

Rare Disease Advisory Council Health Care Providers Subcommittee Meeting Minutes

Tuesday, September 17, 2024 12:00 p.m. EST Virtual

Welcome/Introductions:

Dr. Anita Davis, Chair, welcomed everyone and began the meeting at 12:03 p.m. EST.

The following members or designees were in attendance:

Dr. Anita Davis Zana Dupee India Steinbaugh

Guests and Staff:

Yolanda Bonds, Florida Department of Health Jon Conley, Florida Department of Health Maggie Dilger, Florida Department of Health Leslie Dughi, Metz, Husband & Daughton, P.A.

Business

1. Approval of Meeting Minutes:

Dr. Davis motioned to approve August 2024 Meeting Minutes, and India Steinbaugh seconded. The August 2024 meeting minutes were approved.

2. Member Updates

No member updates were provided.

3. Discussion Topics

a. Next quarterly meeting of the RDAC: The next meeting of the Rare Disease Advisory Council is scheduled for Monday, October 7, 2024, from 12:00 – 1:00 p.m. EST. The meeting will be a hybrid format via Microsoft Teams and at Florida State University's campus. Further details and meeting materials will be shared on the council's webpage and shared via email.

b. Review of Resources, Tasks, and Recommendations:

- The subcommittee reviewed previously compiled resources and established recommendations.
- The council agreed the recommendations should remain.
- Council staff will share previous minutes to help clarify previous discussions held on screening tools available.
- A survey was discussed, and more information is needed to determine what the previous goals of
 the subcommittee were. Council staff directed members to the published <u>meeting minutes</u>. Staff
 explained surveys have been mentioned in the other subcommittees as well, and a future
 roundtable discussion is being planned to include other state RDACs who have conducted or are
 currently conducting surveys.

c. Next Steps/Future Meeting Dates

Full Council meets October 7, from 12:00 – 1:00 p.m. EST

- Next Subcommittee Meeting is scheduled for November 12, from 12:00 1:00 p.m. EST
- Tentative Full Council Meeting and State RDAC Roundtable on December 11 from 11:00 a.m. –
 1:00 p.m. EST.

4. Public Comments/Open Discussion:

No public comments were received.

5. Adjournment:

Dr. Davis asked for a motion to adjourn. Ms. Steinbaugh motioned to adjourn, and Ms. Dupee seconded. All were in favor and the meeting concluded at 12:51 p.m. EST.