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 formitted material is material to be omitted.

AN ACT relating to health care; authorizing the Department of Brain Health at 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; requiring the establishment and maintenance of an Internet website for the system; making an appropriation; and providing other matters properly relating thereto.

Legislative Counsel's Digest:

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; (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 sickle cell disease or a variant thereof, lupus or a variant thereof, or cancer or another neoplasm. (NRS 439.4933, 439.498, 457.250) Sections 2.5-8 of this bill define certain terms for the purposes of sections 2-17 of this bill. Section 9 of this bill authorizes the Department of Brain Health at the University of Nevada, Las Vegas, to establish and maintain a similar system for the reporting of information on Parkinson's disease, Parkinsonisms, multiple sclerosis, Alzheimer's disease and other neurodegenerative diseases. **Section 9** requires the Department of Brain Health to provide the Chief Medical Officer and the Department of Health and Human Services with access to the data and reports provided to the Department of Brain Health for inclusion in the system. Section 10 of this bill requires the Department of Brain Health, in consultation with the Chief Medical Officer, to



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prescribe: (1) the neurodegenerative diseases for which information may be reported; (2) the form and manner of making such a report; and (3) the protocol for allowing access to and preserving the confidentiality of the records of patients needed for research into neurodegenerative diseases. Section 11 of this bill prescribes a procedure by which a patient may opt in to the reporting of information relating to him or her. If the patient opts in to such reporting, section 11 authorizes a hospital, medical laboratory, other facility or provider of health care to report information concerning the patient to the system. Section 14.5 of this bill requires the Department of Brain Health to: (1) establish and maintain an Internet website for the system; or (2) enter into an agreement for the Chief Medical Officer to perform those duties. Section 14.5 authorizes the Department of Brain Health or the Chief Medical Officer to post an annual report concerning the activities of the system on that Internet website. Section 15 of this bill authorizes the Department of Brain Health to apply for and accept gifts, grants and donations to carry out the provisions of sections 2-17. 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 Department of Brain Health in accordance with the provisions of sections 10 and 11. Section **18.5** of this bill appropriates money to the Department of Brain Health to establish and maintain: (1) the system for the reporting of information on neurodegenerative diseases pursuant to section 9; 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:

- **Section 1.** Chapter 439 of NRS is hereby amended by adding thereto the provisions set forth as sections 2 to 17, inclusive, of this act.
- Sec. 2. As used in sections 2 to 17, inclusive, of this act, unless the context otherwise requires, the words and terms defined in sections 2.5 to 8, inclusive, of this act have the meanings ascribed to them in those sections.
 - Sec. 2.5. "Designated department" means:
- 1. The Department of Brain Health at the University of Nevada, Las Vegas, or its successor department; or
- 2. If that department ceases to exist, another department at the University of Nevada, Las Vegas, designated by the Board of Regents of the University of Nevada to perform the functions prescribed by sections 2 to 17, inclusive, of this act.
- 15 Sec. 3. "Health care facility" has the meaning ascribed to it 16 in NRS 162A.740.
 - **Sec. 4.** (Deleted by amendment.)
- 18 Sec. 5. "Neurodegenerative disease" means a chronic and 19 progressive neurological disease that affects the central nervous 20 system and causes neurons to stop working or die, including,



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without limitation, Parkinson's disease, Parkinsonisms, multiple sclerosis and Alzheimer's disease.

- Sec. 6. "Parkinsonisms" means conditions that cause a combination of the movement abnormalities seen in Parkinson's disease which overlap with and evolve from Parkinson's disease.
- Sec. 7. "Parkinson's disease" means a chronic and progressive neurological disorder resulting from a deficiency of the neurotransmitter dopamine as a consequence of specific degenerative changes in the basal ganglia of the brain.
- Sec. 8. "Provider of health care" has the meaning ascribed to it in NRS 629.031.
- Sec. 9. 1. The designated department may establish and maintain a system for the reporting of information on neurodegenerative diseases.
- 2. If a system for the reporting of information on neurodegenerative diseases is established pursuant to subsection 1, the designated department shall provide the Chief Medical Officer and Department with access to all individual and aggregate data included in the system and all reports provided to or compiled by the designated department for inclusion in the system.
- Sec. 10. If a system for the reporting of information on neurodegenerative diseases is established pursuant to section 9 of this act, the designated department shall, in consultation with the Chief Medical Officer:
- 1. Prescribe the neurodegenerative diseases for which information may be reported in accordance with section 11 of this act, which may include, without limitation, Parkinson's disease, Parkinsonisms, multiple sclerosis and Alzheimer's disease;
- 2. Prescribe the form and manner for reporting information on cases of neurodegenerative diseases and the information that may be included in each report; and
- 3. Establish protocol for allowing access to and preserving the confidentiality of the records of patients needed for research into neurodegenerative diseases.
- Sec. 11. 1. If a system for the reporting of information on neurodegenerative diseases is established pursuant to section 9 of this act, the designated department shall prescribe a form which provides a patient with:
- (a) Written notice concerning the collection of information pursuant to sections 2 to 17, inclusive, of this act and the purposes for which such information is collected; and
 - (b) The opportunity to opt in to the collection of such information by executing the form.





