



Meeting Minutes

Rare Disease Advisory Council (RDAC) State Agencies Subcommittee Meeting

Date: Tuesday, March 26, 2024

Time: 10:00 – 11:00 AM EST

Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Vacant	A representative of the Office of Insurance Regulation.		
Eric Biernacki	An individual who is, or was previously, a caregiver for individuals with a rare disease.	X	
Ann Dalton	A representative of the Agency for Health Care Administration.	X	
Jon Hawayek	A representative of the biotechnology industry.	X	
Kathy Hebda, Vice-Chair	A representative of the Department of Education.	X	
Melissa Jordan, Chair	A representative of the Department of Health.	X	
Dr. Scott McClelland	A representative of health insurance companies.	X	
Jennifer Sutherland	An individual who is a caregiver of an individual with a rare disease.		X

Guests: Jon Conley (Florida Department of Health), Maggie Dilger (Florida Department of Health), Jenna Doerr (Artia Solutions), Leslie Dughi, Holly Murphy (Acadia), Kemi Olabisi (Acadia), Crystal Stickle

Call to Order and Member Roll Call – *Maggie Dilger, Florida Department of Health*

The meeting was called to order at 10:03 a.m. Roll was taken, and a quorum was established.

Approval of Meeting Minutes – *Council Members*

Members approved the minutes from the previous subcommittee meeting.

Discussion of Work Plan – *Council Members*

Florida Department of Health reviewed the subcommittee’s work plan and explained the council’s Annual Report is due by July 1. Due to the routing process, the report should be completed in April. The council will have an opportunity to review the document at the April 24, 2024, RDAC meeting. Mr. Conley led the group in reviewing the plan and asked the subcommittee to provide any updates.

Melissa Jordan expressed a desire to focus on getting access to commercial data to fill in the gaps of the incidence/prevalence data already obtained, and suggested researching what other states are using for data sets. There was discussion on obtaining data from the Office of Insurance Regulation (OIR) and Department of Management Services (DMS). Council staff was asked to reach out to DMS to request data regarding State Employee Health System.

Jon Hawayek mentioned other states are using an opt-in program on their websites to allow organizations to submit resources.

Member Updates – Council Members

Ann Dalton with the Agency for Health Care Administration (AHCA) noted AHCA is continuing its work with partners on coverage of gene therapies. Mr. Conley suggested a future presentation from AHCA to provide broader information as the Medicaid coverage for this program has been of interest to all members of the council.

Eric Biernacki mentioned the RDAC was a topic of conversation during Rare Disease Day and the work of the council was recognized by the legislature.

Future Agenda Items Discussion

There was no discussion of future agenda items.

Public Comment

No public comment was made.

Adjournment – Maggie Dilger, Florida Department of Health

Melissa Jordan motioned to adjourn the meeting and Kathy Hebda seconded the motion. The meeting adjourned at 10:42 a.m.