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SENATE BILL NO. 390–SENATORS SCHEIBLE, NEAL; DALY, D. HARRIS AND OHRENSCHALL

MARCH 27, 2023

Referred to Committee on Health and Human Services

SUMMARY—Enacts provisions relating to neurodegenerative diseases. (BDR 40-135)

FISCAL NOTE: Effect on Local Government: No. Effect on the State: Yes.

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

AN ACT relating to health care; authorizing the University of Nevada, Las Vegas, to establish and maintain a system for the reporting and analysis of certain information on neurodegenerative diseases; authorizing a patient to opt in to the reporting of such information; authorizing the University of Nevada, Las Vegas, to establish and maintain an Internet website for the system; making an appropriation; and providing other matters properly relating thereto.

Legislative Counsel's Digest:

1 Existing law requires the Chief Medical Officer appointed by the Director of 234567 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; (2) lupus and its variants; and (3) cancer and other neoplasms. (NRS 439.4929, 439.4976, 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 8 sickle cell disease or a variant thereof, lupus or a variant thereof, or cancer or ġ another neoplasm. (NRS 439.4933, 439.498, 457.250) Sections 3-8 of this bill 10 define certain terms for the purposes of sections 2-17 of this bill. Section 9 of this 11 bill authorizes the University of Nevada, Las Vegas, to establish and maintain a similar system for the reporting of information on Parkinson's disease, Parkinsonisms, Alzheimer's disease and other neurodegenerative diseases prescribed by the University of Nevada, Las Vegas. **Sections 9 and 10** of this bill 12 13 14 15 require hospitals, medical laboratories, certain other facilities and providers of 16 health care to report certain information prescribed by the University of Nevada, 17 Las Vegas, concerning cases of such neurodegenerative diseases diagnosed or 18 treated at the facility or by the provider, as applicable, if the system is established





19 and the patient opts in to such reporting. Section 11 of this bill prescribes a 20 21 22 23 24 25 26 27 28 29 30 procedure by which a patient may opt in to the reporting of information relating to him or her. Section 14.5 of this bill authorizes the University of Nevada, Las Vegas, to: (1) establish and maintain an Internet website for the system; and (2) post an annual report concerning the activities of the system on that Internet website. Section 15 of this bill authorizes the University of Nevada, Las Vegas, to apply for and accept gifts, grants and donations to carry out the provisions of sections 2-17 of this bill. Sections 10, 16 and 18 of this bill provide for the confidentiality of the reported information concerning patients, providers of health care and facilities. Section 17 of this bill provides immunity from liability for any person or organization who discloses information in good faith to the University of Nevada, Las Vegas, in accordance with the requirements of sections 9 and 10. 31 Section 18.5 of this bill appropriates money to the Department of Brain Health at 32 33 the University of Nevada, Las Vegas, to establish and maintain: (1) the system for the reporting of information on neurodegenerative diseases pursuant to section 9; 34 and (2) the Internet website for the system pursuant to section 14.5.

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

1 **Section 1.** Chapter 439 of NRS is hereby amended by adding 2 thereto the provisions set forth as sections 2 to 17, inclusive, of this 3 act.

4 Sec. 2. As used in sections 2 to 17, inclusive, of this act, 5 unless the context otherwise requires, the words and terms defined 6 in sections 3 to 8, inclusive, of this act have the meanings ascribed 7 to them in those sections.

8 Sec. 3. "Health care facility" has the meaning ascribed to it 9 in NRS 162A.740.

10 Sec. 4. "Medical laboratory" has the meaning ascribed to it 11 in NRS 652.060.

12 Sec. 5. "Neurodegenerative disease" means a chronic and 13 progressive neurological disease that affects the central nervous 14 system and causes neurons to stop working or die, including, 15 without limitation, Parkinson's disease, Parkinsonisms and 16 Alzheimer's disease.

17 Sec. 6. "Parkinsonisms" means conditions that cause a 18 combination of the movement abnormalities seen in Parkinson's 19 disease which overlap with and evolve from Parkinson's disease.

20 Sec. 7. "Parkinson's disease" means a chronic and 21 progressive neurological disorder resulting from a deficiency of 22 the neurotransmitter dopamine as a consequence of specific 23 degenerative changes in the basal ganglia of the brain.

24 Sec. 8. "Provider of health care" has the meaning ascribed 25 to it in NRS 629.031.





1 Sec. 9. 1. The University of Nevada, Las Vegas, may 2 establish and maintain a system for the reporting of information 3 on neurodegenerative diseases.

