



# Meeting Minutes

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

**Date: Tuesday, January 17, 2023**

**Time: 11:00 AM – 12:00 PM EST**

**Microsoft Teams Video Conference**

Member Name	Member Seat	Present	Absent
David Altmaier	A representative of the Office of Insurance Regulation.		X
Eric Biernacki	An individual who is, or was previously, a caregiver for individuals with a rare disease.	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 representative of health insurance companies.	X	
Jennifer Sutherland	An individual who is a caregiver of an individual with a rare disease.		X

Guests: Vera Beloshitzkaya (Florida Department of Health), Chris Cogle (Agency for Health Care Administration), Kelly Rogers (Florida Department of Health)

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

The meeting was called to order at 11:05 AM. Role was taken, and a quorum was not established. Chris Cogle, Chief Medical Officer at the Agency for Health Care Administration, stood in place for Ann Dalton.

### **Approval of Subcommittee Meeting Minutes** – Casey Omeke, Florida Department of Health

Casey Omeke moved for the Meeting Minutes from the December 14, 2022 Subcommittee meeting to be tabled for review and approval during the February 21, 2023, Subcommittee meeting.

### **Review and Discussion of Shared Data** – Council Members

Subcommittee members reviewed and discussed the data shared with Subcommittee members gifted from Spark Therapeutics for the top 50 most prevalent rare conditions, as well as the ICD-10 codes for the

conditions screened for by the Florida Newborn Screening program. Subcommittee members Jon Hawayek and Eric Biernacki are working on reviewing state and national resources available for the listed conditions. The Agency for Health Care Administration has sent the dataset to their analytics team to identify prevalence of the listed conditions

**Year 1 Objectives Implementation Plan Updates and Next Steps** – *Casey Omeke, Florida Department of Health*

The Subcommittee continued the discussion and finalized the Year 1 Objectives Implementation Plan. Council members provided status updates for the action steps on the Recommendations and Objectives they are responsible for.

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

No public comment was provided.

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

The meeting adjourned at 11:48 AM.