

<b>Tab 1</b>	<b>SB 892</b> by <b>Simon</b> ; Similar to H 01055 Florida State University Election Law Center
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<b>Tab 2</b>	<b>SB 1356</b> by <b>Burton</b> ; Similar to CS/H 00907 Florida Institute for Pediatric Rare Diseases
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758458 D S RCS HE, Burton Delete everything after 03/17 01:58 PM

**The Florida Senate**  
**COMMITTEE MEETING EXPANDED AGENDA**

**EDUCATION POSTSECONDARY**

**Senator Calatayud, Chair**

**Senator Simon, Vice Chair**

**MEETING DATE:** Monday, March 17, 2025

**TIME:** 1:30—3:30 p.m.

**PLACE:** 301 Senate Building

**MEMBERS:** Senator Calatayud, Chair; Senator Simon, Vice Chair; Senators Berman, Fine, Harrell, Jones, and Rodriguez

TAB	BILL NO. and INTRODUCER	BILL DESCRIPTION and SENATE COMMITTEE ACTIONS	COMMITTEE ACTION
1	<b>SB 892</b> Simon (Similar H 1055)	Florida State University Election Law Center; Creating the center within the Florida State University College of Law; defining the term “election law”; authorizing the center to provide assistance to the Legislature and other governmental entities; providing mechanisms for the funding of the center, etc.  HE 03/17/2025 Favorable AHE FP	Favorable Yeas 7 Nays 0
2	<b>SB 1356</b> Burton (Similar CS/H 907)	Florida Institute for Pediatric Rare Diseases; Establishing the Florida Institute for Pediatric Rare Diseases within the Florida State University College of Medicine; requiring the institute to establish and administer the Sunshine Genetics Pilot Program for a specified period; providing institute responsibilities and duties relating to the pilot program; providing requirements for participation in the pilot program and data collection in the pilot program, etc.  HE 03/17/2025 Fav/CS AHS FP	Fav/CS Yeas 7 Nays 0

Other Related Meeting Documents

**The Florida Senate**  
**BILL ANALYSIS AND FISCAL IMPACT STATEMENT**

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

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Prepared By: The Professional Staff of the Committee on Education Postsecondary

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BILL: SB 892

INTRODUCER: Senator Simon

SUBJECT: Florida State University Election Law Center

DATE: March 13, 2025

REVISED: \_\_\_\_\_

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Brick	Bouck	HE	<b>Favorable</b>
2.			AHE	
3.			FP	

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## I. Summary:

SB 892 creates the Florida State University Election Law Center within the Florida State University College of Law to conduct nonpartisan research, provide training, and serve as a resource on election law issues. The center will study topics including:

- Voting rights, redistricting, and campaign finance.
- Election administration, election disputes, and related issues.
- Election integrity and best practices for electoral systems.

The bill authorizes the center to:

- Hire faculty, develop courses, and host events.
- Assist government entities with election law matters.
- Offer student scholarships and fellowships.

The bill provides that the center will be funded through appropriations as provided in the General Appropriations Act, charitable donations and grants, and other university funds.

The bill takes effect July 1, 2025.

## II. Present Situation:

### Election Law

Election law covers a wide array of topics, including political spending, voting rights, ballot propositions, redistricting, gerrymandering, and campaign finance. Useful secondary materials include legal resources as well as interdisciplinary sources in the areas of political science,

history, and public policy.<sup>1</sup> Federal statutes, such as the Voting Rights Act of 1965 and the National Voter Registration Act of 1993, regulate key aspects of election law, while state laws dictate voter eligibility, ballot access, and election procedures.<sup>2</sup>

At the state level, elections are primarily governed by Chapters 97 through 106, Florida Statutes, which address voter registration, election administration, campaign finance, and recount procedures.<sup>3</sup> The Florida Division of Elections, under the Department of State, provides guidance and oversight for elections, while county supervisors of elections administer elections locally.<sup>4</sup> Legal challenges related to election law arise in state and federal courts, particularly concerning issues of voter access, redistricting, and campaign finance regulations.<sup>5</sup>

### **Florida State University College of Law**

Florida State University (FSU) College of Law, located in Tallahassee, Florida, is a nationally recognized public law school. The college offers a range of legal education programs, including specialized courses in constitutional law, administrative law, and public policy, leveraging its proximity to the Florida Capitol to provide students with access to state government institutions and legal practitioners.<sup>6</sup>

### ***Florida State University Election Law Center***

The FSU Election Law Center, housed within the FSU College of Law, provides nonpartisan research, training, and policy analysis on election law.<sup>7</sup> The center collaborates with election officials, legislators, and scholars to improve election administration, voting rights, and election integrity.<sup>8</sup> It also offers student scholarships, externships, and research fellowships to support careers in election law.<sup>9</sup>

The center is led by a Faculty Director and an Executive Director, who oversee its academic, research, and outreach initiatives.<sup>10</sup> The center hosts conferences, lectures, and training sessions, including the Election Law Conference and the Distinguished Lecture in Election Law.<sup>11</sup>

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<sup>1</sup> University of California, Irvine School of Law, *Election Law Research Guide*, available at <https://libguides.law.uci.edu/election> (last visited Mar. 11, 2025).

<sup>2</sup> 52 U.S.C. ss. 10301–10508 (Voting Rights Act of 1965); 52 U.S.C. ss. 20501–20511 (National Voter Registration Act of 1993).

<sup>3</sup> See generally Chapters 97–106, F.S.

<sup>4</sup> See Florida Department of State, Division of Elections, *About Us*, <https://dos.fl.gov/elections/about-us/> (last visited Mar. 11, 2025).

<sup>5</sup> See, e.g., *League of Women Voters of Fla. v. Lee*, 595 F. Supp. 3d 1042 (N.D. Fla. 2022) (addressing Florida’s voting restrictions and their impact on minority voters).

<sup>6</sup> Florida State University College of Law, *College of Law*, <https://law.fsu.edu/> (last visited Mar. 11, 2025).

<sup>7</sup> Florida State University College of Law, *Election Law Center*, <https://law.fsu.edu/academics/election-law-center> (last visited Mar. 12, 2025).

<sup>8</sup> Florida State University College of Law, *Election Law Center*, <https://law.fsu.edu/academics/election-law-center> (last visited Mar. 12, 2025).

<sup>9</sup> Florida State University College of Law, *Election Law Center—Student Opportunities*, <https://law.fsu.edu/academics/election-law-center> (last visited Mar. 12, 2025).

<sup>10</sup> Florida State University College of Law, *Election Law Center Welcomes Executive Director*, <https://law.fsu.edu/press-release/election-law-center-welcomes-executive-director> (last visited Mar. 12, 2025).

<sup>11</sup> Florida State University College of Law, *2024 Distinguished Lecture in Election Law*, <https://law.fsu.edu/2024-distinguished-lecture-election-law> (last visited Mar. 12, 2025).

### **Intellectual Freedom and Viewpoint Diversity**

"Intellectual freedom and viewpoint diversity" is the exposure of students, faculty, and staff to, and the encouragement of their exploration of, a variety of ideological and political perspectives.<sup>12</sup> State universities are prohibited from shielding students, faculty, or staff from ideas or opinions they may find uncomfortable, unwelcome, disagreeable, or offensive.<sup>13</sup>

The Board of Governors of the State University System is required to conduct an annual assessment of intellectual freedom and viewpoint diversity at each state university, using an objective, nonpartisan, and statistically valid survey. This survey measures the extent to which competing ideas and perspectives are presented and whether members of the university community feel free to express their beliefs and viewpoints.<sup>14</sup>

### **III. Effect of Proposed Changes:**

SB 892 establishes the Florida State University (FSU) Election Law Center within the FSU College of Law. The bill creates s. 1004.421, F.S., to codify the center's establishment and define its purpose and scope.

