



Meeting Minutes

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

Date: Wednesday, March 27, 2024

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: Jon Conley (Florida Department of Health), Maggie Dilger (Florida Department of Health), Jenna Doerr (Artia Solutions), Leslie Dughi, Holly Murphy, Folger Tuggle

Call to Order and Member Roll Call – Maggie Dilger, Florida Department of Health

The meeting was called to order at 12:02 p.m. Roll was taken, and a quorum was established.

Approval of Meeting Minutes – Council Members

A motion to approve the January meeting minutes was made by India Steinbaugh and seconded by Dr. Anita Davis. The motion carried.

Discussion of Work Plan – Council Members

Jon Conley with the Florida Department of Health presented the subcommittee’s work plan and explained the council’s Annual Report is due by July 1. Due to the routing process, the report should be completed in April. The council will have an opportunity to review the document at the April 24, 2024, RDAC meeting.

Council members asked if the objectives should be reviewed by the subcommittee and determined if they are still attainable or should be revisited at a later time. Mr. Conley explained that the goal for the Annual Report is to discuss the accomplishments the council has made, and in future meetings the work plan will need some updates and possible council leads to accomplish.

There were additional questions from members related to the development of surveys. Staff explained that they have been researching surveys completed by other state RDACs and indicated that there would be further explained opportunities to collaborate with other groups within the Department to survey the rare disease community, health care providers, and physicians. Any members with survey questions were directed to email council staff and those suggestions would be discussed at future meetings.

Member Updates – *Council Members*

Dr. Davis asked if there was anything the council members should be working on between meetings, and staff directed her to review the work plan and provide any suggestions to council staff via email to be discussed/voted on during future council meetings.

Future Agenda Items

No comment was made.

Public Comment

No public comment was made.

Adjournment – *Maggie Dilger, Florida Department of Health*

A motion to adjourn was made by Dr. Davis. The meeting adjourned at 12:28 p.m.