4 2. If a system for the reporting of information on neurodegenerative diseases is established pursuant to subsection 5 1. the system must include a record of the cases of 6 7 neurodegenerative diseases for which reporting is required 8 pursuant to section 10 of this act and for which patients opt in to such reporting pursuant to section 11 of this act which occur in 9 this State along with such information concerning those cases as 10 11 may be appropriate to form the basis for:

12 (a) Conducting comprehensive epidemiologic surveys of 13 neurodegenerative diseases in this State; and

14 (b) Evaluating the appropriateness of measures for the 15 prevention and control of neurodegenerative diseases.

16 3. If a system for the reporting of information on neurodegenerative diseases is established pursuant to subsection 17 18 1, hospitals, medical laboratories and other facilities that provide screening, diagnostic or therapeutic services to patients with 19 20 respect to neurodegenerative diseases shall report to the system the 21 information prescribed by the University of Nevada, Las Vegas, 22 pursuant to section 10 of this act for patients who opt in to such 23 reporting pursuant to section 11 of this act.

24 If a system for the reporting of information on 4. 25 neurodegenerative diseases is established pursuant to subsection 26 1, the provider of health care who diagnoses or is primarily 27 responsible for providing treatment for a neurodegenerative 28 disease, except for a case directly referred to the provider or a case 29 that has been previously admitted to a hospital, medical laboratory 30 or other facility described in subsection 3, shall report to the system the information prescribed by the University of Nevada, 31 32 Las Vegas, pursuant to section 10 of this act for patients who opt 33 in to such reporting pursuant to section 11 of this act.

34 Sec. 10. If a system for the reporting of information on 35 neurodegenerative diseases is established pursuant to section 9 of 36 this act, the University of Nevada, Las Vegas, shall:

37 1. Prescribe the neurodegenerative diseases for which
38 information must, to the extent authorized by section 11 of this
39 act, be reported, which may include, without limitation,
40 Parkinson's disease, Parkinsonisms and Alzheimer's disease;

41 **2.** Prescribe the form and manner in which information on 42 cases of neurodegenerative diseases must be reported;

43 3. Prescribe the information that must be included in each 44 report, including, without limitation:

45 (a) The name, address, age and ethnicity of the patient;





1 (b) The neurodegenerative disease which the person has been 2 diagnosed:

3 (c) The method of treatment, including, without limitation, any medication prescribed for the patient and whether the patient has 4 5 adequate access to that medication;

6

7 (e) Information concerning the usage of and access to health 8 care services by the patient; and

(d) Any other disease from which the patient suffers;

9 (f) If a patient is diagnosed with a neurodegenerative disease 10 and dies, his or her age at death; and

11 Establish protocol for allowing access to and preserving 4. 12 the confidentiality of the records of patients needed for research 13 into neurodegenerative diseases.

Sec. 11. 1. If a system for the reporting of information on 14 15 neurodegenerative diseases is established pursuant to section 9 of this act, the University of Nevada, Las Vegas, shall prescribe a 16 17 form which provides a patient with:

(a) Written notice concerning the collection of information 18 pursuant to sections 2 to 17, inclusive, of this act and the purposes 19 20 for which such information is collected; and

(b) The opportunity to opt in to the collection of such 21 22 information by executing the form.

2. If a system for the reporting of information on 23 24 neurodegenerative diseases is established pursuant to section 9 of this act, a hospital, medical laboratory or other facility that 25 provides screening, diagnostic or therapeutic services to patients 26 27 with respect to neurodegenerative diseases or a provider of health 28 care who diagnoses or provides treatment for neurodegenerative 29 diseases shall provide to each patient with a neurodegenerative 30 disease for which reporting is required pursuant to section 10 of 31 this act:

32 (a) Oral notice concerning the collection of information 33 pursuant to sections 2 to 17, inclusive, of this act and the purpose for which such information is collected; and 34 35

(b) A copy of the form prescribed pursuant to subsection 1.

The hospital, medical laboratory, other facility or provider 36 *3*. of health care, as applicable, shall provide the patient with 37 sufficient time to review any documents provided to him or her 38 and answer any questions of the patient concerning the provisions 39 40 of sections 2 to 17, inclusive, of this act.

If a patient does not execute the form provided to the 41 4. 42 patient pursuant to subsection 2, the hospital, medical laboratory, 43 other facility or provider of health care, as applicable, shall not 44 report any information concerning the patient pursuant to section 45 9 of this act.





