SB3804

LRB10418503TRT31945b

104TH GENERAL ASSEMBLY

State of Illinois

2025 and 2026

SB3804

Introduced 2/6/2026, by Sen. Linda Holmes

SYNOPSIS AS INTRODUCED:

New Act
30 ILCS 105/5.1038 new

Creates the Neurodegenerative Disease Patient Protection and Progress Act. Requires the Department of Public Health to convene a Neurodegenerative Disease Advisory Council within the Department. Sets forth provisions concerning the membership of the Advisory Council, terms of the members, meetings of the Advisory Council, and administrative support, and duties of the Advisory Council Provides that the Director of Public Health shall designate or hire a full-time Neurodegenerative Disease Coordinator within the Department to implement and administer the Act. Requires the Coordinator, acting through and under the supervision of the Director, and with input from the Advisory Council, to develop and publish a State plan to address neurodegenerative diseases. Sets forth required components of the Plan. Establishes a voluntary statewide clinical and population registry to collect de-identified information and, with the patient's informed consent, limited identifying information, to (i) improve understanding of burden imposed by neurodegenerative diseases, natural history, and outcomes, (ii) facilitate public health planning and service delivery, and (iii) support research consistent with applicable privacy protections. Establishes the Neurodegenerative Disease Research Support And Grant Fund to make grants to public or private not-for-profit entities for the purpose of conducting neurodegenerative disease research. Sets forth provisions concerning equity and rural access; coordination with federal programs, academic centers, and private partners; reporting; limitations; and rulemaking. Amends the State Finance Act to make a conforming change. Effective immediately.

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A BILL FOR

AN ACT concerning health.

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

Section 1. Short title. This Act may be cited as the Neurodegenerative Disease Patient Protection and Progress Act.

Section 5. Findings; legislative intent.

(a) The General Assembly finds that:

(1) Neurodegenerative diseases, including Parkinson's disease, atypical parkinsonism, amyotrophic lateral sclerosis, Huntington's disease, multiple sclerosis, and related neurodegenerative conditions impose substantial human, social, and economic burdens on individuals, families, and communities. Through coordinated State action, the State can improve surveillance, research, care, and support services, and a State plan and advisory structure will facilitate better outcomes.

(2) Certain environmental and occupational exposures, including pesticides, solvents, and other toxic substances, have been associated in scientific studies with an increased risk of developing Parkinson's disease or atypical parkinsonism, amyotrophic lateral sclerosis, Huntington's disease, multiple sclerosis, and related neurodegenerative conditions. Prevention-oriented

education and risk-reduction strategies are important components of public health planning and coordination among State agencies is necessary to evaluate emerging evidence, reduce avoidable exposures, and protect the health of Illinois residents.

(b) It is the intent of the General Assembly to establish a coordinated framework to guide statewide planning, promote equitable access to specialty care and supportive services, strengthen data collection and research capacity, and provide regular public reporting on progress and outcomes, while ensuring that patient privacy is protected and that recommendations regarding environmental risk factors are developed through scientific review and interagency collaboration consistent with existing State authority.

Section 10. Definitions. As used in this Act:

"Advisory Council" means the Neurodegenerative Disease Advisory Council created under this Act.

"Annual Report" means the single consolidated report required under this Act regarding the implementation of this Act.

"Care coordination" means services that assist persons living with neurodegenerative diseases in navigating health care, social services, long-term services and supports, and related community resources.

"Caregiver" means an individual 18 years of age or older

who, because of the age, disability, chronic illness, or functional limitation of another individual, regularly provides the care recipient with assistance or supervision necessary to support the care recipient's health, safety, or daily functioning, including assistance with activities of daily living or instrumental activities of daily living, and who is identified by the care recipient or the care recipient's legal representative as a caregiver. "Caregiver" does not include an individual who provides services to the care recipient for compensation as an employee or contractor in the ordinary course of a business or profession, including a health care professional or direct care worker, unless the individual is also a family member providing care outside the compensated relationship.

"De-identified information" means health information that does not identify an individual and with respect to which there is no reasonable basis to believe the information can be used to identify an individual, consistent with applicable federal law and guidance.

"Department" means the Department of Public Health.

"Director" means the Director of Public Health.