#### **Election Law**

The bill defines "election law" broadly to include, but not be limited to, the following areas:

- Voting rights.
- Election administration.
- Election emergencies.
- Election integrity.
- Voter registration and voter registration databases.
- Cyber or other technical issues relating to elections.
- Federal, state, and local legal provisions governing the electoral process.
- Election contests for any federal, state, or local office.
- Matters relating to the Electoral College or the casting, counting, or validity of electoral votes.
- Federal and state campaign finance law.
- Election audits.
- Apportionment and redistricting.
- Doctrines relating to justiciability, civil procedure, and remedies in election-related cases.

Additionally, the bill extends the definition of election law to historical, empirical, and comparative studies of the specified topics, as well as philosophical and theoretical discussions on democracy, democratic theory, and republicanism.

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<sup>12</sup> Section 1001.706(13)(a)1., F.S.

<sup>13</sup> Section 1001.706(13)(a)2., F.S.

<sup>14</sup> Section 1001.706(13)(b), F.S.

### **Goals of the Florida State University Election Law Center**

The bill establishes the goals of the FSU Election Law Center, directing it to advance scholarship, education, and public confidence in election law. The bill specifically provides that the goals of the center are to:

- Conduct and promote rigorous, objective, nonpartisan, and evidence-based research on significant constitutional, statutory, and regulatory issues related to election law.
- Plan and host events to facilitate learning about the electoral process and election law, providing opportunities for students, scholars, legislators, judges, election administrators, attorneys, and members of the public to engage in discussions.
- Develop and sponsor publicly accessible materials and resources that educate the public on elections and election law, ensuring transparency and accessibility.
- Assist students by providing learning opportunities, practical experience, and career pathways in election law.
- Enhance the reputation of the FSU College of Law as a nationally recognized center for cutting-edge legal scholarship and technical expertise in election law.
- Serve as a nonpartisan resource to address election law inquiries from federal, state, and local election officials, the Legislature, and legislative staff. The center supports understanding of the electoral process and promotes public confidence in Florida's electoral system.
- Develop objective, evidence-based analysis, best practices, and potential reforms to election statutes, regulations, and policies to:
  - Strengthen electoral systems to effectively manage natural disasters and other emergencies that could disrupt elections.
  - Promote public confidence in the electoral process by promoting transparency and integrity.
  - Ensure that all qualified United States citizens in Florida have a reasonable, adequate, and safe opportunity to exercise their right to vote.
  - Minimize the risks of mistakes, fraud, violations, accidents, or other irregularities that could affect elections.

### **Authorized Activities of the Center**

The bill authorizes the FSU Election Law Center to undertake a range of activities to fulfill its mission of advancing election law research, education, and policy development. The bill authorizes the center to:

- Hire necessary faculty and staff to support the center's operations and develop and teach courses related to election law.
- Organize and host events such as workshops, symposia, roundtables, interviews, public discussions, lectures, and conferences.
- Conduct, aid, and sponsor research on election law and publish or make publicly available articles, reports, analyses, databases, or websites to disseminate election law scholarship and policy insights.
- Provide training and continuing education for members of the federal and state judiciaries and judicial organizations, attorneys, Department of State personnel, supervisors of elections and their employees, and other election administrators.

- Offer formal and informal assistance to the Legislature and governmental entities or officials at the federal, state, and county levels on matters related to elections and election law. This assistance may include research, reports, public comments, testimony, or briefs.
- Award scholarships and research assistantships to outstanding students interested in election law and sponsors fellowships to fund qualified students to work with the center or at local, state, or federal offices and nonpartisan entities engaged in election law matters.
- Form partnerships with other centers, programs, institutes, and associations as appropriate to promote the center's goals.

### **Data Sharing and Confidentiality Requirements**

The bill authorizes the Department of State, supervisors of elections, the State Library, and the State Archives to cooperate with the FSU Election Law Center by sharing electronic copies of information or data in their possession, custody, or control upon request of the center's faculty director.

The bill requires the center and its employees to be subject to, and to store such information or data consistent with, confidentiality and security requirements that are comparable to those that apply to the Department of State, supervisors of elections, and their employees.

### **Funding for the Center**

The bill provides that the center will be funded through appropriations as provided in the General Appropriations Act, charitable donations and grants, and other university funds.

### **Leadership and Governance**

The bill requires the dean of the FSU College of Law to appoint a faculty director to lead the center who is a tenured member of the faculty of the law school. The bill requires the faculty director to hire an executive director to conduct the center's day-to-day operations.

The bill requires the faculty director, in consultation with the executive director, to:

- Establish programs that promote the center's goals.
- Develop the budget and disburse the funds appropriated, donated, or provided to the center.
- Hire employees for the center.
- Oversee the center's research, education, and training programs, events, and work product.

### **Academic Freedom and Intellectual Diversity Protections**

The bill requires the center's research, work, activities, filings, speakers, events, and operations be subject to academic freedom protections. The bill prohibits the center or any of its full-time faculty or staff from being compelled to conduct, consult on, or otherwise assist any research or initiatives by any outside federal, state, or local official or agency or private person or entity. The bill further requires the center to promote intellectual freedom and viewpoint diversity, which is the exposure of students, faculty, and staff to, and the encouragement of their exploration of, a variety of ideological and political perspectives.

The bill takes effect July 1, 2025.

**IV. Constitutional Issues:**

A. Municipality/County Mandates Restrictions:

None.

B. Public Records/Open Meetings Issues:

None.

C. Trust Funds Restrictions:

None.

D. State Tax or Fee Increases:

None.

E. Other Constitutional Issues:

None.

**V. Fiscal Impact Statement:**

A. Tax/Fee Issues:

None.

B. Private Sector Impact:

None.

C. Government Sector Impact:

The Florida State University Election Law Center may incur costs to implement the bill's requirements. The bill provides that the center will be funded through appropriations in the General Appropriations Act, charitable donations and grants, and other university funds.

**VI. Technical Deficiencies:**

None.

**VII. Related Issues:**

None.



**VIII. Statutes Affected:**

This bill creates section 1004.421 of the Florida Statutes.

**IX. Additional Information:**

**A. Committee Substitute – Statement of Changes:**

(Summarizing differences between the Committee Substitute and the prior version of the bill.)

None.

**B. Amendments:**

None.

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This Senate Bill Analysis does not reflect the intent or official position of the bill's introducer or the Florida Senate.

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By Senator Simon

3-01557-25

2025892

1 A bill to be entitled  
 2 An act relating to the Florida State University  
 3 Election Law Center; creating s. 1004.421, F.S.;  
 4 creating the center within the Florida State  
 5 University College of Law; defining the term "election  
 6 law"; providing the goals of the center; authorizing  
 7 the center to hire staff and develop courses;  
 8 authorizing the center to hold events and conduct,  
 9 aid, and sponsor specified research; authorizing the  
 10 center to provide training and continuing education;  
 11 authorizing the center to provide assistance to the  
 12 Legislature and other governmental entities;  
 13 authorizing the center to provide scholarships and  
 14 assistantships and to partner with specified entities;  
 15 authorizing specified entities to cooperate with the  
 16 center and share specified information; providing  
 17 mechanisms for the funding of the center; requiring  
 18 the dean of the college of law to appoint a faculty  
 19 director; providing the duties of the faculty and  
 20 executive directors; providing an effective date.  
 21  
 22 Be It Enacted by the Legislature of the State of Florida:  
 23  
 24 Section 1. Section 1004.421, Florida Statutes, is created  
 25 to read:  
 26 1004.421 Election Law Center at the Florida State  
 27 University.—The Florida State University Election Law Center is  
 28 hereby created at the Florida State University College of Law.  
 29 (1)(a) For purposes of this section, the term "election

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CODING: Words ~~stricken~~ are deletions; words underlined are additions.

