FLORIDA HOUSE OF REPRESENTATIVES
BILL ANALYSIS

This bill analysis was prepared by nonpartisan committee staff and does not constitute an official statement of legislative intent.

BILL #: CS/HB 497	**COMPANION BILL:** SB 1060 (Rodriguez)
TITLE: Neurofibromatosis Research Grants	**LINKED BILLS:** None
SPONSOR(S): Gonzalez Pittman	**RELATED BILLS:** None

Committee References

Health Professions & Programs (14 Y, 0 N, As CS) ➤ Health Care Budget ➤ Health & Human Services

SUMMARY

Effect of the Bill:
CS/HB 497 establishes the Neurofibromatosis Disease Grant Program within the Department of Health (DOH) with the purpose of advancing the progress of research and cures for neurofibromatosis. The bill requires DOH, in consultation with the Rare Disease Advisory Council, to award program grants through a competitive, peer-reviewed process.

Fiscal or Economic Impact:
The bill has an indeterminate, negative fiscal impact on state government. See Fiscal Comments. The bill has no fiscal impact on local governments.

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ANALYSIS

EFFECT OF THE BILL:

The bill establishes the Neurofibromatosis Disease Grant Program (Program) within the Department of Health (DOH) with the purpose of advancing the progress of research and cures for neurofibromatosis. The bill requires DOH in consultation with the Rare Disease Advisory Council (RDAC), to award program grants through a competitive, peer-reviewed process. (Section 1)

DOH will award grants to universities or established research institutes in the state for scientific and clinical research to further the search for new diagnostics, treatments, and cures for neurofibromatosis. The bill establishes a preference for grant proposals which foster collaboration among institutions, researchers, and community practitioners. (Section 1)

The bill requires DOH to appoint peer review panels of independent, scientifically qualified individuals to review the scientific merit of each proposal and establish its priority score. DOH must provide the priority score to the RDAC which must consider the priority score in its recommendations for funding. (Section 1)

The bill requires the RDAC and peer-review panels to establish and follow rigorous guidelines for ethical conduct and adhere to a strict policy in regard to conflict of interest. (Section 1)

The bill provides an effective date of July 1, 2026. (Section 2)

FISCAL OR ECONOMIC IMPACT:

STATE GOVERNMENT:

The bill establishes a research grant program subject to legislative appropriation. The fiscal impact is indeterminate and will depend on whether the Legislature provides funding for the program through the General

Appropriation Act. However, DOH may experience minimal absorbable administrative workload associated with establishing the grant program, coordinating peer-review panels and consultation with its Rare Disease Advisory Council.

PRIVATE SECTOR:

Private research institutions who are eligible for the Neurofibromatosis Disease Grant Program may experience a positive fiscal impact from access to this additional funding.

RELEVANT INFORMATION

SUBJECT OVERVIEW:

Rare Diseases

In the United States, a rare disease is any condition that nationally affects fewer than 200,000 people. There may be as many as 10,000[1] rare diseases impacting the lives of 25 to 30 million Americans and their families.[2] So, while the individual diseases may be rare, the total number of people impacted by a rare disease is large.

Rare diseases include genetic disorders, infectious diseases, cancers, and various other pediatric and adult conditions. A rare disease can affect anyone at any point in their life, and can be acute or chronic. It is estimated that 80 percent or more of rare diseases are genetic. For genetic rare diseases, genetic testing is often the only way to make a definitive diagnosis. Rare diseases present a fundamentally different array of challenges compared to those of more common diseases; often patients are set on a "diagnostic odyssey," in order to determine the cause of their symptoms as they seek treatment in health care settings where their condition may have never been seen before.[3]

Neurofibromatosis

Neurofibromatosis (NF) refers to a group of genetic conditions that cause tumors to form on nerves throughout the body, including those in the brain, spinal cord, and nervous system.[4] There are an estimated 4 million[5] people worldwide are living with Neurofibromatosis.

