



# Meeting Minutes

## Rare Disease Advisory Council (RDAC) State Agencies Subcommittee Meeting

**Date: Wednesday, January 19, 2022**

**Time: 10:00 AM – 11:00 AM EST**

**Microsoft Teams Video Conference**

Member Name	Member Seat	Present	Absent
David Altmaier	A representative of the Office of Insurance Regulation.	X	
Ann Dalton	A representative of the Agency for Health Care Administration.	X	
John Hawayek	A representative of the biotechnology industry.	X	
Kathy Hebda, Vice-Chair	A representative of the Department of Education.		X
Melissa Jordan, Chair	A representative of the Department of Health.	X	
Dr. Scott McClelland	A pharmacist who is licensed and practicing in this state who has experience with drugs that are used in the treatment of rare diseases.		X
Jennifer Sutherland	An individual who is a caregiver of an individual with a rare disease.		X

Guests: Debra Webber

### **Call to Order, Member Roll Call**– Casey Omeke, Florida Department of Health

The meeting was called to order at 10:00 AM. Role was taken, and a quorum was established.

### **Overview of Draft Legislative Report** – Casey Omeke, Florida Department of Health

An overview of the subcommittee’s statutory requirement listed in 381.99 (4)(d), Florida Statutes was given. The subcommittee reviewed each of the recommendations developed during the previous council meetings.

### **Development of Recommendations** – Council Members

Council members discussed, revised, and expanded upon the recommendations. In order to better understand the incidence and prevalence of rare diseases in Florida, the council members proposed researching current published literature on the top 50 most diagnosed rare diseases in the state.

### **Subcommittee Next Steps** – Casey Omeke, Florida Department of Health

The council members felt it would be better to meet again prior to the next scheduled Rare Disease Advisory

Council meeting scheduled for February 17, 2022.

**Public Comment** – *Casey Omeke, Florida Department of Health*

No public comment was provided.

**Adjournment** – *Casey Omeke, Florida Department of Health*

The meeting adjourned at 10:47 AM.