



Meeting Minutes

Rare Disease Advisory Council (RDAC) Meeting

Date: Monday, May 8, 2023
Time: 12:00 PM – 1:00 PM EST
Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Eric Biernacki	An individual who is, or was previously, a caregiver for individuals with a rare disease.	X	
Dr. Barry Byrne	A representative from an academic research institution in Florida, which receives grant funding for research regarding rare diseases.	X	
Ann Dalton	A representative of the Agency for Health Care Administration.		X
Dr. Anita Davis	A representative of organizations in this state which provide care or other support to individuals with rare diseases.	X	
Rebekah Dorr	A representative of organizations in this state which provide care or other support to individuals with rare diseases.		X
Zana Dupee	An individual who is a caregiver of an individual with a rare disease.		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	
Jessica O'Reilly	An individual who is 18 years of age or older who has a rare disease.		X
Dr. Divya Patel	A physician who is licensed under Ch. 458 or 459, F.S., practices in this state, and has experience in treating rare diseases.	X	
India Steinbaugh	An individual who is 18 years of age or older who have a rare disease.	X	
Jennifer Sutherland	An individual who is a caregiver of an individual with a rare disease.	X	

Dr. Mustafa Tekin	A representative from an academic research institution in this state which receives grant funding for research regarding rare diseases.		X
Dr. Rajan Wadhawan	A physician who is licensed under chapter 458 or chapter 459 and practicing in this state with experience in treating rare diseases.		X
Vacant	An individual who is, or was previously, a caregiver for individuals with a rare disease.		
Vacant	A geneticist practicing in this state.		
Vacant	A registered nurse or advanced practice registered nurse who is licensed and practicing in this state with experience in treating rare diseases.		
Vacant	A hospital administrator from a hospital in this state which provides care to individuals diagnosed with rare diseases.		
Vacant	A representative of health insurance companies.		
Vacant	A representative of the Office of Insurance Regulation.		

Guests: Danielle Uribe (Florida Department of Health), Tara Cockman (Florida Department of Health), Marci Perkins (Florida Department of Health), Christopher Cogle (in for Dr. Ann Dalton), Grace Boran, Leslie Dughi, Crystal Stickle, Katie Steigelman, Holly Murphy, Haley Tobias, and Steve Khan.

Call to Order, Member Roll Call – Melissa Jordan, Chair

The meeting was called to order at 12:02 PM by Melissa Jordan, Council Chair. Roll was taken and a quorum was established.

Approval of Council and Subcommittee Meeting Minutes – Council Members

Melissa Jordan moved for the minutes to be accepted from the April 17, 2023, council meeting. The council unanimously approved the minutes.

Review of finalized Legislative Annual Report and Recommendations – Council Members

Council members were broken up into their respective subcommittees to review their section of the annual report along with corresponding appendices while in breakout rooms. A copy of this report was included in the chat of the meeting for all to view.

Council Feedback and discussion of Legislative Annual Report and Recommendations – Council Members

All participants were returned to the main virtual meeting room. A spokesperson from each subcommittee provided a summary to the council regarding edits requested to the annual legislative report.

Legislative annual Report next Steps – Melissa Jordan, Chair

The final draft of the report will begin internal routing through the Department for approval. Once routed and

approved, the Legislative Annual Report will be made available on the Department's website. The council will have a break during the month of June 2023. Council meetings from July to December will be scheduled and posted in advance on the Department website.

Public Comment – *Melissa Jordan, Chair*

No public comment was provided.

Adjournment – *Melissa Jordan, Chair and Chancellor, Kathy Hebda, Vice-Chair*

The meeting adjourned at 12:55 PM.