Sec. 12. (Deleted by amendment.) 1

2 Sec. 13. (Deleted by amendment.)

Sec. 14. (Deleted by amendment.) 3

Sec. 14.5. If a system for the reporting of information on 4 5 neurodegenerative diseases is established pursuant to section 9 of 6 this act, the University of Nevada, Las Vegas, may establish and 7 maintain an Internet website for the system that may include, 8 without limitation:

9 An annual summary of the activities conducted pursuant to 1. sections 2 to 17, inclusive, of this act, which may include, without 10 11 *limitation:*

12 (a) The incidence and prevalence of Parkinson's disease, 13 Parkinsonisms and Alzheimer's disease reported to the system 14 during the immediately preceding year, in total and disaggregated 15 for each county of this State;

16 (b) The number of reports made to the system pursuant to 17 section 9 of this act for the immediately preceding year; and

18 (c) Demographic information concerning the patients to which the reports described in paragraph (b) pertain, including, without 19 20 limitation, information concerning the age, sex and race of such 21 patients. 22

Other information relating to the system. 2.

23 Sec. 15. If a system for the reporting of information on 24 neurodegenerative diseases is established pursuant to section 9 of this act, the University of Nevada, Las Vegas, may apply for and 25 26 accept any gifts, grants and donations available to:

27 1. Carry out the provisions of sections 2 to 17, inclusive, of 28 this act:

29 2. Coordinate with any other state programs relating to 30 research concerning neurodegenerative diseases or assistance to patients diagnosed with neurodegenerative diseases; 31

32 *Pay for research concerning neurodegenerative diseases; 3*.

33 4. *Provide education concerning neurodegenerative diseases;* 34 and

Provide 35 5. support to diagnosed with persons 36 neurodegenerative diseases.

37 Sec. 16. If the system for the reporting of information on neurodegenerative diseases is established pursuant to section 9 of 38 this act, the University of Nevada, Las Vegas, shall not reveal the 39 identity of any patient, provider of health care or health care 40 facility which is involved in the reporting required by section 9 of 41 42 this act, unless the patient, provider of health care or health care 43 facility gives prior written consent to such a disclosure.

44 Sec. 17. A person or governmental entity that provides 45 information to the University of Nevada, Las Vegas, in accordance





with sections 9 and 10 of this act must not be held liable in a civil
or criminal action for sharing confidential information unless the
person or organization has done so in bad faith or with malicious
purpose.
Sec. 18. NRS 239.010 is hereby amended to read as follows:
239.010 1. Except as otherwise provided in this section and

Except as otherwise provided in this section and 7 NRS 1.4683, 1.4687, 1A.110, 3.2203, 41.0397, 41.071, 49.095, 8 49.293, 62D.420, 62D.440, 62E.516, 62E.620, 62H.025, 62H.030, 9 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, 10 87.5413, 87A.200, 87A.580, 87A.640, 88.3355, 88.5927, 88.6067, 88A.345, 11 88A.7345, 89.045, 89.251, 90.730, 91.160, 116.757, 116A.270, 12 13 116B.880, 118B.026, 119.260, 119.265, 119.267, 119.280, 119A.280, 119A.653, 119A.677, 119B.370, 119B.382, 120A.640, 14 120A.690, 125.130, 125B.140, 126.141, 126.161, 126.163, 126.730, 15 16 127.007, 127.057, 127.130, 127.140, 127.2817, 128.090, 130.312, 17 130.712, 136.050, 159.044, 159A.044, 172.075, 172.245, 176.015, 176.0625, 176.09129, 176.156, 176A.630, 178.39801, 178.4715, 18 19 178.5691, 179.495, 179A.070, 179A.165, 179D.160, 200.3771, 20 200.3772. 200.5095, 200.604, 202.3662, 205.4651, 209.392, 21 209.419. 209.429. 209.521. 211A.140. 209.3923. 209.3925. 22 213.010, 213.040, 213.095, 213.131, 217.105, 217.110, 217.464, 23 217.475, 218A.350, 218E.625, 218F.150, 218G.130, 218G.240, 218G.350, 224.240, 226.300, 228.270, 228.450, 228.495, 228.570, 24 25 231.069, 231.1473, 232.1369, 233.190, 237.300, 239.0105, 239.0113, 239.014, 239B.026, 239B.030, 239B.040, 239B.050, 26 239C.140, 239C.210, 239C.230, 239C.250, 239C.270, 239C.420, 27 28 240.007, 241.020, 241.030, 241.039, 242.105, 244.264, 244.335, 247.540, 247.550, 247.560, 250.087, 250.130, 250.140, 250.150, 29 268.095, 268.0978, 268.490, 268.910, 269.174, 271A.105, 281.195, 30 281.805, 281A.350, 281A.680, 281A.685, 281A.750, 281A.755, 31 32 281A.780, 284.4068, 284.4086, 286.110, 286.118, 287.0438, 289.025, 289.080, 289.387, 289.830, 293.4855, 293.5002, 293.503, 33 293.504, 293.558, 293.5757, 293.870, 293.906, 293.908, 293.910, 34 293B.135, 293D.510, 331.110, 332.061, 332.351, 333.333, 333.335, 35 338.1593, 338.1725, 338.1727, 348.420, 36 338.1379. 338.070. 349.597, 349.775, 353.205, 353A.049, 353A.085, 37 353A.100, 353C.240, 360.240, 360.247, 360.255, 360.755, 361.044, 361.2242, 38 361.610, 365.138, 366.160, 368A.180, 370.257, 370.327, 372A.080, 39 40 378.290. 378.300. 379.0075, 379.008, 379.1495, 385A.830, 385B.100, 387.626, 387.631, 388.1455, 388.259, 388.501, 388.503, 41 42 388.513, 388.750, 388A.247, 388A.249, 391.033, 391.035. 391.0365, 391.120, 391.925, 392.029, 392.147, 392.264, 392.271, 43 392.315, 392.317, 392.325, 392.327, 392.335, 392.850, 393.045, 44 394.16975, 394.1698, 394.447, 394.460, 45 394.167. 394.465.



