



Meeting Minutes

Rare Disease Advisory Council (RDAC) Meeting

Date: Tuesday, December 14, 2021

Time: 11:30 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: Leslie Dughi (Metz, Husband & Daughton, P.A.), Kara Godwin (UF Health), Bethany Linderman (Florida Blue), Casey Omeke (Florida Department of Health), Kelly Rogers (Florida Department of Health), Debra Webber

Call to Order, Member Roll Call– *Melissa Jordan, Chair and Chancellor Kathy Hebda, Vice-Chair*

The meeting was called to order at 11:30 AM by Melissa Jordan, Council Chair and Kathy Hebda, Vice-Chair. Roll was taken and a quorum was established.

Approval of November 2, 2021 Meeting Minutes – *Council Members*

Melissa Jordan moved for the minutes to be accepted from the November 2, 2021 meeting at 11:34 AM. The council unanimously approved the minutes at 11:35 AM.

Legislative Annual Report Subcommittee Breakout Rooms – *Council Members*

Council members were divided into their respective subcommittees in which they further discussed and expanded upon the considerations documented in the Legislative Report Draft Outline from the November 2, 2021 meeting.

Legislative Annual Report Subcommittee Report Out – *Council Members*

One representative from each subcommittee provided a report on the outcomes of their group discussions to the council. Members of the council provided feedback and discussion on the considerations that were presented.

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

Melissa Jordan reported that during the month of January, subcommittees will meet individually to continue the development of their respective section on the Legislative Report Draft Outline.

Public Comment – *Melissa Jordan, Chair*

A member of the public shared a personal experience regarding their spouse, who suffers from a rare disease, experiencing challenges seeking treatment.

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

The meeting adjourned at 12:30 PM.