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; requiring the Chief Medical Officer to establish and maintain a system for the reporting and analysis of certain information on neurodegenerative diseases; authorizing administrative penalties for the failure to comply with the reporting requirements; requiring the Division of Public and Behavioral Health of the Department of Health and Human Services to report certain information on neurodegenerative diseases; authorizing a patient to opt out of the reporting of such information; 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 3-8 of this bill define certain terms for the purposes of sections 2-17 of this bill. Section 9 of this bill requires the Chief Medical Officer 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 regulation of the State Board of Health. Sections 9 and 10 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 cases of



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17 such neurodegenerative diseases diagnosed or treated at the facility or by the 18 provider, as applicable. Section 11 of this bill prescribes a procedure by which a 19 patient may opt out of the reporting of information relating to him or her, except for 20 his or her diagnosis. Section 12 of this bill requires the chief administrative officer 21 22 23 24 25 26 27 28 29 30 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 certain cases of neurodegenerative diseases for abstraction by the Division of Public and Behavioral Health of the Department. Section 12 also provides for the imposition of an administrative penalty against a person who fails to make such records available for abstraction. Sections 13 and 14 of this bill provide for analysis, reporting and research of the reported and abstracted information concerning cases of neurodegenerative diseases. Section 15 of this bill requires the Division 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 31 the reported information concerning patients, providers of health care and facilities. 32 33 Section 17 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 9, 10 and 12.

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 3 to 8, inclusive, of this act have the meanings ascribed to them in those sections.
- 8 Sec. 3. "Health care facility" has the meaning ascribed to it 9 in NRS 162A.740.
 - Sec. 4. "Medical laboratory" has the meaning ascribed to it in NRS 652.060.
 - Sec. 5. "Neurodegenerative disease" means a chronic and progressive neurological disease that affects the central nervous system and causes neurons to stop working or die, including, without limitation, Parkinson's disease, Parkinsonisms 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.



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Sec. 9. 1. The Chief Medical Officer shall, pursuant to the regulations adopted by the State Board of Health pursuant to section 10 of this act, establish and maintain a system for the reporting of information on neurodegenerative diseases.

2. The system must include a record of the cases of neurodegenerative diseases for which reporting is required by the regulations adopted pursuant to section 10 of this act, which occur in this State along with such information concerning those cases as may be appropriate to form the basis for:

(a) Conducting comprehensive epidemiologic surveys of

neurodegenerative diseases in this State; and

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

- 3. Except as otherwise provided in section 11 of this act, hospitals, medical laboratories and other facilities that provide screening, diagnostic or therapeutic services to patients with respect to neurodegenerative diseases shall report the information prescribed by the State Board of Health pursuant to section 10 of this act to the system established pursuant to subsection 1.
- 4. Except as otherwise provided in section 11 of this act, any provider of health care who diagnoses or provides treatment for neurodegenerative diseases, 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 10 of this act to the system established pursuant to subsection 1.

Sec. 10. The State Board of Health, in consultation with the University of Nevada, Las Vegas, School of Medicine, shall by regulation:

- 1. Prescribe the neurodegenerative diseases for which information must be reported, which must include, without limitation, Parkinson's disease, Parkinsonisms and Alzheimer's disease;
- 2. Prescribe the form and manner in which information on cases of neurodegenerative diseases must be reported;
- 3. Prescribe the information that must be included in each report, including, without limitation:

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

- (b) The neurodegenerative disease which the person has been diagnosed;
- (c) The method of treatment, including, without limitation, any medication prescribed for the patient and whether the patient has adequate access to that medication;
 - (d) Any other disease 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 is diagnosed with a neurodegenerative disease and dies, his or her age at death; and
- 4. Establish protocol for allowing access to and preserving the confidentiality of the records of patients needed for research into neurodegenerative diseases.
- Sec. 11. 1. The State Board of Health 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 out of the collection of such information by executing the form.
- 2. 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 shall provide to each patient with a neurodegenerative disease for which reporting is required by the regulations adopted 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. The hospital, medical laboratory, other facility or provider of health care, as applicable, shall provide the patient with sufficient time to review any documents provided to him or her and answer any questions of the patient concerning the provisions of sections 2 to 17, inclusive, of this act.
- 4. If a patient executes 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 pursuant to section 9 of this act or make such information available for abstraction pursuant to section 12 of this act. A facility or provider of health care who diagnoses a patient with a neurodegenerative disease for which such reporting is required shall report the diagnosis without reporting any other information concerning the patient.
- Sec. 12. 1. Except as otherwise provided in section 11 of this act, the chief administrative officer of each health 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 a neurodegenerative disease for which reporting is





required by the regulations adopted pursuant to section 10 of this act.

- 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 10 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. 13. 1. The Division shall publish reports based upon the information obtained pursuant to sections 9, 10 and 12 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 neurodegenerative diseases in a particular area or population, advance research and education concerning neurodegenerative diseases and improve the treatment of neurodegenerative diseases and associated disorders. The report must include, without limitation:
- (a) Information concerning the locations in which patients diagnosed with neurodegenerative diseases 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 a neurodegenerative disease who are over 60 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 9, 10 and 12 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. 14. 1. The Chief Medical Officer or a qualified person designated by the Administrator of the Division shall analyze the information obtained pursuant to sections 9, 10 and 12 of this act and reports published pursuant to section 13 of this act to determine whether any trends exist in the usage of and access to health care services by patients with neurodegenerative diseases in a particular area or population.





- 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 neurodegenerative diseases 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 neurodegenerative diseases and associated disorders.
- Sec. 15. The Division shall apply for and accept any gifts, grants and donations available to:
- Carry out the provisions of sections 2 to 17, inclusive, of this act;
- Coordinate and administer 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
- 5. **Provide** to diagnosed with support persons neurodegenerative diseases.
- Sec. 16. The Division shall not reveal the identity of any patient, provider of health care or health care facility which is involved in the reporting required by section 12 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 Division in accordance with sections 9, 10 and 12 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 NRS 1.4683, 1.4687, 1A.110, 3.2203, 41.0397, 41.071, 49.095, 34 49.293, 62D.420, 62D.440, 62E.516, 62E.620, 62H.025, 62H.030, 35 62H.170, 62H.220, 62H.320, 75A.100, 75A.150, 76.160, 78.152, 36
- 37 80.113, 81.850, 82.183, 86.246, 86.54615, 87.515,
- 87A.200, 87A.580, 87A.640, 88.3355, 88.5927, 88.6067, 88A.345, 38 88A.7345, 89.045, 89.251, 90.730, 91.160, 116.757, 116A.270, 39
- 40 116B.880, 118B.026, 119.260, 119.265, 119.267, 119.280,
- 119A.280, 119A.653, 119A.677, 119B.370, 119B.382, 120A.640, 41
- 42 120A.690, 125.130, 125B.140, 126.141, 126.161, 126.163, 126.730,
- 43 127.007, 127.057, 127.130, 127.140, 127.2817, 128.090, 130.312,
- 130.712, 136.050, 159.044, 159A.044, 172.075, 172.245, 176.015, 44
- 176.0625, 176.09129, 176.156, 176A.630, 178.39801, 178.4715, 45