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30 law" shall be construed broadly to include, but not be limited  
 31 to, issues related to:  
 32 1. Voting rights.  
 33 2. Election administration.  
 34 3. Election emergencies.  
 35 4. Election integrity.  
 36 5. Voter registration and voter registration databases.  
 37 6. Cyber or other technical issues relating to elections.  
 38 7. Federal, state, and local legal provisions governing the  
 39 electoral process.  
 40 8. Election contests for any federal, state, or local  
 41 office.  
 42 9. Matters relating to the Electoral College or the  
 43 casting, counting, or validity of electoral votes.  
 44 10. Federal and state campaign finance law.  
 45 11. Election audits.  
 46 12. Apportionment and redistricting.  
 47 13. Doctrines relating to justiciability, civil procedure,  
 48 and remedies which may arise in election-related cases.  
 49 (b) Election law includes the historical, empirical, and  
 50 comparative aspects of the topics specified in paragraph (a), as  
 51 well as philosophical and theoretical issues relating to  
 52 democracy, democratic theory, and republicanism more broadly.  
 53 (2) The goals of the center are to:  
 54 (a) Conduct and promote rigorous, objective, nonpartisan,  
 55 evidence-based research concerning important constitutional,  
 56 statutory, and regulatory issues relating to election law.  
 57 (b) Plan and host events to allow students, scholars,  
 58 legislators, judges, election administrators, attorneys, and

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CODING: Words ~~stricken~~ are deletions; words underlined are additions.

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members of the public to learn about the electoral process and election law.

(c) Develop and sponsor publicly accessible materials and resources concerning elections and election law.

(d) Assist students in learning about, gaining practical experience with, and pursuing career opportunities relating to election law.

(e) Enhance the Florida State University College of Law's reputation as a nationally respected source for cutting-edge legal scholarship and technical legal expertise.

(f) Serve as a credible, objective, nonpartisan resource to address election law inquiries from federal, state, and local election officials and the Legislature and legislative staff; bolster understanding of the electoral process; and promote public confidence in Florida's electoral system.

(g) Develop objective, evidence-based analysis, best practices, and potential reforms to statutes, regulations, and other policies governing elections to:

1. Enable electoral systems to deal more effectively with natural disasters and other emergencies that can impede or undermine an election;

2. Bolster public confidence in the electoral process;

3. Ensure that United States citizens who meet this state's voter qualification requirements have a reasonable, adequate, and safe opportunity to exercise their right to vote; and

4. Minimize the possibility of mistake, fraud, violations, accidents, or other irregularities impacting elections.

(3) The center may do all of the following:

(a) Hire necessary faculty and staff and develop and teach

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2025892

courses relating to election law.

(b) Hold events, including workshops, symposia, roundtables, interviews, public discussions, lectures, and conferences.

(c) Conduct, aid, and sponsor research relating to election law, to publish or otherwise make publicly available articles, reports, analyses, databases, or websites relating to election law issues.

(d) Provide training and continuing education for the federal and state judiciaries and judicial organizations, attorneys, Department of State personnel, supervisors of elections and their employees, and other election administrators.

(e) Provide formal or informal assistance to the Legislature, as well as to governmental entities or officials at the federal, state, or county levels, concerning elections or election law, including, but not limited to, research, reports, public comments, testimony, or briefs.

(f) Provide scholarships and research assistantships to outstanding students interested in election law and sponsor fellowships to pay for qualified students to work with the center or at any local, state, or federal office or nonpartisan entity that deals with election law.

(g) Partner with other centers, programs, institutes, and associations, as appropriate, to promote the center's goals.

(4) The Department of State, supervisors of elections, the State Library, and the State Archives may cooperate and share with the center electronic copies of information or data in their possession, custody, or control upon request of the

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117 center's faculty director to further the goals of the center,  
 118 provided that the center and its employees are subject to, and  
 119 store such information or data consistent with, confidentiality  
 120 and security requirements comparable to those that apply to the  
 121 department, supervisors of elections, and their employees.

122 (5) The center shall be funded through appropriations as  
 123 provided in the General Appropriations Act, charitable donations  
 124 and grants, and other university funds.

125 (6) The dean of the Florida State University College of Law  
 126 shall appoint a faculty director to lead the center. The faculty  
 127 director must be a tenured member of the faculty of the law  
 128 school. The faculty director shall hire an executive director to  
 129 conduct the center's day-to-day operations. The faculty  
 130 director, in consultation with the executive director, shall do  
 131 all of the following:

132 (a) Establish programs that promote the center's goals.

133 (b) Develop the budget and disburse the funds appropriated,  
 134 donated, or provided to the center.

135 (c) Hire employees for the center.

136 (d) Oversee the center's research, education, and training  
 137 programs, events, and work product.

138 (7) The center's research, work, activities, filings,  
 139 speakers, events, and operations shall be subject to academic  
 140 freedom protections. The center or any of its full-time faculty  
 141 or staff may not be compelled to conduct, consult on, or  
 142 otherwise assist any research or initiatives by any outside  
 143 federal, state, or local official or agency or private person or  
 144 entity. The center shall seek to promote intellectual freedom  
 145 and viewpoint diversity as defined in s. 1001.706(13)(a)1.

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

The Florida Senate

**APPEARANCE RECORD**

Deliver both copies of this form to  
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SB 892

Bill Number or Topic

Amendment Barcode (if applicable)

3/17/25

Meeting Date

(S) Edu Postsec

Committee

Name

Lina Rojas

Phone

305-301-8407

Address

222 S. Copeland St.

Email

lina.rojas@fsu.edu

Street

Tallahassee

City

FL

State

32304

Zip

Speaking: ☐ For ☐ Against ☐ Information

**OR**

Waive Speaking: ☒ In Support ☐ Against

**PLEASE CHECK ONE OF THE FOLLOWING:**

☐ I am appearing without  
compensation or sponsorship.

☒ I am a registered lobbyist,  
representing:

FSU

☐ I am not a lobbyist, but received  
something of value for my appearance  
(travel, meals, lodging, etc.),  
sponsored by:

*While it is a tradition to encourage public testimony, time may not permit all persons wishing to speak to be heard at this hearing. Those who do speak may be asked to limit their remarks so that as many persons as possible can be heard. If you have questions about registering to lobby please see Fla. Stat. §11.045 and Joint Rule 1. [2020-2022 Joint Rules.pdf \(flsenate.gov\)](#)*

This form is part of the public record for this meeting.

S-001 (08/10/2021)

The Florida Senate  
**APPEARANCE RECORD**

Deliver both copies of this form to  
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3/17/25  
Meeting Date  
(S) Edu Postsec  
Committee

SB 892  
Bill Number or Topic

Name Professor Michael Morley Phone 850 778-3883  
Address 222 S. Copeland St. Email mmorley@law.fsu.edu  
Tallahassee FL 32304  
City State Zip

Speaking: ☐ For ☐ Against ☐ Information

**OR**

Waive Speaking: ☒ In Support ☐ Against

**PLEASE CHECK ONE OF THE FOLLOWING:**

☒ I am appearing without  
compensation or sponsorship.