NF is not a single disorder and includes Neurofibromatosis type 1 (*NF1*), and all types of Schwannomatosis (*SWN*), including NF2-related schwannomatosis (*NF2-SWN*).[6] NF1, is the most common, occurring in approximately 1 in 2,500 births. NF2-related schwannomatosis (NF2-SWN) is significantly less common, affecting about 1 in 25,000 births, and the other forms of schwannomatosis occur in roughly 1 in 70,000 births.[7]

Neurofibromatosis Type 1 (NF 1)[8]

Neurofibromatosis Type 1 (*NF1*) is the most common form of the condition and is usually diagnosed in childhood. Symptoms of *NF1* include:[9]

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[1] National Center for Advancing Translational Sciences, *Our Impact on Rare Diseases*, National Institute of Health, available at https://ncats.nih.gov/research/our-impact/our-impact-rare-diseases (last visited February 7, 2026).
[2] National Organization for Rare Diseases, *Rare Disease Day: Frequently Asked Questions*. Available at https://rarediseases.org/wp-content/uploads/2023/04/Rare-Disease-Fact-Sheet.pdf (last visited February 7, 2026).
[3] Department of Health, *Rare Disease Advisory Council: Legislative Report, Fiscal Year 2023-2024* (2024), p. 6-7, Available at https://www.floridahealth.gov/wp-content/uploads/2025/08/2024-rdac-annual-report.pdf (last visited February 7, 2026).
[4] National Institute of Neurological Disorders & Stroke, *Neurofibromatosis*, National Institute of Health, available at https://www.ninds.nih.gov/health-information/disorders/neurofibromatosis (last visited February 6, 2026)
[5] Children's Tumor Foundation, *Understanding NF*, available at https://www.ctf.org/about-nf/ (last visited February 8, 2026).
[6] *Id.*
[7] *Id.*
[8] *Supra* Note 4

- Flat, light brown spots on the skin ("café au lait" spots);
- Freckling in the armpits or the groin;
- Soft, pea-sized bumps called neurofibromas;
- Plexiform neurofibromas;
- Growths on the iris of the eye (known as Lisch nodules or iris hamartomas);
- A tumor of the optic pathway (optic pathway glioma);
- Bone deformities;
- Shorter than average height and a larger head size; and
- Learning difficulties and attention deficit hyperactivity disorder.

Complications of NF1 include various vascular conditions, more common and aggressive scoliosis and increased risk of gastrointestinal stromal tumors, among others. Additionally, children with NF1 have a higher risk for learning disabilities.[10]

Neurofibromatosis Type 2 (NF2-SWN)[11]

NF2-Schwannomatosis (*NF2-SWN*) is usually diagnosed in young adulthood and up to age 30, although they can begin at any age. The most common features of *NF-2* include benign, slow-growing tumors affecting cranial, spinal and peripheral nerves and the covering of the brain and spinal cord.[12]

Complications of NF2-SWN include:[13]

- Hearing loss or ringing in the ears and problems with balance related to vestibular schwannomas;
- Vision problems such as cataracts;
- Peripheral neuropathy; and,
- Schwannomas[14] on the skin.

Treating Neurofibromatosis

Currently, there is no cure for neurofibromatosis, but treatments are available to help manage symptoms and other conditions that may develop. People with neurofibromatosis are recommended to get regular screenings through routine eye and physical exams and be seen regularly by a specialist.[15]

Children with NF1 have a higher risk for learning disabilities and are recommended to undergo neuropsychological assessments, and for individuals with NF2-SWN, cochlear implants, hearing aids, auditory brain stem implants, mobility devices, and corrective eyewear may help manage hearing, movement, and vision problems.[16]

Research and Clinical Trials

The National Institute of Neurological Disorders and Stroke (NINDS) is the leading federal funder of NF research. NINDS supports new and innovative research to understand, prevent, diagnose, and treat NF.[17] NF research is also supported at the federal level through the Department of Defense's Congressional Directed Medical Research

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[9] *Id.*
[10] *Id.*
[11] *Id.*
[12] *Id.*
[13] *Id.*
[14] A schwannoma is a tumor that develops from Schwann cells in your peripheral nervous system or nerve roots. *Schwannoma*, Cleveland Clinic, available at https://my.clevelandclinic.org/health/diseases/17877-schwannoma (last viewed February 9, 2026).
[15] *Supra* Note 4
[16] *Id.*
[17] *Supra* Note 4

Programs (CDMRP)[18], which administers the Neurofibromatosis Research Program (NFRP) to advance studies in tumor biology, biomarker development, and clinical therapeutics.