- 2. If a system for the reporting of information on neurodegenerative diseases is established pursuant to section 9 of this act, a hospital, medical laboratory or other facility that provides screening, diagnostic or therapeutic services to patients with respect to neurodegenerative diseases or a provider of health care who diagnoses or provides treatment for neurodegenerative diseases may provide to a patient with a neurodegenerative disease for which reporting is authorized pursuant to section 10 of this act:
- (a) Oral notice concerning the collection of information pursuant to sections 2 to 17, inclusive, of this act and the purpose for which such information is collected; and
 - (b) A copy of the form prescribed pursuant to subsection 1.
 - 3. If a patient:

- (a) Executes the form provided to the patient pursuant to subsection 2, the hospital, medical laboratory, other facility or provider of health care, as applicable, may report information concerning the patient to the system established pursuant to section 9 of this act.
- (b) Does not execute the form provided to the patient pursuant to subsection 2, the hospital, medical laboratory, other facility or provider of health care, as applicable, shall not report any information concerning the patient to the system established pursuant to section 9 of this act.
- 4. As used in this section, "medical laboratory" has the meaning ascribed to it in NRS 652.060.
 - Sec. 12. (Deleted by amendment.)
 - Sec. 13. (Deleted by amendment.)
 - **Sec. 14.** (Deleted by amendment.)
- Sec. 14.5. 1. If a system for the reporting of information on neurodegenerative diseases is established pursuant to section 9 of this act, the designated department shall, except as otherwise provided in subsection 2, establish and maintain an Internet website for the system that may include, without limitation:
- (a) An annual summary of the activities conducted pursuant to sections 2 to 17, inclusive, of this act, which may include, without limitation:
- (1) The incidence and prevalence of Parkinson's disease, Parkinsonisms, multiple sclerosis and Alzheimer's disease reported to the system during the immediately preceding year, in total and disaggregated for each county of this State;
- (2) The number of reports made to the system pursuant to section 11 of this act for the immediately preceding year; and
- (3) Demographic information concerning the patients to which the reports described in subparagraph (2) pertain,





including, without limitation, information concerning the age, sex and race of such patients.

(b) Other information relating to the system.

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- The designated department may enter into an agreement with the Chief Medical Officer and the Department for the Chief Medical Officer to establish and maintain the Internet website pursuant to subsection 1.
- Sec. 15. If a system for the reporting of information on neurodegenerative diseases is established pursuant to section 9 of this act, the designated department may apply for and accept any gifts, grants and donations available to:
- Carry out the provisions of sections 2 to 17, inclusive, of *1*. this act;
- Coordinate with any other state programs relating to research concerning neurodegenerative diseases or assistance to patients diagnosed with neurodegenerative diseases;
 - Pay for research concerning neurodegenerative diseases;
- Provide education concerning neurodegenerative diseases; 4. and
- **Provide** 5. to diagnosed with support persons neurodegenerative diseases.
- Sec. 16. If the system for the reporting of information on neurodegenerative diseases is established pursuant to section 9 of this act, the designated department, Chief Medical Officer and Department shall not reveal the identity of any patient, provider of health care or health care facility which is involved in the reporting of information to the system established pursuant to section 9 of this act, unless the patient, provider of health care or health care facility gives prior written consent to such a disclosure.
- Sec. 17. A person or governmental entity that provides information to the designated department in accordance with sections 10 and 11 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:
- 1. Except as otherwise provided in this section and NRS 1.4683, 1.4687, 1A.110, 3.2203, 41.0397, 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,
- 43 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, 44 45 116B.880. 118B.026, 119.260, 119.265, 119.267,