☐ I am a registered lobbyist,  
representing:

☐ I am not a lobbyist, but received  
something of value for my appearance  
(travel, meals, lodging, etc.),  
sponsored by:

*While it is a tradition to encourage public testimony, time may not permit all persons wishing to speak to be heard at this hearing. Those who do speak may be asked to limit their remarks so that as many persons as possible can be heard. If you have questions about registering to lobby please see Fla. Stat. §11.045 and Joint Rule 1. [2020-2022 Joint Rules.pdf \(flsenate.gov\)](#)*

This form is part of the public record for this meeting.

S-001 (08/10/2021)

3/17/25

The Florida Senate  
**APPEARANCE RECORD**

SB 892

Meeting Date  
Post Secondary

Deliver both copies of this form to  
Senate professional staff conducting the meeting

Bill Number or Topic

Committee

Name

Jack Rowan

Phone

(904) 891-4391

Address

521 E 7th Ave Unit 1

Email

jmr206@fsu.edu

Street

Tallahassee

FL

32303

City

State

Zip

Speaking:

☒

For

☐

Against

☐

Information

**OR**

Waive Speaking:

☐

In Support

☐

Against

**PLEASE CHECK ONE OF THE FOLLOWING:**

☒

I am appearing without  
compensation or sponsorship.

☐

I am a registered lobbyist,  
representing:

☐

I am not a lobbyist, but received  
something of value for my appearance  
(travel, meals, lodging, etc.),  
sponsored by:

While it is a tradition to encourage public testimony, time may not permit all persons wishing to speak to be heard at this hearing. Those who do speak may be asked to limit their remarks so that as many persons as possible can be heard. If you have questions about registering to lobby please see Fla. Stat. §11.045 and Joint Rule 1. [2020-2022 Joint Rules.pdf \(flsenate.gov\)](#)

This form is part of the public record for this meeting.

S-001 (08/10/2021)

**The Florida Senate**  
**BILL ANALYSIS AND FISCAL IMPACT STATEMENT**

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

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Prepared By: The Professional Staff of the Committee on Education Postsecondary

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BILL: CS/SB 1356

INTRODUCER: Education Postsecondary Committee and Senator Burton

SUBJECT: Florida Institute for Pediatric Rare Diseases

DATE: March 19, 2025      REVISED:

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	Jahnke	Bouck	HE	<b>Fav/CS</b>
2.			AHS	
3.			FP	

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**Please see Section IX. for Additional Information:**

COMMITTEE SUBSTITUTE - Substantial Changes

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**I. Summary:**

CS/SB 1356 codifies the Florida Institute for Pediatric Rare Diseases (Institute) within the Florida State University College of Medicine as a statewide resource dedicated to research and clinical care related to pediatric rare diseases. The Institute will conduct research, develop diagnostic and genetic screening tools, provide multidisciplinary clinical services and care, educate and train healthcare professionals, and collaborate with other institutions and organizations.

The bill requires the Institute to establish and administer the Sunshine Genetics Pilot Program for five years. This opt-in pilot program offers genetic screening, to include whole genome sequencing to newborns, contingent upon parental consent. Clinical findings from the screening must be released to the newborn's healthcare practitioner and parent. The Institute is required to maintain a secure database of pilot program data and provide deidentified data to support research.

Additionally, the bill establishes the Sunshine Genetics Consortium (Consortium) to facilitate collaboration among researchers, geneticists, and physicians from Florida's state universities and children's hospitals. The Consortium's responsibilities include integrating genomic sequencing technologies, advancing genetic and precision medicine research, educating healthcare professionals, leveraging artificial intelligence in genomics, and securing external funding to expand genetic screening efforts. An oversight board appointed by state universities and government officials will administer the Consortium and meet at least once every six months.



The bill appropriates \$5 million in recurring funds from the General Revenue Fund for Fiscal Year 2025-2026 to support the Institute, with an additional appropriation of \$20 million in nonrecurring funds specifically designated for the implementation of the Sunshine Genetics Pilot Program.

The bill takes effect July 1, 2025.

## **II. Present Situation:**

### **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 rare diseases impacting the lives of 30 million Americans and their families.<sup>1</sup> 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 rare genetic diseases, genetic testing is often the only way to make a definitive diagnosis.<sup>2</sup>

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 healthcare settings where their condition may have never been seen before.<sup>3</sup>

### **The Andrew John Anderson Pediatric Rare Disease Grant Program**

In 2024, the Florida Legislature established the Andrew John Anderson Pediatric Rare Disease Grant Program (Grant Program) within the Department of Health (DOH) to support research on pediatric rare diseases. The Grant Program awards grants through a competitive, peer-reviewed process to advance new diagnostics, treatments, and cures.<sup>4</sup>

The DOH, in consultation with the Rare Diseases Advisory Council,<sup>5</sup> awards grants to universities and established research institutes in Florida for scientific and clinical research. Preference may be given to proposals that foster collaborations among institutions, researchers, and community practitioners.<sup>6</sup>

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<sup>1</sup> National Organization for Rare Diseases (NORD), *NORD Rare Disease Database*, <https://rarediseases.org/rare-diseases/> (last visited Mar. 10, 2025).

<sup>2</sup> Department of Health, *Rare Disease Advisory Council: Legislative Report, Fiscal Year 2023-2024* (2024), at 6-7, available at <https://www.floridahealth.gov/provider-and-partner-resources/rdac/documents/2024-rdac-annual-report.pdf>.

<sup>3</sup> *Id.*

<sup>4</sup> Section 381.991(1)(a), F.S.; *See also* ch. 224-246, Laws of Fla.

<sup>5</sup> *See* Section 381.99, F.S. The Rare Disease Advisory Council is created adjunct to the DOH for the purpose of providing recommendations on ways to improve health outcomes for individuals residing in this state who have a rare disease.

<sup>6</sup> Section 381.991(1)(b) – (2)(a), F.S. *See also*, Florida Health, *Rare Pediatric Diseases Research Grant Program*, <https://www.floridahealth.gov/provider-and-partner-resources/research/research-programs1/RarePediatricDiseasesResearchGrantProgram.html> (last visited Mar. 10, 2025).

In both 2023 and 2024, the Legislature appropriated \$500,000 for the Grant Program.<sup>7</sup>

### **Florida State University Institute for Pediatric Rare Diseases**

In 2024, Florida State University (FSU) established the Institute for Pediatric Rare Diseases (Institute) at the FSU College of Medicine. It is the mission of the Institute to transform the lives of children affected by rare diseases through research, education, diagnosis, and clinical care.<sup>8</sup>

The goals include:<sup>9</sup>

- Harnessing interdisciplinary collaboration by bringing together scientists, clinicians, and educators to address the challenges of pediatric rare diseases.
- Leveraging advancements in gene therapy and immune response research to improve treatment outcomes.
- Enhancing the quality of life for the 15 million children across the United States affected by pediatric rare diseases.

