

By the Committees on Fiscal Policy; and Education Postsecondary;
and Senators Burton and Berman

594-03194-25

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1 A bill to be entitled
2 An act relating to the Florida Institute for Pediatric
3 Rare Diseases; creating s. 1004.4211, F.S.;
4 establishing the Florida Institute for Pediatric Rare
5 Diseases within the Florida State University College
6 of Medicine; providing the purpose of the institute;
7 providing the goals of the institute; requiring the
8 institute to establish and administer the Sunshine
9 Genetics Pilot Program for a specified period;
10 providing the purpose of the pilot program; providing
11 institute responsibilities and duties relating to the
12 pilot program; providing requirements for
13 participation in the pilot program and data collection
14 and release in the pilot program; defining the term
15 "health care practitioner"; providing reporting
16 requirements for the pilot program; establishing the
17 Sunshine Genetics Consortium for specified purposes;
18 requiring the consortium to be administered at the
19 institute by an oversight board; providing for the
20 membership and terms of the board; providing reporting
21 requirements for the consortium; specifying that
22 implementation of the act is subject to appropriation;
23 providing an effective date.

24
25 Be It Enacted by the Legislature of the State of Florida:

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27 Section 1. Section 1004.4211, Florida Statutes, is created
28 to read:

29 1004.4211 The Florida Institute for Pediatric Rare

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30 Diseases; the Sunshine Genetics Pilot Program; the Sunshine
31 Genetics Consortium.—

32 (1) The Florida Institute for Pediatric Rare Diseases is
33 established within the Florida State University College of
34 Medicine as a statewide resource for pediatric rare disease
35 research and clinical care. The purpose of the institute is to
36 improve the quality of life and health outcomes for children and
37 families affected by rare diseases by advancing knowledge,
38 diagnosis, and treatment of pediatric rare diseases through
39 research, clinical care, education, and advocacy.

40 (2) The goals of the institute are to:

41 (a) Conduct research to better understand the causes,
42 mechanisms, and potential treatments for pediatric rare
43 diseases, including leveraging emerging research methods.

44 (b) Develop advanced diagnostic and genetic screening tools
45 and techniques to enable health care providers to identify rare
46 diseases in newborns and children more rapidly, accurately, and
47 economically.

48 (c) Provide comprehensive multidisciplinary clinical
49 services and care for children with rare diseases. Such care may
50 include, but is not limited to, patient, family, and caregiver
51 support and resources to help navigate the challenges associated
52 with these conditions, support groups, and patient advocacy.

53 (d) Educate and train health care professionals, including,
54 but not limited to, genetic counselors, pediatricians,
55 scientists, and other specialists in the field of pediatric rare
56 diseases.

57 (e) Establish collaborations with other research
58 institutions, medical centers, patient and family advocacy

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59 organizations, and government agencies whenever deemed
60 appropriate by the institute director to share expertise, raise
61 awareness, and promote a collective effort to tackle pediatric
62 rare diseases.

63 (3) (a) The institute shall establish and administer the
64 Sunshine Genetics Pilot Program to be administered for a period
65 of 5 years. The pilot program shall provide newborn genetic
66 screening, including, but not limited to, whole genome
67 sequencing. Genetic screening shall be performed by the
68 institute and institutional members of the oversight board upon
69 approval of the oversight board.

70 (b) The institute may establish partnerships with Florida
71 universities and colleges and health care service providers to
72 promote and assist in the implementation of the pilot program.

73 (c) The pilot program shall be an opt-in program and a
74 parent of a newborn must provide consent to participate in the
75 pilot program.

76 (d) The institute and institutional members of the
77 oversight board shall release clinical findings of a newborn's
78 screening to the newborn's health care practitioner and the
79 newborn's parent. As used in this paragraph, the term "health
80 care practitioner" means a physician or physician assistant
81 licensed under chapter 458; an osteopathic physician or
82 physician assistant licensed under chapter 459; an advanced
83 practice registered nurse, registered nurse, or licensed
84 practical nurse licensed under part I of chapter 464; a midwife
85 licensed under chapter 467; a speech-language pathologist or
86 audiologist licensed under part I of chapter 468; a dietitian or
87 nutritionist licensed under part X of chapter 468; or a genetic

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88 counselor licensed under part III of chapter 483.

89 (e) The institute shall:

90 1. Maintain a secure database to collect and store all
91 pilot program data, including, but not limited to, newborn
92 genomics sequence data and deidentified newborn data.

93 2. Provide deidentified newborn data to members of the
94 consortium pursuant to a data sharing agreement to support
95 ongoing and future research.

96 (f) By December 1, 2030, the institute shall provide a
97 report on the Sunshine Genetics Pilot Program to the Governor,
98 the President of the Senate, and the Speaker of the House of
99 Representatives. The report must include, at a minimum:

100 1. Study population and enrollment metrics.

101 2. Whole genome sequencing metrics.

102 3. Clinical and public health impact.

103 4. Cost effectiveness and economic benefits.

104 (4) (a) The Sunshine Genetics Consortium is established to
105 create a network of clinical and academic research
106 professionals, geneticists, and physicians from state
107 universities and this state's children's hospitals to
108 collaborate with leaders in the genetics industry and build and
109 support a culture of collaborative research and the development
110 of cutting-edge genetic and precision medicine in the state. The
111 consortium shall:

112 1. Integrate state-of-the-art genomic sequencing
113 technologies.

114 2. Advance research and the development of cutting-edge
115 genetic and precision medicine.

116 3. Leverage advancements in artificial intelligence

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117 utilization in genomics.

118 4. Develop educational opportunities for clinicians on
119 genomic tools.

120 5. Support the growth and education of geneticists to meet
121 demand.

122 6. Solicit and leverage funds from nonprofits, private
123 industry, and others for the purpose of expanding the Sunshine
124 Genetics Pilot Program and to support genetic screenings by
125 institutional members of the oversight board.

126 7. Promote patient care that supports families with
127 children diagnosed with genetic disorders.

128 8. Report on the use of deidentified newborn data by
129 members of the consortium.

130 (b)1. The consortium shall be administered at the institute
131 by an oversight board. The board shall convene at least once
132 every 6 months.

133 2. The oversight board for the consortium shall consist of
134 the director of the institute, who shall serve as chair, and the
135 following voting members, who shall serve 2-year terms:

136 a. One member nominated by the dean of the University of
137 Florida's College of Medicine and approved by the university's
138 president.

139 b. One member nominated by the dean of the University of
140 South Florida's College of Medicine and approved by the
141 university's president.

142 c. One member nominated by the dean of the University of
143 Miami's School of Medicine and approved by the university's
144 president.

145 d. One member nominated by the dean of Florida

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146 International University's School of Medicine and approved by
147 the university's president.

148 e. One member nominated by Nicklaus Children's Hospital and
149 approved by the hospital's president and chief executive
150 officer.

151 f. One member appointed by the Governor.

152 g. One member appointed by the President of the Senate.

153 h. One member appointed by the Speaker of the House of
154 Representatives.

155 3. The board shall be responsible for the promotion and
156 oversight of the consortium, including, but not limited to, the
157 nomination and appointment of members of the consortium.

158 (c) Beginning October 15, 2026, and annually thereafter,
159 the consortium shall provide a report to the Governor, the
160 President of the Senate, and the Speaker of the House of
161 Representatives on research projects, research findings,
162 community outreach initiatives, and future plans for the
163 consortium.

164 (5) The provisions of this section shall be implemented to
165 the extent of available appropriations contained in the annual
166 General Appropriations Act for such purpose.

167 Section 2. This act shall take effect July 1, 2025.