



Rare Disease Advisory Council Health Care Providers Subcommittee Meeting Minutes

Wednesday, August 14, 2024

12:00 p.m. EST

Virtual

Welcome/Introductions:

Jon Conley with the Florida Department of Health welcomed everyone and began the meeting at 12:05 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.

Anna Grace Lewis, Metz, Husband & Daughton, P.A.

Lee Willer-Spector, caretaker and VHLA's Board of Directors

Business

1. Approval of Meeting Minutes:

Zana Dupee motioned to approve past meeting minutes. Dr. Anita Davis seconded. The March 2024 meeting minutes were approved.

2. Appointment of Health Care Providers Chair

Dr. Anita Davis was nominated and approved as the Chair of the subcommittee for the next year. Moving forward, council staff will consult with Dr. Davis on the subcommittee's agendas to ensure the work of the subcommittee is achieved.

3. Target Priorities for the Year

Mr. Conley reviewed the subcommittee's previous priorities.

- Members agreed Recommendation 1: Promote education on rare diseases to health care providers should remain a target priority.
- Members agreed Recommendation 2: Promote advancements in the process of achieving a diagnosis for rare diseases needed to be clarified.
- Members agree Recommendation 3: Promote Education on Rare Diseases and Enhance Support Resources should remain a top priority.

4. Pre-discussion for Hybrid Meeting in October

Maggie Dilger with the Department reminded the group there would be a quarterly meeting of the RDAC scheduled the week of October 7, 2024. More information will be shared as soon as dates/times are confirmed.

5. Public Comments/Open Discussion:

No public comments were received.

6. Adjournment:

Meeting adjourned at 12:36 p.m. EST.