"Family member" means, with respect to a patient diagnosed with a neurodegenerative disease, the patient's spouse, civil union partner, or domestic partner; child (including a biological, adopted, step, or foster child, a legal ward, or a child for whom the patient or the individual stands in loco

parentis); parent (including a biological, adoptive, step, or foster parent, a legal guardian, or an individual who stood in loco parentis to the patient or the individual when the patient or the individual was a minor); sibling (including a biological, adopted, step, or half-sibling); grandparent or grandchild; in-law (including a mother-in-law, father-in-law, son-in-law, daughter-in-law, brother-in-law, or sister-in-law); or any other individual related to the patient by blood or affinity whose close association with the patient is the equivalent of a family relationship.

"Fund" means the Neurodegenerative Disease Research and Program Fund under this Act.

"Neurodegenerative disease" means Parkinson's disease or atypical parkinsonism, amyotrophic lateral sclerosis, Huntington's disease, multiple sclerosis, and any related neurodegenerative condition included by the Department by rule.

"Neurodegenerative Disease Coordinator" or "Coordinator" means the Department employee designated or hired by the Director to administer and coordinate the implementation of this Act.

"Plan" means the State plan to address neurodegenerative diseases under this Act.

"Registry" means the voluntary statewide clinical and population registry created under this Act.

"Stakeholders" means persons and entities with an interest

in neurodegenerative disease policy, including persons living with these conditions, caregivers, clinicians, researchers, advocacy organizations, payers, and health systems.

"Qualified researcher" means an individual affiliated with an Illinois-based academic institution, hospital, health system, nonprofit research organization, or other entity approved by the Department who seeks access to registry data for a specific research purpose and who agrees to applicable data use, privacy, and security requirements.

Section 15. Neurodegenerative Disease Advisory Council.

(a) The Department shall convene a Neurodegenerative Disease Advisory Council within the Department.

(b) The Advisory Council shall include the following members:

(1) one or more members of the Senate appointed by the President of the Senate;

(2) one or more members of the Senate appointed by the Minority Leader of the Senate;

(3) one or more members of the House of Representatives appointed by the Speaker of the House of Representatives;

(4) one or more members of the House of Representatives appointed by the Minority Leader of the House of Representatives;

(5) one member appointed by the Governor representing

the Governor's Office; and

(6) members appointed by the Governor as follows:

(A) at least 2 licensed neurologists with expertise in the listed conditions;

(B) a palliative care clinician and a rehabilitation clinician;

(C) representatives of patient advocacy organizations for Parkinson's disease or atypical parkinsonism, amyotrophic lateral sclerosis, Huntington's disease, and multiple sclerosis;

(D) at least 2 persons living with a neurodegenerative disease or the caregiver or family member of someone with a neurodegenerative disease;

(E) a representative from academic or clinical research institutions;

(F) a representative from a State Medicaid or health payer program;

(G) a representative from the Department of Financial and Professional Regulation with knowledge of health care licensing; and

(H) other members designated by the Director to ensure geographic diversity, racial and ethnic diversity, and socioeconomic diversity.

(c) The Council shall operate as follows:

(1) Each member of the Council shall be appointed for a 2-year term and until the member's successor is

appointed. The Governor may stagger the members' terms to ensure continuity in the performance of the Council's responsibilities.

(2) The Advisory Council shall meet initially no later than 90 days after all of the members of the Advisory Council listed in subsection (b) of this Section are appointed, and at least quarterly thereafter, at the times and places in the State that the Advisory Council designates.

(3) The Department shall provide administrative and other support to the Advisory Council. The Department may designate a third party to provide administrative support in a paid or volunteer capacity. The Department may delay the implementation of this subsection if the Department is unable to find a third party to provide administrative support to the Advisory Council.

(4) Members of the Advisory Council shall receive no compensation for their participation but, subject to appropriation, may be reimbursed by the Department of Human Services for expenses in connection with their participation, including travel, subject to the rules of the appropriate travel control board.

(d) The Advisory Council shall have the following duties:

(1) advise on development, implementation, and revision of the Plan;

(2) recommend best practices for clinical care, care

coordination, surveillance, and workforce training;

(3) advise on the registry design, privacy, data governance, and research priorities; and

(4) recommend public awareness strategies and equity-focused outreach.

(e) The Advisory Council shall submit an Annual Report in accordance with Section 50 of this Act.

