



Meeting Minutes

Rare Disease Advisory Council (RDAC) Meeting

Date: Thursday, April 14, 2022

Time: 12:00 PM – 1:30 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), Nancy Bryan (BioFlorida, Inc.), Tara Cockman (Florida Department of Health), Leslie Dughi (Metz, Husband & Daughton, P.A.), Linda Ebelini (Florida Department of Health), Kara Godwin (UF Health), Bethany Linderman (Florida Blue), Casey Omeke (Florida Department of Health), Kelly Rogers (Florida Department of Health), Lisa Reardon (Nova Southeastern University), Emily Reeves (Florida Department of Health), John Reilly (Florida Office of Insurance Regulation), Linda Starnes (Florida Department of Health), Tommy Suter, Reese Williams.

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

The meeting was called to order at 12:05 PM by Melissa Jordan, Council Chair and Kathy Hebda, Vice-Chair. Roll was taken and a quorum was established.

Approval of 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 February 15th, March 11th, March 22nd, March 29th, and April 4th subcommittee meetings. The council unanimously approved the minutes at 12:08 PM.

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 recommendations they have developed.

Subcommittee Report Out on Final Recommendations – *Council Members*

One representative from each subcommittee provided a report on the finalized recommendations 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 the State Agencies Subcommittee would meet one additional time prior to the May 4, 2022 council meeting.

Public Comment – *Melissa Jordan, Chair*

No public comment was provided.

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

The meeting adjourned at 1:37 PM.