In 2023, the Legislature allocated \$1,000,000 to the Institute,<sup>10</sup> and another \$5,000,000 in 2024.<sup>11</sup>

### **Newborn Screening Program**

The Legislature created the Florida Newborn Screening Program (NSP) within the DOH, to promote the screening of all newborns for metabolic, hereditary, and congenital disorders known to result in significant impairment of health or intellect.<sup>12</sup> The NSP also promotes the identification and screening of all newborns in the state and their families for environmental risk factors such as low income, poor education, maternal and family stress, emotional instability, substance abuse, and other high-risk conditions associated with increased risk of infant mortality and morbidity to provide early intervention, remediation, and prevention services.<sup>13</sup>

The NSP attempts to screen all newborns for hearing impairment and to identify, diagnose, and manage newborns at risk for select disorders that, without detection and treatment, can lead to permanent developmental and physical damage or death.<sup>14</sup> The NSP is intended to screen all

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<sup>7</sup> Specific Appropriation 539A, s. 3, ch. 2023-239, Laws of Fla., and Specific Appropriation 546A, s. 3, ch. 2024-231, Laws of Fla.

<sup>8</sup> Florida State University, Florida State University News, *FSU launches groundbreaking Institute for Pediatric Rare Diseases*, <https://news.fsu.edu/news/health-medicine/2024/02/01/fsu-launches-groundbreaking-institute-for-pediatric-rare-diseases/>; See also, Florida State University, *Institute for Pediatric Rare Diseases*, <https://med.fsu.edu/iprd/home> (last visited Mar. 10, 2025).

<sup>9</sup> *Id.*

<sup>10</sup> Specific Appropriation 143, s. 2, ch. 2023-239, L.O.F.

<sup>11</sup> Specific Appropriation 147, s. 2, ch. 2024-231, L.O.F.

<sup>12</sup> Section 383.14(1), F.S.

<sup>13</sup> Section 383.148(1), F.S.

<sup>14</sup> Florida Department of Health, *Florida Newborn Screening 2022 Guidelines*, available at <https://floridanewbornscreening.com/wp-content/uploads/NBS-Protocols-2022-FINAL.pdf>. See also, Florida Newborn Screening, <https://floridanewbornscreening.com/> (last visited Mar. 10, 2025).

prenatal women and newborns, however, parents and guardians may choose to decline the screening.<sup>15</sup>

Newborn screenings are completed after the baby is 24 hours of age and before discharge from the hospital. For births outside a hospital setting, the birth provider either completes the screening or arranges for testing within 1- 2 days after birth.<sup>16</sup>

The Florida Genetics and Newborn Screening Advisory Council advises the DOH on disorders to be included in the NSP panel of screened disorders and the procedures for collecting and transmitting specimens.<sup>17</sup> Florida's NSP currently screens for 58 conditions, 55 of which are screened through the collection of blood spots.<sup>18</sup> Healthcare providers collect drops of blood from the newborn's heel on a standardized specimen collection card which is then sent to the state laboratory for testing.<sup>19</sup>

If necessary, healthcare providers refer patients to the appropriate health, education, and social services.<sup>20</sup> Screening results are released to the newborn's healthcare provider; in the event of an abnormal result, the baby's healthcare provider or a nurse or specialist from NSP's Follow-up Program provides follow-up services and referrals for the child and his or her family.<sup>21</sup>

### III. Effect of Proposed Changes:

CS/SB 1356 creates s. 1004.4210, F.S., to codify the Florida Institute for Pediatric Rare Diseases (Institute) within the Florida State University College of Medicine as a statewide resource for pediatric rare disease research and clinical care. The Institute's purpose is to enhance the quality of life and health outcomes for children and families affected by rare diseases by advancing knowledge, diagnosis, and treatment of pediatric rare diseases through research, clinical care, education, and advocacy. The bill specifies the goals of the Institute, which are:

- Conducting research to better understand the causes, mechanisms, and potential treatments for pediatric rare diseases, including leveraging emerging research methods
- Developing advanced diagnostic and genetic screening tools and techniques to enable healthcare providers to identify rare diseases in newborns and children more rapidly, accurately, and economically.
- Providing comprehensive, multidisciplinary clinical services and care for affected children and their families. Such care may include, but is not limited to, patient, family, and caregiver

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<sup>15</sup> Section 383.14(4), F.S.; Rule 64C-7.008, F.A.C.; The hospital provider shall request any parent or guardian who objects to infant (postnatal) risk screening of their child or ward, after the purpose of the screening has been fully explained, to indicate the objection in writing on the electronic birth record risk screening instrument.

<sup>16</sup> Florida Newborn Screening, *What is Newborn Screening?*, <https://floridanewbornscreening.com/parents/what-is-newborn-screening/> (last visited Mar. 10, 2025).

<sup>17</sup> Section 383.14(6)(a), F.S.

<sup>18</sup> Department of Health, *2024 Agency Analysis of HB 1441* (Feb. 5, 2024).

<sup>19</sup> Florida Newborn Screening Program, *What is Newborn Screening?* available at <https://floridanewbornscreening.com/parents/what-is-newborn-screening/> (last visited March 10, 2025). See also, Florida Newborn Screening, Specimen Collection Card, <http://floridanewbornscreening.com/wp-content/uploads/Order-Form.png> (last visited March 10, 2025).

<sup>20</sup> *Id.*

<sup>21</sup> Department of Health, *2024 Agency Analysis of HB 1441* (Feb. 5, 2024).

support and resources to help navigate the challenges associated with these conditions, support groups, and patient advocacy.

- Educating and training healthcare professionals, including, but not limited to, genetic counselors, pediatricians, scientists, and other specialists.
- Establishing collaborations with other research institutions, medical centers, patient and family advocacy organizations, and government agencies.

The bill requires the Institute to establish and administer the Sunshine Genetics Pilot Program for five years, providing genetic screening, including, but not limited to, whole genome sequencing to newborns in addition to the state's existing newborn screening program. Upon approval of the oversight board, the genetic screening will be performed by the Institute and institutional members of the oversight board. The Institute is authorized to partner with Florida universities and colleges and healthcare service providers to promote and assist in the implementation of the pilot program. Parental consent is required for participation and the Institute and institutional members of the oversight board must release clinical findings of a newborn's screening to the newborn's health care practitioner and the newborn's parent.

The bill defines "health care practitioner" to include:

- a physician or physician assistant licensed under chapter 458;
- an osteopathic physician or physician assistant licensed under chapter 459;
- an advanced practice registered nurse, registered nurse, or licensed practical nurse licensed under part I of chapter 464;
- a midwife licensed under chapter 467;
- a speech-language pathologist or audiologist licensed under part I of chapter 468;
- a dietitian or nutritionist licensed under part X of chapter 468; or
- a genetic counselor licensed under part III of chapter 483.

The bill requires the Institute to:

- Maintain a secure database to collect and store all pilot program data, including, but not limited to, newborn genomics sequence data and deidentified newborn data.
- Provide deidentified newborn data to members of the Consortium pursuant to a data sharing agreement to support ongoing and future research.

Additionally, by December 1, 2030, the Institute is required to provide a report to the Governor, the President of the Senate, and the Speaker of the House of Representatives on the pilot program, including, at a minimum:

- Study population and enrollment metrics.
- Whole genome sequencing metrics.
- Clinical and public health impact.
- Cost effectiveness and economic benefits.

The bill also establishes the Sunshine Genetics Consortium (Consortium) to create a network of clinical and academic research professionals, geneticists, and physicians from state universities and the state's children's hospitals to collaborate with leaders in the genetic industry, build, and support a culture of collaborative research and the development of cutting-edge genetic and precision medicine in the state. The Consortium will:

- Integrate state-of-the-art genomic sequencing technologies.
- Advance research and the development of cutting-edge genetic and precision medicine.
- Leverage artificial intelligence in genomics.
- Develop clinician education on genomic tools.
- Support education and growth of geneticists to meet demand.
- Solicit and leverage external funding to expand the pilot program and support genetic screenings by institutional members of the oversight board.
- Promote patient care to support families with children diagnosed with genetic disorders.
- Report on the use of deidentified newborn data by members of the Consortium.

