

Committee on Education Postsecondary

CS/CS/HB 907 — Florida Institute for Pediatric Rare Diseases

by Health Care Budget Subcommittee; Education Administration Subcommittee; and Rep. Anderson and others (CS/CS/SB 1356 by Fiscal Policy Committee; Education Postsecondary Committee; and Senators Burton and Berman)

The bill codifies the Florida Institute for Pediatric Rare Diseases (Institute) within the Florida State University College of Medicine as a statewide resource to advance research, clinical care, and education related to pediatric rare diseases. The Institute's responsibilities include:

- Conducting research on the causes, diagnosis, and treatment of pediatric rare diseases;
- Developing advanced diagnostic and genetic screening tools;
- Providing multidisciplinary clinical services and family support;
- Educating and training healthcare professionals; and
- Collaborating with research institutions, medical centers, advocacy organizations, and government agencies.

The bill creates the Sunshine Genetics Consortium (Consortium), a statewide network of researchers, geneticists, and physicians from Florida's public universities and children's hospitals. The Consortium is responsible for:

- Integrating genomic sequencing technologies;
- Advancing research in genetic and precision medicine;
- Leveraging artificial intelligence in genomics;
- Promoting clinician education and workforce development; and
- Securing external funding to support and expand genetic screening efforts.

The Consortium will be overseen by an oversight board chaired by the director of the Institute and composed of representatives from:

- Florida State University,
- University of Florida,
- University of South Florida,
- University of Miami,
- Florida International University,
- Nicklaus Children's Hospital, and
- One member each appointed by of the Governor, Senate President, and Speaker of the House of Representatives.

The oversight board must meet at least twice annually and submit its first report on research and outreach activities to the Governor, the President of the Senate, and the Speaker of the House of Representatives by October 15, 2026.

The bill requires the Institute to establish the Sunshine Genetics Pilot Program, a five-year opt-in initiative offering newborn genetic screening, including whole genome sequencing, with parental consent. Under the program:

- Clinical results must be provided to the newborn's healthcare practitioner and parent.
- The Institute must maintain a secure database of screening data; and
- Deidentified data must be shared with Consortium researchers under a data-sharing agreement.

The Institute must submit a report to the Governor, the President of the Senate, and the Speaker of the House of Representatives by December 1, 2030, evaluating the pilot program's outcomes, including clinical impact and cost-effectiveness.

Implementation of the Institute, Consortium, and pilot program is contingent upon funding provided in the General Appropriations Act.

If approved by the Governor, or allowed to become law without the Governor's signature, these provisions take effect July 1, 2025.

Vote: Senate 37-0; House 116-0