



Rare Disease Advisory Council State Agencies Subcommittee Meeting Minutes

Thursday, August 15, 2024

12:00 p.m. EST

Virtual

Welcome:

Maggie Dilger with the Department welcomed attendees at 12:06 p.m. EST and took roll.

The following members or designees were in attendance:

Eric Bernacki

Ann Dalton

Kathy Hebda

Melissa Jordan

Jennifer Sutherland

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

Approval of Meeting Minutes:

Eric Biernacki motioned to approve. Kathy Hebda seconded. Minutes were approved unanimously.

Subcommittee Business:

Jon Conley with the Department provided an update on term limits. Members with expiring term limits wanting to be reappointed were encouraged to write a letter to their appointment authority expressing continued interest in the council.

Mr. Conley asked if there would be a need for a subcommittee chair. Kathy Hebda nominated Melissa Jordan and Eric Biernacki seconded. The motion was approved unanimously.

Pre-discussion for Hybrid Meeting in October:

Maggie Dilger with the Department reminded the council that the scheduling survey would close on August 16 and emphasized how results would help schedule upcoming meetings. Staff will update and confirm an October meeting of the full council soon. The meeting is tentatively planned to be hybrid (in-person at FSU Discovery Days and virtually via Microsoft Teams).

Target Priorities for the Year:

After reviewing the goals of the subcommittee from last fiscal year, subcommittee members established the following priorities for the 2024-2025 FY:

- State Agencies' resources assessment
- Creation of a survey for the rare disease community

Next Steps:

- Council staff will work with Chair Jordan to invite or possibly nominate an ad hoc member from the Department who can provide insight on disaster preparedness.
- Council staff will confirm presentations/collaborations with other state RDACs.

Public Comments/Open Discussion:

No public comments were received.

Adjournment:

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