



Meeting Minutes

Rare Disease Advisory Council (RDAC) Health Care Provider Subcommittee Meeting

Date: Monday, April 11, 2022
Time: 12:00 p.m. – 1:00 p.m. EST
Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Dr. Anita Davis	A representative of organizations in this state which provide care or other support to individuals with rare diseases.		X
Rebekah Dorr	A representative of organizations in this state which provide care or other support to individuals with rare diseases.		X
Zana Dupee	An individual who is a caregiver of an individual with a rare disease.	X	
Jessica O'Reilly	An individual who is 18 years of age or older who has a rare disease.		X
India Steinbaugh	An individual who is 18 years of age or older who have a rare disease.	X	

Guests: Tara Cockman (Department of Health), Kara Godwin (UF Health), Debra Webber

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

The meeting was called to order at 12:00 p.m. by Casey Omeke. Roll was taken, and a quorum was not established.

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

Casey provided a review of the draft legislative report and the recommendations that were created during the previous subcommittee meetings.

Development of Recommendations – Council Members

Council members discussed recommendations. Council members agreed that because a quorum could not be established, they would review and finalize recommendations during the reserved time of the upcoming RDAC meeting before presenting the recommendations to the council.

Subcommittee Next Steps – Casey Omeke, Florida Department of Health

Casey agreed that she would share the draft subcommittee recommendations with council members to review prior to the RDAC meeting held on April 14, 2022.

Public Comment – Casey Omeke, Florida Department of Health

A member of the public shared a personal experience regarding their spouse, who suffers from a rare disease, experiencing challenges seeking treatment. Additionally, they shared examples of frustrations they deal with as a caregiver of someone with a rare disease.

A member of the public shared information regarding a pediatric rare neuromuscular and disease center which has developed a list of established diagnostic and treatment resources on specific rare diseases.

Adjournment – *Casey Omeke, Florida Department of Health*

The meeting adjourned at 12:34 p.m.