The bill requires the Consortium to be administrated at the Institute by an oversight board and meet at least once every six months. The oversight board consist of the director of the Institute, who serves as chair, and the following voting members who are required to serve two-year terms:

- One member nominated by the dean of the University of Florida's College of Medicine and approved by the university's president.
- One member nominated by the dean of the University of South Florida's College of Medicine and approved by the university's president.
- One member nominated by the dean of the University of Miami's School of Medicine and approved by the university's president.
- One member appointed by the Governor.
- One member appointed by the President of the Senate.
- One member appointed by the Speaker of the House of Representatives.

The oversight board is responsible for the promotion and oversight of the Consortium, including, but not limited to, the nomination and appointment of members of the Consortium.

The bill requires the Consortium, beginning October 15, 2026, and annually thereafter, to provide a report to the Governor, the President of the Senate, and the Speaker of the House of Representatives on research projects, research findings, community outreach initiatives, and future plans for the Consortium.

The bill appropriates \$5 million in recurring funds from the General Revenue Fund for Fiscal Year 2025-2026 to support the Institute, with an additional appropriation of \$20 million in nonrecurring funds specifically designated for the implementation of the Sunshine Genetics Pilot Program.

The bill takes effect July 1, 2025.

#### **IV. Constitutional Issues:**

##### **A. Municipality/County Mandates Restrictions:**

None.

**B. Public Records/Open Meetings Issues:**

None.

**C. Trust Funds Restrictions:**

None.

**D. State Tax or Fee Increases:**

None.

**E. Other Constitutional Issues:**

None.

**V. Fiscal Impact Statement:****A. Tax/Fee Issues:**

None.

**B. Private Sector Impact:**

None.

**C. Government Sector Impact:**

The bill appropriates \$5 million in recurring funds from the General Revenue Fund for Fiscal Year 2025-2026 to support the Institute, with an additional appropriation of \$20 million in nonrecurring funds specifically designated for the implementation of the Sunshine Genetics Pilot Program..

**VI. Technical Deficiencies:**

None.

**VII. Related Issues:**

None.

**VIII. Statutes Affected:**

This bill creates section 1004.4210 of the Florida Statutes.

**IX. Additional Information:****A. Committee Substitute – Statement of Substantial Changes:**

(Summarizing differences between the Committee Substitute and the prior version of the bill.)

**CS by Education Postsecondary on March 17, 2025:**

The committee substitute maintains provisions in SB 1356, with the following modifications:

- Removes the requirement for the Consortium to create a biorepository network.
- Removes the requirement for the pilot program to be implemented in accordance with specific genetic testing regulations.
- Extends the duration of the Sunshine Genetics Pilot Program from three years to five years.
- Clarifies genetic testing as whole genome sequencing.
- Specifies that the Institute and institutional members of the oversight board, upon approval, will perform the genetic screening.
- Authorizes, rather than requires, the Institute to establish partnerships to promote and assist in the implementation of the pilot program.
- Clarifies that clinical findings of a newborn's screenings must be delivered to both the newborn's healthcare practitioner and parent.
- Specifies that the Institute must collect and store pilot program data, explicitly including genomics sequence data and deidentified newborn data.
- Requires the Institute to provide deidentified newborn data to members of the Consortium pursuant to a data sharing agreement to support ongoing and future research.
- Revises the Institute's reporting requirements on the pilot program specifying that, by December 1, 2030, the Institute must provide a report to include an overview of key metrics and the program's impact on health, cost-effectiveness, and economic benefits.
- Requires the Consortium to advance research and the development of cutting edge genetic and precision medicine.
- Clarifies that the Consortium must solicit and leverage funds, rather than simply raise them, and expands the purpose of funding to explicitly support genetic screenings by institutional members of the oversight board in addition to expanding the pilot program.
- Requires the Consortium to report on the use of deidentified newborn data by members of the Consortium.
- Specifies that the Consortium's oversight board must meet at least every six months.
- Requires the director of the Institute to serve as the chair of the oversight board.
- Modifies the selection process for university-approved members of the Consortium oversight board.
- Revises the oversight board's responsibilities from financial and technical management to general promotion and oversight of the Consortium.
- Specifies that the Consortium's annual reporting must begin on October 15, 2026, and expands reporting requirements to include research projects, findings, community outreach initiatives, and future plans.

- Broadens the scope of the \$20 million appropriation from funding only whole genome sequencing at birthing centers to supporting the full implementation of the Sunshine Genetics Pilot Program.

B. Amendments:

None.

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This Senate Bill Analysis does not reflect the intent or official position of the bill's introducer or the Florida Senate.

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LEGISLATIVE ACTION

Senate	.	House
Comm: RCS	.	
03/17/2025	.	
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The Committee on Education Postsecondary (Burton) recommended the following:

**Senate Amendment (with title amendment)**

Delete everything after the enacting clause  
and insert:

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

1004.4211 The Florida Institute for Pediatric Rare  
Diseases; the Sunshine Genetics Pilot Program; the Sunshine  
Genetics Consortium.—

(1) The Florida Institute for Pediatric Rare Diseases is



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established within the Florida State University College of  
Medicine as a statewide resource for pediatric rare disease  
research and clinical care. The purpose of the institute is to  
improve the quality of life and health outcomes for children and  
families affected by rare diseases by advancing knowledge,  
diagnosis, and treatment of pediatric rare diseases through  
research, clinical care, education, and advocacy.

(2) The goals of the institute are to:

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

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

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

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

(e) Establish collaborations with other research  
institutions, medical centers, patient and family advocacy  
organizations, and government agencies whenever deemed  
appropriate by the institute director to share expertise, raise  
awareness, and promote a collective effort to tackle pediatric



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rare diseases.

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

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

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

(d) The institute and institutional members of the oversight board shall release clinical findings of a newborn's screening to the newborn's health care practitioner and the newborn's parent. As used in this paragraph, the term "health care practitioner" means a physician or physician assistant licensed under chapter 458; an osteopathic physician or physician assistant licensed under chapter 459; an advanced practice registered nurse, registered nurse, or licensed practical nurse licensed under part I of chapter 464; a midwife licensed under chapter 467; a speech-language pathologist or audiologist licensed under part I of chapter 468; a dietitian or nutritionist licensed under part X of chapter 468; or a genetic counselor licensed under part III of chapter 483.

(e) The institute shall:

1. Maintain a secure database to collect and store all



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pilot program data, including, but not limited to, newborn  
genomics sequence data and deidentified newborn data.

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

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

1. Study population and enrollment metrics.

2. Whole genome sequencing metrics.

3. Clinical and public health impact.

4. Cost effectiveness and economic benefits.

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

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

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

3. Leverage advancements in artificial intelligence  
utilization in genomics.

4. Develop educational opportunities for clinicians on  
genomic tools.



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

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

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

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

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

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

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

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

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

d. One member appointed by the Governor.

e. One member appointed by the President of the Senate.

f. One member appointed by the Speaker of the House of Representatives.



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

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

Section 2. For the 2025-2026 fiscal year, the sum of \$5 million in recurring funds is appropriated from the General Revenue Fund to the Florida Institute for Pediatric Rare Diseases.

Section 3. For the 2025-2026 fiscal year, the sum of \$20 million in nonrecurring funds is appropriated from the General Revenue Fund to the Florida Institute for Pediatric Rare Diseases for the implementation of the Sunshine Genetics Pilot Program established in s. 1004.4211, Florida Statutes.