Section 20. Neurodegenerative Disease Coordinator.

(a) The Director shall designate or hire a full-time Neurodegenerative Disease Coordinator within the Department.

(b) The Department shall implement and administer this Act through the Coordinator, under the supervision of the Director, except where this Act requires action by the Director or the Advisory Council.

(c) The Coordinator shall, at a minimum:

(1) serve as the primary staff to the Advisory Council and coordinate Advisory Council meetings, agendas, materials, and stakeholder engagement;

(2) coordinate development, publication, implementation, and periodic updating of the Plan, including tracking performance measures and progress on measurable objectives;

(3) administer and oversee the clinical and population registry program, including provider outreach, enrollment processes, data quality procedures, and coordination with

information technology and security functions;

(4) develop and maintain the Department's public website and dashboard required under this Act, consistent with confidentiality requirements;

(5) coordinate interagency consultation and external partnerships to implement this Act, including coordination with relevant State agencies and federally supported research centers;

(6) administer the Fund and grants program under this Act, including development of grant criteria, solicitation materials, scoring processes, and grant monitoring, in consultation with the Council; and

(7) prepare drafts of the annual reports required under this Act for Department review and submission.

(d) Except as authorized by the Department, nothing in this Section authorizes the Coordinator to adopt rules, execute intergovernmental agreements or memoranda of understanding, or approve disclosure of confidential registry information.

(e) Unless otherwise expressly provided in this Act, any duty, power, or function assigned to the Director or the Department under this Act may be carried out through the Neurodegenerative Disease Coordinator or other Department staff under the Director's supervision. Nothing in this Section shall be construed to authorize the Coordinator to adopt rules or execute intergovernmental agreements or

memoranda of understanding, except as explicitly authorized by the Director.

Section 25. State plan to address neurodegenerative diseases.

(a) Within 12 months after the effective date of this Act, the Coordinator, acting through and under the supervision of the Director, and with input from the Advisory Council, shall develop and publish a State plan to address neurodegenerative diseases.

(b) At a minimum, the Plan shall include:

(1) an epidemiologic assessment, including current estimates of prevalence, incidence, and demographic distribution for each condition and identification of data gaps;

(2) goals and measurable objectives (short-term and long-term) for prevention (where applicable), diagnosis, care, research, surveillance, workforce, and support services;

(3) strategy for improving early diagnosis and timely access to specialists;

(4) care coordination and caregiver support strategies;

(5) workforce development plan, including training for neurologists, primary care clinicians, allied health professionals, and long-term care staff;

(6) a public awareness and education plan emphasizing equity and culturally competent outreach;

(7) data and registry integration strategy, including mechanisms for secure data sharing and research access;

(8) a research and innovation agenda with prioritized areas for translational and clinical research;

(9) recommendations for sustainable financing, including public and private funding streams and potential creation of a dedicated research or program fund; and

(10) evaluation metrics and a schedule for monitoring, reporting, and Plan updates at least every 5 years.

(c) The Plan shall include a prevention-oriented component assessing environmental risk factors associated with neurodegenerative diseases, including pesticides, solvents, and other exposures, and shall identify education, voluntary, and regulatory recommendations for reducing public and occupational exposures in coordination with relevant State agencies. In developing the environmental risk factors component, the Council and the Department shall consult and coordinate, as appropriate, with the Environmental Protection Agency, the Department of Labor (including occupational safety and health functions), the Department of Agriculture, the Department of Natural Resources, and other relevant agencies to promote scientific review, alignment with existing authority, and stakeholder engagement. At a minimum, the assessment shall include:

(1) the current scientific evidence on environmental risk factors associated with neurodegenerative diseases, including, but not limited to, pesticides (such as paraquat), solvents, and other high-risk exposures;

(2) implementation of information from consultation with experts in toxicology, occupational health, environmental health, and epidemiology, as well as affected communities, in preparing assessments;

(3) identification of high-priority environmental exposures that warrant State-level action, including phase-out, substitution, or stricter regulation; and

(4) the recommended prevention, education, and regulatory strategies to reduce public and occupational exposures linked to neurodegenerative disease.

(d) Reporting under this Section shall be provided according to the requirements under Section 50 of this Act.

Section 30. Statewide clinical and population registry.