396.1415, 396.1425, 396.143, 396.159, 396.3295, 396.405, 396.525, 1 2 396.535. 396.9685. 398A.115. 408.3885. 408.3886. 408.3888. 408.5484, 3 412.153, 414.280, 416.070, 422.2749, 422.305. 422A.342, 422A.350, 425.400, 427A.1236, 427A.872, 432.028, 4 5 432.205, 432B.175, 432B.280, 432B.290, 432B.4018, 432B.407, 432B.430, 432B.560, 432B.5902, 432C.140, 432C.150, 433.534, 6 7 433A.360, 439.4941, 439.4988, 439.840, 439.914, 439A.116, 439A.124, 439B.420, 439B.754, 439B.760, 439B.845, 440.170, 8 441A.195, 441A.220, 441A.230, 442.330, 442.395, 9 442.735. 442.774, 445A.665, 445B.570, 445B.7773, 447.345, 449.209, 10 449.245, 449.4315, 449A.112, 450.140, 450B.188, 450B.805, 11 453.164, 453.720, 458.055, 458.280, 459.050, 459.3866, 459.555, 12 13 459.7056, 459.846, 463.120, 463.15993, 463.240, 463.3403, 463.3407, 463.790, 467.1005, 480.535, 480.545, 480.935, 480.940, 14 481.063, 481.091, 481.093, 482.170, 482.368, 482.5536, 483.340, 15 483.575, 483.659, 483.800, 484A.469, 16 483.363, 484B.830. 17 484B.833, 484E.070, 485.316, 501.344, 503.452, 522.040. 534A.031, 561.285, 571.160, 584.655, 587.877, 598.0964, 598.098, 18 598A.110, 598A.420, 599B.090, 603.070, 603A.210, 604A.303, 19 20 604A.710, 612.265, 616B.012, 616B.015, 616B.315, 616B.350, 618.341, 618.425, 622.238, 622.310, 623.131, 623A.137, 624.110, 21 22 624.327, 625.425, 625A.185, 628.418, 624.265. 628B.230, 23 628B.760. 629.047, 629.069, 630.133, 630.2671, 630.2672. 630.2673, 630.30665, 630.336, 630A.327, 630A.555, 631.332, 24 631.368, 632.121, 632.125, 632.3415, 632.3423, 632.405, 633.283, 25 26 633.301, 633.4715, 633.4716, 633.4717, 633.524, 634.055. 27 634.1303. 634.214, 634A.169, 634A.185, 635.111, 635.158. 28 636.262, 636.342, 637.085, 637.145, 637B.192, 637B.288, 638.087, 29 638.089, 639.183, 639.2485, 639.570, 640.075, 640.152, 640A.185, 30 640A.220, 640B.405, 640B.730, 640C.580, 640C.600, 640C.620, 640C.745, 640C.760, 640D.135, 640D.190, 640E.225, 640E.340, 31 641.090, 641.221, 641.2215, 641.325, 641A.191, 641A.217, 32 641A.262, 641B.170, 641B.281, 641B.282, 641C.455, 641C.760, 33 641D.260, 641D.320, 642.524, 643.189, 644A.870, 645.180, 34 645.625, 645A.050, 645A.082, 645B.060, 645B.092, 645C.220, 35 645C.225, 645D.130, 645D.135, 645G.510, 645H.320, 645H.330, 36 37 647.0945, 647.0947, 648.033, 648.197, 649.065, 649.067, 652.126, 652.228, 653.900, 654.110, 656.105, 657A.510, 661.115, 665.130, 38 665.133, 669.275, 669.285, 669A.310, 671.170, 673.450, 673.480, 39 675.380, 676A.340, 676A.370, 677.243, 678A.470, 678C.710, 40 678C.800, 679B.122, 679B.124, 679B.152, 679B.159, 679B.190, 41 42 679B.285, 679B.690, 680A.270, 681A.440, 681B.260, 681B.410, 43 681B.540, 683A.0873, 685A.077, 686A.289, 686B.170, 686C.306, 687A.060, 687A.115, 687B.404, 687C.010, 688C.230, 688C.480, 44 45 688C.490, 689A.696, 692A.117, 692C.190, 692C.3507, 692C.3536,