Section 4. This act shall take effect July 1, 2025.

===== T I T L E   A M E N D M E N T =====

And the title is amended as follows:

Delete everything before the enacting clause  
and insert:

A bill to be entitled  
An act relating to the Florida Institute for Pediatric  
Rare Diseases; creating s. 1004.4211, F.S.;  
establishing the Florida Institute for Pediatric Rare  
Diseases within the Florida State University College  
of Medicine; providing the goals of the institute;



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requiring the institute to establish and administer the Sunshine Genetics Pilot Program for a specified period; providing the purpose of the pilot program; providing institute responsibilities and duties relating to the pilot program; providing requirements for participation in the pilot program and data collection and release in the pilot program; defining the term "health care practitioner"; providing reporting requirements for the pilot program; establishing the Sunshine Genetics Consortium for specified purposes; requiring the consortium to be administered at the institute by an oversight board; providing for the membership and terms of the board; providing meeting and reporting requirements for the consortium; providing appropriations; providing an effective date.

By Senator Burton

12-01277B-25

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A bill to be entitled

An act relating to the Florida Institute for Pediatric Rare Diseases; creating s. 1004.4210, F.S.; establishing the Florida Institute for Pediatric Rare Diseases within the Florida State University College of Medicine; providing the goals of the institute; requiring the institute to establish and administer the Sunshine Genetics Pilot Program for a specified period; providing the purpose of the pilot program; providing institute responsibilities and duties relating to the pilot program; providing requirements for participation in the pilot program and data collection in the pilot program; providing reporting requirements for the pilot program; establishing the Sunshine Genetics Consortium for specified purposes; requiring the consortium to be administered at the institute by a board; providing for the membership and terms of the board; providing reporting requirements for the consortium; providing appropriations; providing an effective date.

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

Section 1. Section 1004.4210, Florida Statutes, is created to read:

1004.4210 The Florida Institute for Pediatric Rare Diseases; the Sunshine Genetics Pilot Program; the Sunshine Genetics Consortium.—

(1) The Florida Institute for Pediatric Rare Diseases is

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**CODING:** Words ~~stricken~~ are deletions; words underlined are additions.

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established within the Florida State University College of Medicine as a statewide resource for pediatric rare disease research and clinical care. The purpose of the institute is to improve the quality of life and health outcomes for children and families affected by rare diseases by advancing knowledge, diagnosis, and treatment of pediatric rare diseases through research, clinical care, education, and advocacy.

(2) The goals of the institute are to:

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

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

(c) Provide comprehensive multidisciplinary clinical services and care for children with rare diseases. Such care may include patient, family, and caregiver support and resources to help navigate the challenges associated with these conditions, support groups, and patient advocacy.

(d) Educate and train health care professionals, including genetic counselors, pediatricians, scientists, and other specialists in the field of pediatric rare diseases.

(e) Establish collaborations with other research institutions, medical centers, and government agencies whenever deemed appropriate by the institute director and to share expertise, raise awareness, and promote a collective effort to tackle pediatric rare diseases.

(3) (a) The institute shall establish and administer the

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**CODING:** Words ~~stricken~~ are deletions; words underlined are additions.



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Sunshine Genetics Pilot Program to be administered for a period of 3 years. The pilot program shall offer genetic testing to newborns in addition to the state's newborn screening program.

(b) The institute shall partner with qualified state universities, colleges, and health care service providers to implement the pilot program and deliver and analyze genetic testing results for the pilot program.

(c) The pilot program shall be an opt-in program and a parent of a newborn must provide parental consent to join the pilot program.

(d) Upon the completion of the genetic testing through the pilot program, all testing data and reports shall be delivered to the parent's health care provider.

(e) The institute shall:

1. Conduct the pilot program in accordance with the requirements of s. 760.40.

2. Maintain a secure database to store all pilot program data, including newborn testing data.

3. Deidentify all patient data.

4. Upon the approval of the board of the Sunshine Genetics Consortium created under subsection (4), enter into an agreement with the consortium to share deidentified patient data.

(f) Upon the completion of the pilot program, the institute shall provide a report to the Governor, the President of the Senate, and the Speaker of the House of Representatives.

(4)(a) The Sunshine Genetics Consortium is established to create a network of clinical and academic research professionals, geneticists, and physicians from state universities and the state's children's hospitals to collaborate

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with leaders in the genetic industry and build and support a culture of collaborative research and the development of cutting-edge genetic and precision medicine in the state. The consortium shall:

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

2. Create a biorepository network and database for ongoing and future research.

3. Leverage advancements in artificial intelligence utilization in genomics.

4. Develop educational opportunities for clinicians on genomic tools.

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

6. Raise funds from nonprofits, private industry, and others to expand the pilot program under subsection (3).

7. Promote patient care to support families with children diagnosed with genetic disorders.

(b)1. The consortium shall be administered at the institute by an oversight board and shall meet periodically.

2. The oversight board for the consortium shall serve 2-year terms and consist of the following voting members:

a. One member from the Florida State University to be appointed by the Dean of the College of Medicine.

b. One member from the University of Florida to be appointed by the Dean of the College of Medicine.

c. One member from the University of South Florida to be appointed by the Dean of the College of Medicine.

d. One member from the University of Miami to be appointed

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by the Dean of the College of Medicine.

e. One member appointed by the Governor.

f. One member appointed by the President of the Senate.

g. One member appointed by the Speaker of the House of Representatives.

3. The board shall be responsible for the technical performance and financial management of the consortium.

(c) The consortium shall annually provide a report to the Governor, the President of the Senate, and the Speaker of the House of Representatives.

Section 2. For the 2025-2026 fiscal year, the sum of \$5 million in recurring funds is appropriated from the General Revenue Fund to the Florida Institute for Pediatric Rare Diseases.

Section 3. For the 2025-2026 fiscal year, the sum of \$20 million in nonrecurring funds is appropriated from the General Revenue Fund to the Florida Institute for Pediatric Rare Diseases to launch and execute whole genome sequencing at birthing centers.

Section 4. This act shall take effect July 1, 2025.

**APPEARANCE RECORD**

3/17

Meeting Date

Education Postsecondary

Deliver both copies of this form to  
Senate professional staff conducting the meeting

1356

Bill Number or Topic

Committee

Amendment Barcode (if applicable)

Name

Robby Holroyd

Phone

Address

Street

Email

City

State

Zip

Speaking:

☐

For

☐

Against

☐

Information

**OR**

Waive Speaking:

☒

In Support

☐

Against

**PLEASE CHECK ONE OF THE FOLLOWING:**☐I am appearing without  
compensation or sponsorship.☒I am a registered lobbyist,  
representing:☐I am not a lobbyist, but received  
something of value for my appearance  
(travel, meals, lodging, etc.),  
sponsored by:

Biotechnology Innovation Organization

While it is a tradition to encourage public testimony, time may not permit all persons wishing to speak to be heard at this hearing. Those who do speak may be asked to limit their remarks so that as many persons as possible can be heard. If you have questions about registering to lobby please see Fla. Stat. §11.045 and Joint Rule 1. [2020-2022 Joint Rules.pdf \(flsenate.gov\)](#)

This form is part of the public record for this meeting.

