously admitted to a hospital, medical laboratory or other facility described in subsection 3, shall report the information prescribed by the State Board of Health pursuant to section 6 of this act to the system established pursuant to subsection 1.
 - 5. As used in this section:

- (a) "Medical laboratory" has the meaning ascribed to it in NRS 652.060.
- (b) "Provider of health care" has the meaning ascribed to it in NRS 629.031.

Sec. 6. The State Board of Health shall by regulation:

- 1. Prescribe the form and manner in which information on cases of lupus and its variants must be reported;
- 2. Prescribe the information that must be included in each report, which must include, without limitation:
 - (a) The name, address, age and ethnicity of the patient;
- (b) The variant of lupus with which the person has been diagnosed;
- (c) The method of treatment, including, without limitation, any opioid prescribed for the patient and whether the patient has adequate access to that opioid;
 - (d) Any other diseases from which the patient suffers;
- (e) Information concerning the usage of and access to health care services by the patient; and
- (f) If a patient diagnosed with lupus and its variants dies, his or her age at death; and
- 3. Establish a protocol for allowing appropriate access to and preserving the confidentiality of the records of patients needed for research into lupus and its variants.
- Sec. 7. 1. The chief administrative officer of each health care facility in this State shall make available to the Chief Medical Officer or his or her representative the records of the health care facility for each case of lupus and its variants.
- 2. The Division shall abstract from the records of a health care facility or shall require a health care facility to abstract from the records of the health care facility such information as is required by the State Board of Health pursuant to section 6 of this act. The Division shall compile the information in a timely





manner and not later than 6 months after the Division abstracts the information or receives the abstracted information from the health care facility.

3. Any person who violates this section is subject to an administrative penalty established by regulation by the State Board

of Health.

- Sec. 8. 1. The Division shall publish reports based upon the information obtained pursuant to sections 5, 6 and 7 of this act and make other appropriate uses of the information to report and assess trends in the usage of and access to health care services by patients with lupus and its variants in a particular area or population, advance research and education concerning lupus and its variants and improve the treatment of lupus and its variants and associated disorders. The reports must include, without limitation:
- (a) Information concerning the locations in which patients diagnosed with lupus and its variants reside, the demographics of such patients and the utilization of health care services by such patients;

(b) The information described in paragraph (a), specific to patients diagnosed with lupus and its variants who are over 60

years of age; and

(c) The transition of patients diagnosed with lupus and its variants from pediatric to adult care upon reaching 18 years of age.

2. The Division shall provide any qualified researcher whom the Division determines is conducting valid scientific research with data from the information reported pursuant to sections 5, 6 and 7 of this act upon the researcher's:

(a) Compliance with appropriate conditions as established pursuant to regulations of the State Board of Health; and

(b) Payment to the Division of a fee established by the Division

by regulation to cover the cost of providing the data.

Sec. 9. 1. The Chief Medical Officer or a qualified person designated by the Administrator of the Division shall analyze the information obtained pursuant to sections 5, 6 and 7 of this act and the reports published pursuant to section 8 of this act to determine whether any trends exist in the usage of and access to health care services by patients with lupus and its variants in a particular area or population.

2. If the Chief Medical Officer or the person designated pursuant to subsection 1 determines that a trend exists in the usage of and access to health care services by patients with lupus and its variants in a particular area or population, the Chief Medical Officer or the person designated pursuant to subsection 1





shall work with appropriate governmental, educational and research entities to investigate the trend, advance research in the trend and facilitate the treatment of lupus and its variants and associated disorders.

Sec. 10. The Division shall apply for and accept any gifts, grants and donations available to:

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- Carry out the provisions of sections 2 to 12, inclusive, of this act, including, without limitation, the provisions of subsection 1 of section 5 of this act requiring coordination with the National Lupus Patient Registry of the Centers for Disease Control and Prevention of the United States Department of Health and Human Services:
- 2. Coordinate and administer any other state programs relating to research concerning lupus and its variants or assistance to patients diagnosed with lupus and its variants;
 - Pay for research concerning lupus and its variants;
 - Provide education concerning lupus and its variants; and
- 5. Provide support to persons diagnosed with lupus and its variants.
- Sec. 11. The Division shall not reveal the identity of any patient, physician or health care facility which is involved in the reporting required by section 7 of this act unless the patient, physician or health care facility gives prior written consent to such a disclosure.
- Sec. 12. A person or governmental entity that provides information to the Division in accordance with sections 5, 6 and 7 of this act must not be held liable in a civil or criminal action for confidential information unless the person organization has done so in bad faith or with malicious purpose.