692C.3538, 692C.354, 692C.420, 693A.480, 693A.615, 696B.550, 1 2 696C.120, 703.196, 704B.325, 706.1725, 706A.230, 710.159, 3 711.600, and section 16 of this act, sections 35, 38 and 41 of 4 chapter 478, Statutes of Nevada 2011 and section 2 of chapter 391, 5 Statutes of Nevada 2013 and unless otherwise declared by law to be 6 confidential, all public books and public records of a governmental 7 entity must be open at all times during office hours to inspection by 8 any person, and may be fully copied or an abstract or memorandum 9 may be prepared from those public books and public records. Any such copies, abstracts or memoranda may be used to supply the 10 general public with copies, abstracts or memoranda of the records or 11 12 may be used in any other way to the advantage of the governmental 13 entity or of the general public. This section does not supersede or in 14 any manner affect the federal laws governing copyrights or enlarge, 15 diminish or affect in any other manner the rights of a person in any 16 written book or record which is copyrighted pursuant to federal law.

17 2. A governmental entity may not reject a book or record 18 which is copyrighted solely because it is copyrighted.

19 A governmental entity that has legal custody or control of a 3. 20 public book or record shall not deny a request made pursuant to 21 subsection 1 to inspect or copy or receive a copy of a public book or 22 record on the basis that the requested public book or record contains 23 information that is confidential if the governmental entity can 24 redact, delete, conceal or separate, including, without limitation, 25 electronically, the confidential information from the information 26 included in the public book or record that is not otherwise 27 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:

33 (a) The public record:

- 34 35
- (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 bymeans of an electronic medium would:

- 38
- (1) Give access to proprietary software; or

39 (2) Require the production of information that is confidential
40 and that cannot be redacted, deleted, concealed or separated from
41 information that is not otherwise confidential.

42 5. An officer, employee or agent of a governmental entity who 43 has legal custody or control of a public record:

(a) Shall not refuse to provide a copy of that public record in themedium 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.

7 Sec. 18.5. 1. There is hereby appropriated from the State
8 General Fund to the Department of Brain Health at the University of
9 Nevada, Las Vegas, the sum of \$150,000 for the purposes of:

10 (a) Establishing and maintaining a system for the reporting of 11 information on neurodegenerative diseases; and

12 (b) Performing the activities authorized by section 14.5 of this 13 act.

14 2. Any remaining balance of the appropriation made by 15 subsection 1 must not be committed for expenditure after June 30, 16 2025, by the entity to which the appropriation is made or any entity 17 to which money from the appropriation is granted or otherwise transferred in any manner, and any portion of the appropriated 18 money remaining must not be spent for any purpose after 19 20 September 19, 2025, by either the entity to which the money was 21 appropriated or the entity to which the money was subsequently 22 granted or transferred, and must be reverted to the State General 23 Fund on or before September 19, 2025.

24 Sec. 19. This act becomes effective on July 1, 2023.

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