119A.280, 119A.653, 119A.677, 119B.370, 119B.382, 120A.640, 1 2 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, 3 130.712, 136.050, 159.044, 159A.044, 172.075, 172.245, 176.015, 4 5 176.0625, 176.09129, 176.156, 176A.630, 178.39801, 178.4715, 178.5691, 179.495, 179A.070, 179A.165, 179D.160, 200.3771, 6 7 200.5095, 200.604, 202.3662, 205.4651, 209.392, 200.3772, 8 209.3923. 209.3925, 209.419, 209.429, 209.521, 211A.140, 213.010, 213.040, 213.095, 213.131, 217.105, 217.110, 217.464, 9 217.475, 218A.350, 218E.625, 218F.150, 218G.130, 218G.240, 10 218G.350, 224.240, 226.300, 228.270, 228.450, 228.495, 228.570, 11 12 231.1473, 232.1369, 233.190, 237.300. 239.0105. 13 239.0113, 239.014, 239B.026, 239B.030, 239B.040, 239B.050, 239C.140, 239C.210, 239C.230, 239C.250, 239C.270, 239C.420, 14 240.007, 241.020, 241.030, 241.039, 242.105, 244.264, 244.335, 15 247.540, 247.550, 247.560, 250.087, 250.130, 250.140, 250.150, 16 268.095, 268.0978, 268.490, 268.910, 269.174, 271A.105, 281.195, 17 281.805, 281A.350, 281A.680, 281A.685, 281A.750, 281A.755, 18 281A.780, 284.4068, 284.4086, 286.110, 286.118, 287.0438, 19 289.025, 289.080, 289.387, 289.830, 293.4855, 293.5002, 293.503, 20 293.504, 293.558, 293.5757, 293.870, 293.906, 293.908, 293.910, 21 22 293B.135, 293D.510, 331.110, 332.061, 332.351, 333.333, 333.335, 23 338.1379, 338.1593, 338.1725, 338.1727, 348.420, 338.070. 349.775, 353.205, 353A.049, 353A.085, 353A.100, 24 349.597. 353C.240, 360.240, 360.247, 360.255, 360.755, 361.044, 361.2242, 25 361.610, 365.138, 366.160, 368A.180, 370.257, 370.327, 372A.080, 26 27 378.300, 379.0075, 379.008, 379.1495, 385A.830. 28 385B.100, 387.626, 387.631, 388.1455, 388.259, 388.501, 388.503, 29 388.513, 388.750, 388A.247, 388A.249, 391.033, 391.035, 391.0365, 391.120, 391.925, 392.029, 392.147, 392.264, 392.271, 30 392.315, 392.317, 392.325, 392.327, 392.335, 392.850, 393.045, 31 394.16975, 394.1698, 394.447, 394.460, 32 394.167, 394,465. 396.1415, 396.1425, 396.143, 396.159, 396.3295, 396.405, 396.525, 33 396.535, 396.9685, 398A.115, 408.3885, 408.3886, 408.3888, 34 35 408.5484, 412.153, 414.280, 416.070, 422.2749, 422.305, 422A.342, 422A.350, 425.400, 427A.1236, 427A.872, 432.028, 36 37 432.205, 432B.175, 432B.280, 432B.290, 432B.4018, 432B.407, 432B.430, 432B.560, 432B.5902, 432C.140, 432C.150, 433.534, 38 433A.360, 439.4941, 439.4988, 439.840, 439.914, 439A.116, 39 439A.124, 439B.420, 439B.754, 439B.760, 439B.845, 440.170, 40 441A.195, 441A.220, 441A.230, 442.330, 442.395, 442.735, 41 42 442.774, 445A.665, 445B.570, 445B.7773, 447.345, 449.209, 43 449.245, 449.4315, 449A.112, 450.140, 450B.188, 450B.805, 453.164, 453.720, 458.055, 458.280, 459.050, 459.3866, 459.555, 44 45 459.7056, 459.846, 463.120, 463.15993, 463.240, 463.3403,