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178.5691, 179.495, 179A.070, 179A.165, 179D.160, 200.3771, 1 2 200.5095, 200.604, 202.3662, 205.4651, 209.392, 200.3772. 209.3923, 209.3925, 209.419, 209.429, 209.521, 211A.140, 3 213.010, 213.040, 213.095, 213.131, 217.105, 217.110, 217.464, 4 5 217.475, 218A.350, 218E.625, 218F.150, 218G.130, 218G.240, 218G.350, 224.240, 226.300, 228.270, 228.450, 228.495, 228.570, 6 7 231.069, 231.1473, 232.1369, 233.190, 237.300, 239.0105, 239.0113, 239.014, 239B.026, 239B.030, 239B.040, 239B.050, 8 239C.140, 239C.210, 239C.230, 239C.250, 239C.270, 239C.420, 9 240.007, 241.020, 241.030, 241.039, 242.105, 244.264, 244.335, 10 247.540, 247.550, 247.560, 250.087, 250.130, 250.140, 250.150, 11 268.095, 268.0978, 268.490, 268.910, 269.174, 271A.105, 281.195, 12 13 281.805, 281A.350, 281A.680, 281A.685, 281A.750, 281A.755, 281A.780, 284.4068, 284.4086, 286.110, 286.118, 287.0438, 14 289.025, 289.080, 289.387, 289.830, 293.4855, 293.5002, 293.503, 15 293.504, 293.558, 293.5757, 293.870, 293.906, 293.908, 293.910, 16 293B.135, 293D.510, 331.110, 332.061, 332.351, 333.333, 333.335, 17 338.1379, 338.1593, 338.1725, 338.1727, 348.420, 18 338.070. 349.775, 353.205, 353A.049, 353A.085, 353A.100, 19 349.597, 20 353C.240, 360.240, 360.247, 360.255, 360.755, 361.044, 361.2242, 361.610, 365.138, 366.160, 368A.180, 370.257, 370.327, 372A.080, 21 22 378.300, 379.0075, 379.008, 379.1495, 385A.830, 378.290, 385B.100, 387.626, 387.631, 388.1455, 388.259, 388.501, 388.503, 23 388.750. 388A.247, 388A.249, 391.033, 391.035. 24 388.513. 391.0365, 391.120, 391.925, 392.029, 392.147, 392.264, 392.271, 25 392.315, 392.317, 392.325, 392.327, 392.335, 392.850, 393.045, 26 27 394.167, 394.16975, 394.1698, 394.447, 394.460, 394,465. 396.1415, 396.1425, 396.143, 396.159, 396.3295, 396.405, 396.525, 28 29 396.535, 396.9685, 398A.115, 408.3885, 408.3886, 408.3888, 30 408.5484. 412.153, 414.280. 416.070. 422.2749. 422.305. 422A.342, 422A.350, 425.400, 427A.1236, 427A.872, 432.028, 31 32 432.205, 432B.175, 432B.280, 432B.290, 432B.4018, 432B.407, 432B.430, 432B.560, 432B.5902, 432C.140, 432C.150, 433.534, 33 433A.360, 439.4941, 439.4988, 439.840, 439.914, 439A.116, 34 439A.124, 439B.420, 439B.754, 439B.760, 439B.845, 440.170, 35 441A.195, 441A.220, 441A.230, 442.330, 442.395, 442.735, 36 37 442.774, 445A.665, 445B.570, 445B.7773, 447.345, 449.209, 449.245, 449.4315, 449A.112, 450.140, 450B.188, 450B.805, 38 453.164, 453.720, 458.055, 458.280, 459.050, 459.3866, 459.555, 39 40 459.7056, 459.846, 463.120, 463.15993, 463.240, 463.3403, 463.3407, 463.790, 467.1005, 480.535, 480.545, 480.935, 480.940, 41 42 481.063, 481.091, 481.093, 482.170, 482.368, 482.5536, 483.340, 43 483.363, 483.575, 483.659, 483.800, 484A.469, 484B.830, 484B.833, 484E.070, 485.316, 501.344, 503.452, 522.040, 44 534A.031, 561.285, 571.160, 584.655, 587.877, 598.0964, 598.098, 45





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

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. 19.** 1. This section becomes effective upon passage and approval.
 - 2. Sections 1 to 18, inclusive, of this act become effective:
- (a) Upon passage and approval for the purpose 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 January 1, 2024, for all other purposes.





