



Meeting Minutes

Rare Disease Advisory Council (RDAC) State Agencies Subcommittee Meeting

Date: Friday, January 26, 2024

Time: 12:00 PM – 1:00 PM 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)

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

The meeting was called to order at 12:05 p.m. Roll was taken, and a quorum was not established.

Approval of Meeting Minutes – Council Members

Approval of the November 16, 2023, meeting minutes were moved to the next meeting.

Discussion of Subcommittee Mission – Jon Conley, Florida Department of Health

Jon Conley with the Department gave a brief overview of the statutory requirements of the Rare Disease Advisory Council (RDAC). He emphasized that the role of the Council was to serve those who are impacted by and those who treat rare diseases, by A) seeking ways to improve the treatment of rare diseases, and B)

developing strategies for providers to better learn how to recognize and diagnose rare diseases. He explained that Department staff would be reviewing the status of the subcommittees' objectives and seeking guidance from the subcommittees on how to continue working on those objectives moving forward.

Kathy Hebda and Ann Dalton agreed the need for clarification on the roles of the subcommittees. Ms. Dalton mentioned it has been helpful when her agency was tasked directly with a project and mentioned looking forward to getting an update on what the subcommittees have been working on at the next full council meeting. Ms. Dalton also expressed interest in getting feedback from the council regarding next steps of data collection/analysis and coverage moving forward – objectives the Agency for Health Care Administration and the Department have been tasked with.

Melissa Jordan stated the importance of having a representative from the Office of Insurance Regulation on the council to accomplish the council's recommendations. Ms. Jordan proposed possibly creating another subcommittee to help with resource inventory across the three established subcommittee (Academic Research Institutions, Health Care Providers, State Agencies). Ms. Hebda voiced support of a website subcommittee. This suggestion will be part of a larger discussion with the full council.

Mr. Conley mentioned the Academic Research Institutions Subcommittee had interest in holding an in-person meeting and explained he is researching options and possibilities.

Member Updates – Council Members

No member updates were presented.

Future Agenda Items Discussion – Council Members

Mr. Conley updated the group that the other RDAC subcommittees are interested in hearing from advocacy groups, specifically the Muscular Dystrophy Association.

Ms. Jordan suggested looking at other states' RDACs to research speakers, patient and caregiver surveys, and additional resources that could be insightful for the committee.

Public Comment

A member of the public, who requested to remain anonymous, asked about insurance guidelines for approving treatments. Jon Conley offered his email for further information.

Adjournment – Maggie Dilger, Florida Department of Health

The meeting adjourned at 12:29 p.m.