S-001 (08/10/2021)

3/17/25

Meeting Date

Education PostSecondary

Committee

The Florida Senate  
**APPEARANCE RECORD**

Deliver both copies of this form to  
Senate professional staff conducting the meeting

SB 1356

Bill Number or Topic

Amendment Barcode (if applicable)

Name **Leslie Dughi** Phone **8505193903**

Address **119 South Monroe Street, Suite 200** Email **Leslie.Dughi@mhdfirm.com**

Street

**Tallahassee** **FL** **32301**

City

State

Zip

Speaking: ☐ For ☐ Against ☐ Information **OR** Waive Speaking: ☒ In Support ☐ Against

**PLEASE CHECK ONE OF THE FOLLOWING:**

☐ I am appearing without  
compensation or sponsorship.

☒ I am a registered lobbyist,  
representing:

**BioFlorida**

☐ I am not a lobbyist, but received  
something of value for my appearance  
(travel, meals, lodging, etc.),  
sponsored by:

While it is a tradition to encourage public testimony, time may not permit all persons wishing to speak to be heard at this hearing. Those who do speak may be asked to limit their remarks so that as many persons as possible can be heard. If you have questions about registering to lobby please see Fla. Stat. §11.045 and Joint Rule 1. [2020-2022JointRules.pdf \(flsenate.gov\)](#)

This form is part of the public record for this meeting.

S-001 (08/10/2021)

The Florida Senate

# APPEARANCE RECORD

Deliver both copies of this form to  
Senate professional staff conducting the meeting

3/17/25

Meeting Date

Education Post-Sec

Committee

13856

Bill Number or Topic

Amendment Barcode (if applicable)

Name PRADEEP BHIDE

Phone 850-645-9847

Address 1115 WEST CALL ST, FSU

Email PBHIDE@FSU.EDU

Street

TALLAHASSEE FL

32306

City

State

Zip

Speaking: ☐ For ☐ Against ☐ Information

OR

Waive Speaking: ☒ In Support ☐ Against

## PLEASE CHECK ONE OF THE FOLLOWING:

☐ I am appearing without  
compensation or sponsorship.

☐ I am a registered lobbyist,  
representing:

☐ I am not a lobbyist, but received  
something of value for my appearance  
(travel, meals, lodging, etc.),  
sponsored by:

While it is a tradition to encourage public testimony, time may not permit all persons wishing to speak to be heard at this hearing. Those who do speak may be asked to limit their remarks so that as many persons as possible can be heard. If you have questions about registering to lobby please see Fla. Stat. §11.045 and Joint Rule 1. [2020-2022 Joint Rules.pdf \(flsenate.gov\)](#)

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S-001 (08/10/2021)

The Florida Senate  
**APPEARANCE RECORD**

Deliver both copies of this form to  
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3/17/25  
Meeting Date  
(S) Edu Postsec  
Committee

SB 1356  
Bill Number or Topic

Name Lina Rojas

Amendment Barcode (if applicable)  
Phone 305 301 8407

Address 222 S. Copeland St.  
Street

Email lina.rojas@fsu.edu

Tallahassee FL 32309  
City State Zip

Speaking: ☐ For ☐ Against ☐ Information

**OR**

Waive Speaking: ☒ In Support ☐ Against

**PLEASE CHECK ONE OF THE FOLLOWING:**

☐ I am appearing without  
compensation or sponsorship.

☒ I am a registered lobbyist,  
representing:

FSU

☐ I am not a lobbyist, but received  
something of value for my appearance  
(travel, meals, lodging, etc.),  
sponsored by:

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S-001 (08/10/2021)



3/17/2025

Meeting Date

EDUCATION POSTSECONDARY

Committee

The Florida Senate  
**APPEARANCE RECORD**

Deliver both copies of this form to  
Senate professional staff conducting the meeting

1356

Bill Number or Topic

Amendment Barcode (if applicable)

Name **CHRIS HANSEN**

Phone **850.577.0444**

Address **201 E PARK AVE, 5TH FLOOR**

Email **chansen@ballardpartners.com**

Street

**TALLAHASSEE**

**FL**

**32301**

City

State

Zip

Speaking: ☐ For ☐ Against ☐ Information **OR** Waive Speaking: ☒ In Support ☐ Against

**PLEASE CHECK ONE OF THE FOLLOWING:**

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☒ I am a registered lobbyist,  
representing:

**ALEXION PHARMACEUTICALS**

☐ I am not a lobbyist, but received  
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(travel, meals, lodging, etc.),  
sponsored by:

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S-001 (08/10/2021)

The Florida Senate

**APPEARANCE RECORD**

03/17/25

Meeting Date

SB 1356

Bill Number or Topic

Education Postsecondary

Committee

Deliver both copies of this form to  
Senate professional staff conducting the meeting

Amendment Barcode (if applicable)

Name Dawn Lambert

Phone 727-420-4219

Address 10142 Beefmaster Ct

Street

Email dawn.lambert.327@gmail.com

New Port Richey FL

City

State

34655

Zip

Speaking: ☒ For ☐ Against ☐ Information

**OR**

Waive Speaking: ☐ In Support ☐ Against

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☐ I am a registered lobbyist, representing:

☐ I am not a lobbyist, but received something of value for my appearance (travel, meals, lodging, etc.), sponsored by:

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S-001 (08/10/2021)



The Florida Senate

**APPEARANCE RECORD**

03/17/25

Meeting Date

SB 1356

Bill Number or Topic

Education Postsecondary

Committee

Deliver both copies of this form to  
Senate professional staff conducting the meeting

Amendment Barcode (if applicable)

Name Garvin Lambert

Phone 727-255-9080

Address 10142 Beefmaster Ct

Street

Email dawn.lambert, 327@gmail.com

New Port Richey FL 34655

City

State

Zip

Speaking: ☒ For ☐ Against ☐ Information **OR** Waive Speaking: ☐ In Support ☐ Against

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S-001 (08/10/2021)

# CourtSmart Tag Report

**Room:** SB 301

**Case No.:**

**Type:**

**Caption:** Senate Committee on Education Postsecondary

**Judge:**

**Started:** 3/17/2025 1:31:35 PM

**Ends:** 3/17/2025 1:46:35 PM

**Length:** 00:15:01

1:31:36 PM Chair Calatayud calls the meeting to order  
1:31:41 PM Roll call  
1:32:00 PM Chair Calatayud makes opening remarks  
1:32:08 PM Tab 2, SB 1356 by Burton, Florida Institute for Pediatric Rare Diseases  
1:32:18 PM Amendment #758458 by Burton  
1:32:32 PM Senator Burton explains the amendment  
1:34:10 PM Senator Burton waives close on the amendment  
1:34:16 PM Chair Calatayud reports the amendment  
1:34:19 PM Back on the bill  
1:34:24 PM Chair Calatayud recognizes public appearances  
1:34:33 PM Gavin Lambert  
1:36:32 PM Dawn Lambert  
1:38:46 PM Debate:  
1:38:50 PM Senator Berman  
1:39:34 PM Senator Harrell  
1:40:51 PM Senator Burton closes on the bill  
1:42:10 PM Roll call  
1:42:34 PM Tab 1, SB 892 by Simon, Florida State University Election Law Center  
1:42:43 PM Senator Simon explains the bill  
1:43:16 PM Questions:  
1:43:19 PM Senator Berman  
1:43:41 PM Senator Simon  
1:44:06 PM Senator Berman  
1:44:15 PM Senator Simon  
1:44:27 PM Chair Calatayud recognizes public appearances  
1:44:37 PM Jack Rowen  
1:45:52 PM Senator Simon waives close on the bill  
1:45:57 PM Roll call  
1:46:27 PM Senator Jones moves to adjourn  
1:46:29 PM Meeting adjourned  
1:46:36 PM