(a) The Department shall establish and maintain a voluntary statewide clinical and population registry to collect de-identified information and, with the patient's informed consent, limited identifying information, to: (i) improve understanding of burden imposed by neurodegenerative diseases, natural history, and outcomes, (ii) facilitate public health planning and service delivery, and (iii) support research consistent with applicable privacy protections.

(b) Participation in the registry shall be voluntary and require informed consent consistent with State and federal law. Providers may inform patients of the registry and assist with enrollment consistent with privacy rules.

(c) A patient may decline to participate or may withdraw consent at any time. Withdrawal shall apply prospectively and shall not require the Department to retrieve or destroy information already disclosed or used in accordance with this Section and applicable data use agreements.

(d) A health care provider may inform patients of the registry and may assist with enrollment and submission of information to the Department in a manner consistent with the federal Health Insurance Portability and Accountability Act of 1996 and other applicable State and federal privacy requirements.

(e) Core data elements may include diagnosis, date of diagnosis, demographic information, basic clinical staging or severity metrics, key comorbidities, treatments, outcomes, and patient-reported outcomes. The Director may add, modify, or remove data elements by rule if any added elements are reasonably necessary to accomplish the purposes of this Section and are subject to the privacy and security safeguards set forth in this Act.

(1) The identity of, and any information or combination of facts that tends to lead to the identity of, any patient whose condition or treatment is submitted

to the registry is confidential, shall not be open to public inspection or dissemination, and is exempt from disclosure under Section 7 of the Freedom of Information Act.

(2) Without limiting paragraph (1) of this subsection (e), the following data elements, alone or in combination, are confidential, not subject to public inspection or dissemination, and exempt from disclosure under Section 7 of the Freedom of Information Act: name, social security number, street address, email address, telephone number, fax number, medical record number, certificate or license number, reporting source (unless permitted by the reporting facility), age (unless aggregated for 5 or more years), zip code (unless aggregated for 5 or more years), and diagnosis date (unless aggregated for one or more years for the entire State or for 3 or more years for a single county).

(3) The identity of any person claimed to be derived from registry data is not admissible in evidence, and no court shall compel production of registry information in discovery if the court determines that the information tends to lead to the identity of any person.

(4) Except as provided by rule and as part of an epidemiologic investigation, an officer or employee of the Department may interview a patient named in a report made under this Section, or relatives of the patient, only with

the express written consent of the patient or the patient's legally authorized representative.

(5) The Department shall maintain administrative, technical, and physical safeguards to protect registry information and shall use and disclose registry information only in compliance with the federal Health Insurance Portability and Accountability Act of 1996 and applicable State law.

(f) The Department shall maintain a written data governance policy addressing data minimization, security controls, retention, permitted uses, and review and approval of requests for access.

(1) Registry data may be used to inform public health planning, improve care delivery, support research, and evaluate program outcomes.

(2) The Department may release de-identified information and, as appropriate, limited data sets to qualified researchers for specific research purposes pursuant to procedures established by the Department, including execution of a data use agreement and any required human-subjects protections. Identifying information shall not be released unless authorized by the patient's informed consent or otherwise permitted by law.

(3) The Department shall adopt rules to implement this Section, including standards for informed consent, submission and validation of data, de-identification and

aggregation, access review procedures, and safeguards for confidential or privileged information.

(f) The Department shall maintain a public website for the registry that includes:

(1) downloadable annual aggregate summaries on incidence and prevalence of Parkinson's disease, atypical parkinsonism, amyotrophic lateral sclerosis, Huntington's disease, and multiple sclerosis;

(2) Advisory Council information; and

(3) additional resources as determined by the Department.

(g) Reporting under this Section shall be provided according to the requirements under Section 50 of this Act.

(h) A hospital, laboratory, other facility, or physician and their officers, employees, and agents, shall not be held civilly liable for the good-faith release of information to the Department in accordance with this Section and rules adopted under this Section.

Section 35. Neurodegenerative Disease Research Support And Grant Fund.

(a) Subject to appropriation, the Director shall establish a Neurodegenerative Disease Research and Program Fund as a special fund in the State treasury to make grants to public or private not-for-profit entities for the purpose of conducting neurodegenerative disease research. The Fund may receive

gifts, grants, and other private contributions. The Department shall deposit any private contributions received for the grant program created pursuant to this Act in the Fund.

