



Meeting Minutes

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

Date: Thursday, March 16, 2023

Time: 12:00 PM – 1:00 PM 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: Kelly Rogers, Tara Cockman

Call to Order, Member Roll Call– *Marci Perkins, Florida Department of Health*

The meeting was called to order at 12:05 PM.

Review and Approval of Meeting Minutes – *Marci Perkins, Florida Department of Health*

Dr. Anita Davis moved to approve the meeting minutes from the January 24, 2023, meeting. Ms. Zana Dupee seconded the motion to approve. The meeting minutes from January 24, 2023, were approved. Dr. Anita Davis moved to approve the meeting minutes from the February 24, 2023, meeting. Ms. Zana Dupee seconded the motion to approve. The meeting minutes from February 24, 2023, were approved.

Review and Discussion of Resources– *Council Members*

Members reviewed barriers and challenges to medical practices and specialists in accepting pediatric and adult individuals with rare diseases. Members pointed out, “how can doctors screen for rare diseases if a vast majority of insurances deny the screening?” Members also reviewed resources on self-advocacy. Topics of discussions appear to overlap and will be discussed in the next State Agency Subcommittee meeting.

Year 1 Objectives Implementation Plan Updates and Next Steps – *Council Members*

The Subcommittee continued the discussion of 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 – *Marci Perkins, Florida Department of Health*

No public comment was provided.

Adjournment – *Marci Perkins, Florida Department of Health*

The meeting was adjourned at 12:31 pm.