



Meeting Minutes

Rare Disease Advisory Council (RDAC) Meeting

Date: Wednesday, August 24, 2022

Time: 12:00 PM – 1:00 PM EST

Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
David Altmaier	A representative of the Office of Insurance Regulation.		X
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	
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	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.		

Guests: Renee Bomar (Novartis AG), Tara Cockman (Florida Department of Health), Brent Fushimi (UCB), Matt Harju (Mirum Pharmaceuticals), Erin Frey (Ultragenyx Pharmaceutical, Inc.), Jessenia Leaphart, Aimee Diaz Lyon (Metz, Husband & Daughton, P.A.), Shelly Nickerson (Marinus Pharmaceuticals, Inc.), Casey Omeke (Florida Department of Health), Nicole Perez, Kelly Rogers (Florida Department of Health), Angel Suarez (GBT), Linda Starnes (Florida Department of Health), Jon Yochum (Provention Bio, Inc.)

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

The meeting was called to order at 12:15 PM by Melissa Jordan, Council Chair. Roll was taken and a quorum was established. Eric Biernacki, recently appointed to the council by Speaker Chris Sprowls, provided a brief introduction.

Approval of Council and Subcommittee Meeting Minutes – Council Members

Melissa Jordan moved for the minutes to be accepted from the July 13th, 2022, council meeting. The council unanimously approved the minutes at 12:20 PM.

Year 1 Objectives Implementation Plan Development – Council Members

Council members discussed the current process of Year 1 Implementation Plan development. It was determined the subcommittees will convene independently prior to the next full 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 12:41 PM.