(b) Money in the Fund shall be used by the Department to cover costs associated with this Act, including, but not limited to, the following:

(1) salary and benefits for the full-time position of the Coordinator within the Department;

(2) research grants and pilot projects focused on diagnosis, treatment, care delivery, and health disparities;

(3) infrastructure to enhance clinical trials capacity and the registry analytics;

(4) workforce training and capacity building; and

(5) public awareness campaigns and caregiver supports.

(c) The Coordinator, in consultation with the Advisory Council, shall develop transparent grant criteria prioritizing scientific merit, potential for impact, equity, and collaboration.

(d) Reporting under this Section shall be provided according to the requirements under Section 50 of this Act.

Section 40. Equity and rural access.

(a) In implementing this Act, the Department shall consider disparities in diagnosis, care, participation, and outcomes associated with race, ethnicity, income, rural

residence, disability, language access, and other social determinants of health and shall, to the extent practicable, incorporate strategies to reduce such disparities in the Plan and in programs administered under this Act.

(b) The Department shall use reasonable efforts to ensure that outreach, enrollment opportunities, and program benefits under this Act are accessible statewide, including in rural areas and historically underserved communities.

(c) Targeted outreach and funding may be prioritized for initiatives that demonstrably increase access, participation, or outcomes in historically underserved communities or rural areas, consistent with the objectives of the Plan and subject to appropriation.

Section 45. Coordination with federal programs, academic centers, and private partners.

(a) The Director shall coordinate activities under this Act with relevant federal agencies, federally supported research centers, academic medical centers, institutions of higher education, and private partners to leverage resources, align initiatives, and avoid duplication.

(b) To the extent permitted by law, the Department may enter into intergovernmental agreements, memoranda of understanding, or other written agreements to facilitate technical assistance, data sharing, and collaborative research, provided that any sharing of information complies

with federal Health Insurance Portability and Accountability Act of 1996, applicable State privacy law, and the confidentiality provisions of this Act and is subject to appropriate data use or security terms.

Section 50. Reporting.

(a) Beginning 12 months after the effective date of this Act and annually thereafter, the Department, with input from the Council, shall prepare, submit, and publish a single consolidated Annual Report regarding implementation of this Act. The Department shall submit the Annual Report to the Governor and the General Assembly and shall post the Annual Report on the Department's publicly available website, so long as no confidential or identifying information is disclosed.

(b) At a minimum, the Annual Report shall include:

(1) plan implementation and progress toward measurable objectives, including actions taken during the prior year and progress on performance measures;

(2) registry summary required under Section 30 of this Act in de-identified or aggregate form, including enrollment totals, demographic summaries, and any incidence or prevalence summaries feasible to report consistent with confidentiality protections;

(3) care and access gaps identified in Illinois, including barriers to diagnosis, specialty care, supportive services, workforce capacity, and caregiver

supports;

(4) a summary of disparities and actions taken to improve access statewide, including rural access and historically underserved communities;

(5) awards made from the Fund (if any), amounts, recipients, purposes, and program outcomes or early findings (if applicable);

(6) a summary of emerging scientific evidence, exposure-reduction education strategies, and any recommendations developed in consultation with relevant State agencies;

(7) recommendations for legislative, regulatory, or administrative action;

(8) the Plan required under Section 25 of this Act and a draft Plan, which shall be made available for public comment for at least 30 days prior to finalization; and

(9) reports required under Section 15 and Section 35 of this Act.

(c) The Department may maintain a public dashboard providing regular updates on select indicators, such as aggregate registry enrollment, grants awarded, and workforce metrics, consistent with privacy protections and confidentiality requirements under this Act.

Section 55. Limitations. Nothing in this Act shall be construed to require insurance coverage beyond what is

otherwise required by State or federal law, except as expressly provided by a future Act of the General Assembly.

Section 60. Rulemaking authority. The Department may adopt rules necessary to implement this Act, consistent with administrative procedure requirements.

Section 90. The State Finance Act is amended by adding Section 5.1038 as follows:

(30 ILCS 105/5.1038 new)

Sec. 5.1038. The Neurodegenerative Disease Research and Program Fund.

Section 97. Severability. The provisions of this Act are severable under Section 1.31 of the Statute on Statutes.

Section 99. Effective date. This Act takes effect upon becoming law.