From: Arellano, Joey

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Subject: FOR IMMEDIATE RELEASE: House Minority Leader Bobby DuBose Proposes Rare Disease Advisory Council

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## **CONTACT:**

Nazbi Chowdhury Office of Leader Bobby DuBose Nazbi.Chowdhury@myfloridahouse.gov

## House Minority Leader Bobby DuBose Proposes Rare Disease Advisory Council

**TALLAHASSEE**, **Fla.** – Florida House of Representatives Minority **Leader Bobby DuBose (D-Ft. Lauderdale)** filed **HB 1373** to improve the health outcomes of Floridians living with a rare disease by creating the Rare Disease Advisory Council.

Sunday, February 28 is <u>Rare Disease Day</u>. The purpose of this day is to raise the public's awareness about rare diseases and its impact on those dealing with these ailments. In the United States alone, approximately 30 million Americans are living with a rare disease, many of which do not have a cure. According to the National Institute of Health, there are as many as 7,000 rare diseases.

"This initiative is very close to me. I've experienced the loss of a loved one due to *scleroderma*, a rare disease," said **Leader DuBose**. "The creation of the Rare Disease Advisory Council will help many Floridians better manage the extremely painful conditions they are living with, especially since there is no cure for a majority of these diseases."

The Rare Disease Advisory Council will be comprised of 20 members from various state agencies, subject matter experts and other stakeholders. The council will serve in an advisory board capacity to the Florida Department of Health by providing expert recommendations regarding rare disease care and research.