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### **CONTACT**

Nazbi Chowdhury  
Office of Leader Bobby DuBose  
[Nazbi.Chowdhury@myfloridahouse.gov](mailto:Nazbi.Chowdhury@myfloridahouse.gov)  
850-717-5094

## **Florida Legislature Unanimously Passes Bill to Establish Rare Disease Advisory by House Minority Leader Bobby DuBose and Senator Dennis Baxley**

**Tallahassee, Fla.** – Today, the Florida House unanimously passed [SB 272](#), by Florida House of Representatives Minority **Leader Bobby DuBose (D-Ft. Lauderdale)** and **Senator Dennis Baxley (R-Lady Lake)**. [SB 272](#), creates a Rare Disease Advisory Council (RDAC) connected to the Florida Department of Health for the purpose of providing recommendations on ways to improve health outcomes for individuals residing in the state who have a rare disease.

A rare disease is any condition that nationally affects fewer than 200,000 people. As many as 7,000 rare diseases affect the lives of 25-30 million Americans and their families. Currently, 16 states have established RDACs. The council will be made up of 20 members from various state agencies, subject matter experts and other stakeholders. Members will be appointed by the Governor, President of the Senate, and Speaker of the House to a four year term.

“What could be more important than helping a person who is struggling with a rare disease connect to resources and support that just might save their life? As a father to a daughter living with a rare disease, I can tell you, there is not much out there for them. This council will be a great starting point for solving these issues and meeting those needs.” said **Senator Baxley**.

“People living in Florida with a rare disease find information to be scarce, resources limited, and a platform to gather data non-existent.” said **Leader DuBose**. “Delays in diagnosis, misdiagnosis, and a lack of treatment options are far too common. This council will work to help solve these issues.”

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