



Meeting Minutes

Rare Disease Advisory Council (RDAC) Meeting

Date: Wednesday, May 4, 2022

Time: 11:00 AM – 12:30 PM EST

Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
David Altmaier	A representative of the Office of Insurance Regulation.	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
John 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 pharmacist who is licensed and practicing in this state who has experience with drugs that are used in the treatment of rare diseases.		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	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.		

Guests: Vera Beloshitzkaya (Florida Department of Health), Tara Cockman (Florida Department of Health), Jessenia Leaphart, Jackie Menzel (Artia Solutions), Casey Omeke (Florida Department of Health), Linda Starnes (Florida Department of Health)

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

The meeting was called to order at 11:03 AM 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 14th, 2022, council meeting as well as minutes from the April 11th, 2022 Health Care Provider Subcommittee meeting. The council unanimously approved the minutes at 11:06 AM.

Review of Finalized Legislative Annual Report and Recommendations – *Council Members*

Council members reviewed the final draft of the Legislative Annual Report which included all finalized subcommittee recommendations.

Council Feedback and Discussion of Legislative Annual Report and Recommendations – *Council Members*

Council members provided feedback on the final draft of the Legislative Annual Report. It was suggested to add additional information about the advancements in health care and available treatments for individuals with rare diseases in Florida to the report.

Legislative Annual Report Next Steps – *Melissa Jordan, Chair*

Melissa Jordan shared that the final draft of the Legislative Annual Report would begin the process for internal approval through the Department of Health before being published on the Department of Health’s website. Melissa informed the council that there would be no meeting during the month of June and that the council would reconvene on July 13, 2022.

Public Comment – *Melissa Jordan, Chair*

No public comment was provided.

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

The meeting adjourned at 12:04 PM.