Rare Disease Grant Program – Florida

In 2024, the Andrew John Anderson Pediatric Rare Disease Grant Program[19] within the DOH was created to advance research and cures for rare pediatric diseases. DOH, in consultation with the Rare Disease Advisory Council (RDAC), awards program grants through a competitive, peer-reviewed process for scientific and clinical research to further the search for new diagnostic, treatments, and cures for pediatric rare diseases, such as NF1.[20] The program receives $500,000 in recurring General Revenue funding, appropriated in the General Appropriations Act, to support innovative clinical research grants. The program awarded two grants in 2024 and one grant in 2025:[21]

2024 Award[22]

- $71,171 – Florida State University: Study on developmental and epileptic encephalopathy using YWHAG mutation models.
- $428,829 – University of Miami: Research on nanoengineered tools to understand oxidative stress and inflammation in Barth Syndrome.

2025 Award[23]

- $500,000 – University of Miami: Unraveling Suppressors of mtDNA Instability: A Path Toward Therapeutic Strategies for Mitochondrial Depletion Syndromes.

Florida Rare Disease Advisory Council

The establishment of RDACs across the country is an initiative spearheaded by the National Organization for Rare Disorders (NORD),[24] a national nonprofit group advocating for individuals and families affected by rare diseases.[25] The Legislature established the Florida Rare Disease Advisory Council (RDAC) in 2021 to assist DOH in providing recommendations to improve health outcomes for individuals with rare diseases residing in the state.[26]

Florida's RDAC is required to:[27]

- Consult with experts on rare diseases and solicit public comments to assist in developing recommendations on improving the treatment of rare diseases in Florida;
- Develop recommended strategies for academic research institutions in Florida to facilitate continued research on rare diseases;
- Develop recommended strategies for health care providers to be informed on how to more efficiently recognize and diagnose rare diseases in order to effectively treat patients; and

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[18] Neurofibromatosis Research Program (NFRP), *Congressional Directed Medical Research Programs*, U.S. Department of Defense, available at https://cdmrp.health.mil/nfrp/default (last visited February 7, 2026).
[19] Ch. 2024-246, Laws of Fla.
[20] *Id.*
[21] *Florida Legislature, General Appropriations Act, Ch. 2024-246, Laws of Fla., Specific Appropriation 546A*
[22] House of Representatives, Meeting Packet, November 5, 2025, Health Professions and Programs Subcommittee, p. 14, available at https://www.flhouse.gov/Sections/Documents/loaddoc.aspx?MeetingId=14862&PublicationType=Committees&DocumentType=Meeting%20Packets (last visited February 8, 2026).
[23] *Id.* at 14
[24] National Organization for Rare Disorders (NORD), *Project RDAC Year One (2021)*, Available at https://rarediseases.org/wp-content/uploads/2021/11/NRD-2200-RDAC-Year1-Highlights_FNL.pdf (last visited February 7, 2026).
[25] National Organization for Rare Disorders (NORD), *About Us*, Available at https://rarediseases.org/about-us/ (last visited February 7, 2026).
[26] S. 381.99, F.S.
[27] S. 381.99(4), F.S.; See also, the Rare Disease Advisory Council: *Legislative Report, Fiscal Year 2024-2025 (2025),* Available at https://www.floridahealth.gov/wp-content/uploads/2025/08/RDAC_Annual_Report_2025_Final.pdf (last visited February 7, 2026).

- Provide input and feedback in writing to DOH, the Medicaid program, and other state agencies on matters that affect people who have been diagnosed with rare diseases.

The RDAC also assists DOH in evaluating and awarding grants under the Andrew John Anderson Pediatric Rare Disease Grant Program.[28]

OTHER RESOURCES:

Florida Department of Health – Rare Disease Research Grant Program
Florida Department of Health – Rare Disease Advisory Council Annual Report (2025)
Florida Department of Health – Rare Disease Advisory Council Funding Opportunity Announcement (2025-2026)

BILL HISTORY

COMMITTEE REFERENCE	ACTION	DATE	STAFF DIRECTOR/ POLICY CHIEF	ANALYSIS PREPARED BY
Health Professions & Programs Subcommittee	14 Y, 0 N, As CS	2/11/2026	McElroy	Aderibigbe
THE CHANGES ADOPTED BY THE COMMITTEE:	• Removed the $5 million appropriation and makes the bill subject to an appropriation.			
Health Care Budget Subcommittee				
Health & Human Services Committee				

THIS BILL ANALYSIS HAS BEEN UPDATED TO INCORPORATE ALL OF THE CHANGES DESCRIBED ABOVE.

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[28] *Supra* Note 26