



Meeting Minutes

Rare Disease Advisory Council (RDAC) State Agencies Subcommittee Meeting

Date: Thursday, November 16, 2023

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: 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 established.

Member Updates – Council Members

No member updates were provided. Maggie Dilger with the Department provided a brief overview of the October 2023 full council meeting:

- Future website ideas are being researched by the Department and staff plans to take inventory of resources previously collected by Council members. More details will be shared in the future.
- AHCA provided updates on Medicaid’s rare disease prevalence data as well as rule developments regarding Medicaid coverage of Rapid Whole Genome Sequencing.

Future Agenda Items Discussion – Council Members

No comment was provided, and members were encouraged to submit suggestions via email to Maggie Dilger with the Department. Staff queried members as to the need for meetings in December, and there was discussion about postponing meetings until after the holiday season. Kathy Hebda voiced support of postponing if council members do not have updates to provide.

Public Comment

No public comment was made.

Adjournment – Maggie Dilger, Florida Department of Health

The meeting adjourned at 12:15 p.m.