



Meeting Minutes

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

Date: Wednesday, January 24, 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)

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

The meeting was called to order at 12:05 p.m., and the roll was taken. A quorum was not established.

Approval of Meeting Minutes – *Council Members*

The approval of the November 15, 2023, meeting minutes were moved to the next meeting.

Discussion of Subcommittee Mission – *Jon Conley, Florida Department of Health*

Jon Conley with the Department gave a brief overview of the statutory requirements of the Rare Disease Advisory Council (RDAC). He emphasized that the role of the Council was to serve those who are impacted by and those who treat rare diseases, by A) seeking ways to improve the treatment of rare diseases, and B) developing strategies for providers to better learn how to recognize and diagnose rare diseases. He explained that Department staff would be reviewing the status of the subcommittees' objectives and seeking guidance from the subcommittees on how to continue working on those objectives moving forward.

Mr. Conley explained the three subcommittees were created by the RDAC to focus on the annual report. He asked the subcommittee to think about how often and how long the subcommittee should meet in the future to ensure the best use of the council members' time.

Dr. Anita Davis asked for a project plan for the subcommittee to be resent in a more digestible format. Mr. Conley agreed, and the Department staff will reformat the previously shared implementation plan and redistribute it to the subcommittee.

Mr. Conley asked the group if the current monthly, one-hour meeting at noon is still the best format and duration. Dr. Davis explained that time is still preferred. Mr. Conley offered to try to begin scheduling meetings six months in advance.

Member Updates – Council Members

Dr. Davis provided an update on her work compiling curricula from medical schools around the state and shared that responses have not been plentiful. Mr. Conley asked if a collaboration with the Physicians Workforce Advisory Council would be beneficial since so many on the council are the deans of Florida University Medical Schools. Dr. Davis expressed a desire to do so.

Future Agenda Items Discussion – Council Members

Mr. Conley mentioned the Academic Research Institutions Subcommittee proposed having someone from the Muscular Dystrophy Association speak to the council and asked for suggestions about additional advocacy groups that the subcommittee would like to hear from.

Public Comment

No public comment was provided.

Adjournment – Maggie Dilger, Florida Department of Health

The meeting adjourned at 12:30 p.m.