463.3407, 463.790, 467.1005, 480.535, 480.545, 480.935, 480.940, 1 2 481.063, 481.091, 481.093, 482.170, 482.368, 482.5536, 483.340, 483.575, 483.659, 483.800, 3 483.363. 484A.469, 484B.830. 484E.070. 485.316, 501.344, 503.452. 4 484B.833, 522.040. 5 534A.031, 561.285, 571.160, 584.655, 587.877, 598.0964, 598.098, 598A.110, 598A.420, 599B.090, 603.070, 603A.210, 604A.303, 6 7 604A.710, 612.265, 616B.012, 616B.015, 616B.315, 616B.350, 8 618.341, 618.425, 622.238, 622.310, 623.131, 623A.137, 624.110, 624.327. 625.425. 9 624.265. 625A.185. 628.418. 628B.230. 628B.760, 629.047, 629.069, 630.133, 10 630.2671, 630.2672, 630.2673, 630.30665, 630.336, 630A.327, 630A.555, 631.332, 11 12 631.368, 632.121, 632.125, 632.3415, 632.3423, 632.405, 633.283, 13 633.301, 633.4715, 633.4716, 633.4717, 633.524, 634.055, 14 634.1303. 634.214. 634A.169. 634A.185. 635.111. 635.158. 15 636.262, 636.342, 637.085, 637.145, 637B.192, 637B.288, 638.087, 16 638.089, 639.183, 639.2485, 639.570, 640.075, 640.152, 640A.185, 17 640A.220, 640B.405, 640B.730, 640C.580, 640C.600, 640C.620, 640C.745, 640C.760, 640D.135, 640D.190, 640E.225, 640E.340, 18 641.090, 641.221, 641.2215, 641.325, 641A.191, 641A.217, 19 641A.262, 641B.170, 641B.281, 641B.282, 641C.455, 641C.760, 20 641D.260, 641D.320, 642.524, 643.189, 644A.870, 21 645.180. 22 645.625, 645A.050, 645A.082, 645B.060, 645B.092, 645C.220, 645C.225, 645D.130, 645D.135, 645G.510, 645H.320, 645H.330, 23 24 647.0945, 647.0947, 648.033, 648.197, 649.065, 649.067, 652.126, 25 652.228, 653.900, 654.110, 656.105, 657A.510, 661.115, 665.130, 26 665.133, 669.275, 669.285, 669A.310, 671.170, 673.450, 673.480, 27 675.380, 676A.340, 676A.370, 677.243, 678A.470, 678C.710, 28 678C.800, 679B.122, 679B.124, 679B.152, 679B.159, 679B.190, 29 679B.285, 679B.690, 680A.270, 681A.440, 681B.260, 681B.410, 681B.540, 683A.0873, 685A.077, 686A.289, 686B.170, 686C.306, 30 687A.060, 687A.115, 687B.404, 687C.010, 688C.230, 688C.480, 31 688C.490, 689A.696, 692A.117, 692C.190, 692C.3507, 692C.3536, 32 33 692C.3538, 692C.354, 692C.420, 693A.480, 693A.615, 696B.550, 696C.120, 703.196, 704B.325, 706.1725, 706A.230, 710.159, 34 711.600, and section 16 of this act, sections 35, 38 and 41 of 35 chapter 478, Statutes of Nevada 2011 and section 2 of chapter 391, 36 37 Statutes of Nevada 2013 and unless otherwise declared by law to be confidential, all public books and public records of a governmental 38 39 entity must be open at all times during office hours to inspection by 40 any person, and may be fully copied or an abstract or memorandum may be prepared from those public books and public records. Any 41 42 such copies, abstracts or memoranda may be used to supply the 43 general public with copies, abstracts or memoranda of the records or 44 may be used in any other way to the advantage of the governmental 45 entity or of the general public. This section does not supersede or in





any manner affect the federal laws governing copyrights or enlarge, diminish or affect in any other manner the rights of a person in any written book or record which is copyrighted pursuant to federal law.

- 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 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. 18.5.** 1. There is hereby appropriated from the State General Fund to the Department of Brain Health at the University of Nevada, Las Vegas, the sum of \$150,000 for the purposes of:
- (a) Establishing and maintaining a system for the reporting of information on neurodegenerative diseases; and
 - (b) Performing the activities required by section 14.5 of this act.





2. Any remaining balance of the appropriation made by subsection 1 must not be committed for expenditure after June 30, 2025, 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 19, 2025, 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 19, 2025.

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