Sec. 13. NRS 239.010 is hereby amended to read as follows:

- 1. Except as otherwise provided in this section and NRS 1.4683, 1.4687, 1A.110, 3.2203, 41.071, 49.095, 49.293, 62D.420, 62D.440, 62E.516, 62E.620, 62H.025, 62H.030, 62H.170, 62H.220, 62H.320, 75A.100, 75A.150, 76.160, 78.152, 80.113, 81.850, 82.183, 86.246, 86.54615, 87.515, 87.5413, 87A.200, 87A.580, 87A.640, 88.3355, 88.5927, 88.6067, 88A.345, 88A.7345, 89.045, 89.251, 90.730, 91.160, 116.757, 116A.270, 116B.880, 118B.026, 119.260, 119.265, 119.267, 119.280, 119A.280. 119A.653, 119A.677, 119B.370, 119B.382, 120A.690, 125.130, 125B.140, 126.141, 126.161, 126.163, 126.730, 127.007, 127.057, 127.130, 127.140, 127.2817, 128.090, 130.312, 130.712, 136.050, 159.044, 159A.044, 172.075, 172.245, 176.01249, 176.015. 176.0625, 176.09129, 176.156, 176A.630, 178.39801, 178.4715,
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209.3923, 209.3925, 209.419, 209.429, 209.521, 211A.140, 1 2 213.010, 213.040, 213.095, 213.131, 217.105, 217.110, 217.464, 217.475, 218A.350, 218E.625, 218F.150, 218G.130, 218G.240, 3 218G.350, 226.300, 228.270, 228.450, 228.495, 228.570, 231.069, 4 5 231.1473, 233.190, 237.300, 239.0105, 239.0113, 239B.030, 239B.040, 239B.050, 239C.140, 239C.210, 239C.230, 6 7 239C.250, 239C.270, 239C.420, 240.007, 241.020, 241.039, 242.105, 244.264, 244.335, 247.540, 247.550, 247.560, 8 250.087, 250.130, 250.140, 250.150, 268.095, 268.0978, 268.490, 9 268.910, 269.174, 271A.105, 281.195, 281.805, 281A.350, 10 281A.680, 281A.685, 281A.750, 281A.755, 281A.780, 284.4068, 11 286.110, 286.118, 287.0438, 289.025, 289.080, 289.387, 289.830, 12 13 293.4855, 293.5002, 293.503, 293.504, 293.558, 293.5757, 293.870, 293.906, 293.908, 293.910, 293B.135, 293D.510, 331.110, 332.061, 14 332.351, 333.333, 333.335, 338.070, 338.1379, 338.1593, 338.1725, 15 348.420, 349.597, 349.775, 353.205, 353A.049, 16 338.1727, 353A.100, 353C.240, 360.240, 360.247, 360.255, 17 353A.085, 360.755, 361.044, 361.2242, 361.610, 365.138, 366.160, 368A.180, 18 370.257, 370.327, 372A.080, 378.290, 378.300, 379.0075, 379.008, 19 20 379.1495, 385A.830, 385B.100, 387.626, 387.631, 388.1455, 388.259, 388.501, 388.503, 388.513, 388.750, 388A.247, 388A.249, 21 22 391.033, 391.035, 391.0365, 391.120, 391.925, 392.029, 392.147, 392.264, 392.271, 392.315, 392.317, 392.325, 392.327, 392.335, 23 392.850, 393.045, 394.167, 394.16975, 394.1698, 394.447, 394.460, 24 396.535, 25 394.465, 396.3295, 396.405, 396.525, 398A.115, 408.3885, 408.3886, 408.3888, 408.5484, 412.153, 26 27 414.280, 416.070, 422.2749, 422.305, 422A.342, 422A.350. 28 425.400, 427A.1236, 427A.872, 432.028, 432.205, 432B.175, 29 432B.280, 432B.290, 432B.407, 432B.430, 432B.560, 432B.5902, 432C.140, 432C.150, 433.534, 433A.360, 437.145, 437.207, 30 439.4941, 439.840, 439.914, 439B.420, 439B.754, 439B.760, 440.170, 441A.195, 441A.220, 441A.230, 442.330, 442.395, 31 32 442.735, 442.774, 445A.665, 445B.570, 445B.7773, 447.345, 33 449.209, 449.245, 449.4315, 449A.112, 450.140, 450B.188, 34 453.164, 453.720, 453A.610, 453A.700, 458.055, 458.280, 459.050, 35 36 459.3866, 459.555, 459.7056, 459.846, 463.120, 463.15993, 37 463.240, 463.3403, 463.3407, 463.790, 467.1005, 480.535, 480.545, 480.935, 480.940, 481.063, 481.091, 481.093, 482.170, 482.5536, 38 483.340, 483.363, 483.575, 483.659, 483.800, 484A.469, 484E.070, 39 485.316, 501.344, 503.452, 522.040, 534A.031, 561.285, 571.160, 40 584.655, 587.877, 598.0964, 598.098, 598A.110, 599B.090, 41 42 603.070, 603A.210, 604A.303, 604A.710, 612.265, 616B.012, 43 616B.015, 616B.315, 616B.350, 618.341, 618.425, 622.310, 623.131, 623A.137, 624.110, 624.265, 624.327, 625.425, 44 625A.185, 628.418, 628B.230, 628B.760, 629.047, 629.069, 45





