

By Senator Rodriguez

40-00931A-26

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A bill to be entitled

An act relating to the neurofibromatosis research grants; creating s. 381.994, F.S.; creating the Neurofibromatosis Disease Grant Program within the Department of Health; providing the purpose of the program; providing that, subject to legislative appropriation, the program award grants for certain purposes; specifying entities that are eligible to apply for grants under the program; allowing certain grant proposals to receive preference in the awarding of grants; requiring the department to award grants after consulting with the Rare Disease Advisory Council; specifying the types of applications that may be considered for grant funding; requiring the department to appoint peer review panels to review the scientific merit of grant applications and establish their priority scores; requiring the council to consider the priority scores in determining which proposals are recommended for grant funding under the program; requiring the council and peer review panels to establish and follow certain guidelines when performing their duties under the program; prohibiting members of the council or peer review panels from participating in discussions or decisions if there are certain conflicts of interest; authorizing certain appropriated funds to be carried forward under certain circumstances; providing an effective date.

Be It Enacted by the Legislature of the State of Florida:

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Section 1. Section 381.994, Florida Statutes, is created to read:

381.994 Neurofibromatosis Disease Grant Program.—

(1)(a) There is created within the Department of Health the Neurofibromatosis Disease Grant Program. The purpose of the program is to advance the progress of research and cures for neurofibromatosis by awarding grants through a competitive, peer-reviewed process.

(b) Subject to an annual recurring appropriation of \$5 million by the Legislature, the program shall award grants for scientific and clinical research to further the search for new diagnostics, treatments, and cures for neurofibromatosis.

(2)(a) Applications for grants for neurofibromatosis disease research may be submitted by any university or established research institute in this state. All qualified investigators in this state, regardless of institutional affiliation, shall have equal access and opportunity to compete for the research funding. Preference may be given to grant proposals that foster collaboration among institutions, researchers, and community practitioners, as such proposals support the advancement of treatments and cures of neurofibromatosis through basic or applied research. Grants shall be awarded by the department, after consultation with the Rare Disease Advisory Council under s. 381.99, on the basis of scientific merit, as determined by the competitive, peer-reviewed process to ensure objectivity, consistency, and high quality. The following types of applications may be considered for funding:

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59 1. Investigator-initiated research grants.

60 2. Institutional research grants.

61 3. Collaborative research grants, including those that
62 advance the finding of treatment and cures through basic or
63 applied research.

64 (b) To ensure appropriate and fair evaluation of grant
65 applications based on scientific merit, the department shall
66 appoint peer review panels of independent, scientifically
67 qualified individuals to review the scientific merit of each
68 proposal and establish its priority score. The priority scores
69 shall be forwarded to the council and must be considered in
70 determining which proposals are recommended for funding.

71 (3) For purposes of performing their duties under this
72 section, the Rare Disease Advisory Council and the peer review
73 panels shall establish and follow rigorous guidelines for
74 ethical conduct and adhere to a strict policy with regard to
75 conflicts of interest. A member of the council or panel may not
76 participate in any discussion or decision of the council or
77 panel with respect to a research proposal by any firm, entity,
78 or agency with which the member is associated as a member of the
79 governing body or as an employee or with which the member has
80 entered into a contractual arrangement.

81 (4) Notwithstanding s. 216.301 and pursuant to s. 216.351,
82 the balance of any appropriation from the General Revenue Fund
83 for the Neurofibromatosis Disease Grant Program which is not
84 disbursed but is obligated pursuant to contract or committed to
85 be expended by June 30 of the fiscal year in which the funds are
86 appropriated may be carried forward for up to 5 years after the
87 effective date of the original appropriation.

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Section 2. This act shall take effect July 1, 2026.