



104TH GENERAL ASSEMBLY

State of Illinois

2025 and 2026

HB5465

Introduced 2/13/2026, by Rep. Kam Buckner

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.

LRB104 19999 BDA 33450 b

1 AN ACT concerning health.

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

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

6 Section 5. Findings; legislative intent.

7 (a) The General Assembly finds that:

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

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

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

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

15 Section 10. Definitions. As used in this Act:

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

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

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

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

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

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

20 "Department" means the Department of Public Health.

21 "Director" means the Director of Public Health.

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

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

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

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

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

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

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

26 "Stakeholders" means persons and entities with an interest

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

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

10 Section 15. Neurodegenerative Disease Advisory Council.

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

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

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

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

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

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

25 (5) one member appointed by the Governor representing

1 the Governor's Office; and

2 (6) members appointed by the Governor as follows:

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

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

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

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

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

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

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

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

24 (c) The Council shall operate as follows:

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

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

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

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

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

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

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

26 (2) recommend best practices for clinical care, care

- 1 coordination, surveillance, and workforce training;
- 2 (3) advise on the registry design, privacy, data
- 3 governance, and research priorities; and
- 4 (4) recommend public awareness strategies and
- 5 equity-focused outreach.
- 6 (e) The Advisory Council shall submit an Annual Report in
- 7 accordance with Section 50 of this Act.

8 Section 20. Neurodegenerative Disease Coordinator.

9 (a) The Director shall designate or hire a full-time

10 Neurodegenerative Disease Coordinator within the Department.

11 (b) The Department shall implement and administer this Act

12 through the Coordinator, under the supervision of the

13 Director, except where this Act requires action by the

14 Director or the Advisory Council.

15 (c) The Coordinator shall, at a minimum:

16 (1) serve as the primary staff to the Advisory Council

17 and coordinate Advisory Council meetings, agendas,

18 materials, and stakeholder engagement;

19 (2) coordinate development, publication,

20 implementation, and periodic updating of the Plan,

21 including tracking performance measures and progress on

22 measurable objectives;

23 (3) administer and oversee the clinical and population

24 registry program, including provider outreach, enrollment

25 processes, data quality procedures, and coordination with

1 information technology and security functions;

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

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

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

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

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

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

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

3 Section 25. State plan to address neurodegenerative
4 diseases.

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

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

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

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

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

21 (4) care coordination and caregiver support
22 strategies;

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

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

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

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

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

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

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

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

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

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

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

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

17 Section 30. Statewide clinical and population registry.

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

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

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

10 (d) A health care provider may inform patients of the
11 registry and may assist with enrollment and submission of
12 information to the Department in a manner consistent with the
13 federal Health Insurance Portability and Accountability Act of
14 1996 and other applicable State and federal privacy
15 requirements.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

9 (2) Advisory Council information; and

10 (3) additional resources as determined by the
11 Department.

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

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

19 Section 35. Neurodegenerative Disease Research Support And
20 Grant Fund.

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

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

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

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

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

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

14 (4) workforce training and capacity building; and

15 (5) public awareness campaigns and caregiver supports.

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

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

22 Section 40. Equity and rural access.

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

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

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

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

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

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

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

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

5 Section 50. Reporting.

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

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

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

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

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

1 supports;

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

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

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

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

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

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

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

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

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

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

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

8 (30 ILCS 105/5.1038 new)

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

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

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