



Rare Disease Advisory Council State Agencies Subcommittee Meeting Minutes

Wednesday, September 18, 2024

12:00 p.m. EST

Virtual

Welcome:

Melissa Jordan, Chair, with the Department welcomed attendees at 12:06 p.m. EST.

The following members or designees were in attendance:

Eric Bernacki
Ann Dalton
Kathy Hebda
Melissa Jordan

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.

Approval of Meeting Minutes:

Eric Biernacki motioned to approve the August 2024 Meeting Minutes, and Kathy Hebda seconded. The minutes were approved unanimously.

Member Updates:

No member updates were provided.

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 about FSU Discovery Days and meeting materials will be shared.
- b. **Resources Assessment:** Request for a future subcommittee meeting to include a panel discussion with Disaster Preparedness/Emergency Management, Children's Medical Services, and a local school representative that oversees emergency shelters.
- c. **Goals of Future Survey:** Discussion on the goals of the survey, possible hurdles, and consideration for collaboration to obtain responses.
- d. **Collaborative Resources for Website and Survey:** An outline of future webpages was discussed and shared.
- e. **Next Steps/Future Meetings**
 - a. RDAC Meeting will be October 7, 2024, at 12:00 p.m. (Hybrid)
 - b. State Agencies Subcommittee will be November 13, 2024, at 12:00 p.m. (Virtual)
 - c. RDAC Meeting and Roundtable Discussion with state RDACs is tentatively scheduled for December 11, 2024, at 11:00 a.m. (Virtual)
 - d. Members will receive a scheduling survey soon to begin planning 2025 meeting dates.

Public Comments/Open Discussion:

No public comments were received.

Adjournment:

Chair Jordan motioned to adjourn, and Mr. Biernacki seconded. The meeting adjourned at 12:46 p.m. EST.

DRAFT