



# Meeting Minutes

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

Date: Wednesday, July 19, 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 (Florida Department of Health), Tara Cockman (Florida Department of Health), Marci Perkins (Florida Department of Health), Maggie Dilger (Florida Department of Health)

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

The meeting was called to order at 12:05 PM. Roll was called, and a quorum was established.

### Approval of Meeting Minutes – Council Members

A motion was made by Dr. Anita Davis to approve the March 16, 2023, subcommittee meeting minutes. India Steinbaugh seconded, and the meeting minutes were approved.

### Year 2 Objectives Implementation Plan – Council Members

Kelly Rogers with the Florida Department of Health asked for subcommittee members' feedback from the 2022-2023 Legislative Report. There was discussion on streamlining subcommittees' recommendations/objectives and goals as well as communication strategies moving forward. Kelly explained the subcommittees' recommendations are flexible and can be changed to ensure needs are being addressed for the rare disease community.

Tara Cockman with the Florida Department of Health reviewed the Year 2 Implementation Plan for the Health Care Providers Subcommittee and asked for council member leads for each objective. She explained ad hoc meetings for individual objectives would be supported by the Florida Department of Health staff as needed/requested by council members.

It was noted that resources cannot be promoted by the Florida Department of Health if any services or products are being sold.

There was a question on compiling information that requires subject matter experts. While the RDAC does not have

financial resources, the recommendations provided by the council are important and it may be more realistic to break down action steps previously listed for year two over the next few years.

The Florida Department of Health staff will offer action steps within the subcommittee's implementation plan and council members will have the opportunity to review/approve during the August 2023 subcommittee meeting.

A joint meeting with the Academic Research Institutions Subcommittee was requested to discuss recommendations that would be of interest to both subcommittees.

Tara Cockman mentioned the implementation plan would evolve over the next few months as action steps are further developed.

**Public Comment** – *Members of the Public*

No public comment was provided.

**Adjournment** – *Tara Cockman, Florida Department of Health*

The meeting was adjourned at 1:03 pm.

DRAFT