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- 2. A governmental entity may not reject a book or record which is copyrighted solely because it is copyrighted.
- 3. A governmental entity that has legal custody or control of a public book or record shall not deny a request made pursuant to subsection 1 to inspect or copy or receive a copy of a public book or record on the basis that the requested public book or record contains information that is confidential if the governmental entity can redact, delete, conceal or separate, including, without limitation, electronically, the confidential information from the information



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included in the public book or record that is not otherwise confidential.

- 4. If requested, a governmental entity shall provide a copy of a public record in an electronic format by means of an electronic medium. Nothing in this subsection requires a governmental entity to provide a copy of a public record in an electronic format or by means of an electronic medium if:
 - (a) The public record:

- (1) Was not created or prepared in an electronic format; and
- (2) Is not available in an electronic format; or
- (b) Providing the public record in an electronic format or by means of an electronic medium would:
 - (1) Give access to proprietary software; or
- (2) Require the production of information that is confidential and that cannot be redacted, deleted, concealed or separated from information that is not otherwise confidential.
- 5. An officer, employee or agent of a governmental entity who has legal custody or control of a public record:
- (a) Shall not refuse to provide a copy of that public record in the medium that is requested because the officer, employee or agent has already prepared or would prefer to provide the copy in a different medium.
- (b) Except as otherwise provided in NRS 239.030, shall, upon request, prepare the copy of the public record and shall not require the person who has requested the copy to prepare the copy himself or herself.
- **Sec. 14.** 1. There is hereby appropriated from the State General Fund to the Department of Health and Human Services to pay for one full-time staff position to support the system for the reporting of information on lupus and its variants established pursuant to section 5 of this act the following sums:

For the Fiscal Year 2021-2022 \$87,593 For the Fiscal Year 2022-2023 \$112,485

2. Any balance of the sums appropriated by subsection 1 remaining at the end of the respective fiscal years must not be committed for expenditure after June 30 of the respective fiscal years by the entity to which the appropriation is made or any entity to which money from the appropriation is granted or otherwise transferred in any manner, and any portion of the appropriated money remaining must not be spent for any purpose after September 16, 2022, and September 15, 2023, respectively, by either the entity to which the money was appropriated or the entity to which the money was subsequently granted or transferred, and must be reverted to the State General Fund on or before September 16, 2022, and September 15, 2023, respectively.





- **Sec. 15.** 1. This section and section 14 of this act become effective upon passage and approval.
 - 2. Sections 1 to 13, inclusive, of this act become effective:
 - (a) Upon passage and approval for the purposes of adopting any regulations and performing any other preparatory administrative tasks that are necessary to carry out the provisions of this act; and
 - (b) On October 1, 2021, for all other purposes.





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