



Meeting Minutes

Rare Disease Advisory Council (RDAC) Meeting

Date: Wednesday, July 13, 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	An individual who is, or was previously, a caregiver for individuals with a rare disease.		
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: Kay Barry (Sarepta Therapeutics), Samantha Bequer (Florida Office of Insurance Regulation), Donna Fogle, Brent Fushimi (UCB), Kara Godwin (UF Health), Steve Kahn, Dan Myers, Casey Omeke (Florida Department of Health), Nicole Perez, Lisa Reardon (Nova Southeastern University), Melissa Reinhold (AdventHealth), Kelly Rogers (Florida Department of Health), Matt Welborn

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

The meeting was called to order at 12:05 AM by Melissa Jordan, Council Chair. Roll was taken and a quorum was established. Kelly Rogers shared with the council that, as of July 1, 2022, the council has gained two additional seats. The title for the two new seats is “An individual who is, or was previously, a caregiver for individuals with a rare disease”.

Approval of Council and Subcommittee Meeting Minutes – *Council Members*

Melissa Jordan moved for the minutes to be accepted from the May,4th, 2022, council meeting as well as minutes from the April 29th, 2022 State Agencies Subcommittee meeting. The council unanimously approved the minutes at 12:08 AM.

Annual Legislative Report Review and Debrief – *Council Members*

Melissa Jordan provided an overview of the Legislative Annual Report that was approved and published on the Department of Health, Rare Disease Advisory Council webpage. Council members provided feedback on the report and shared thoughts for the 2023 Legislative Annual Report.

Year 1 Objectives Implementation Plan Development – *Council Members*

Council members were divided into their respective subcommittees in which they reviewed and discussed the Year 1 Objectives from the Legislative Annual Report and began developing their implementation plans. One representative from each subcommittee provided a report on the status of the subcommittees’ implementation plans to the council.

Public Comment – *Melissa Jordan, Chair*

A member of the public shared information about a resource called the National Society for Genetic

Counselors.

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

The meeting adjourned at 1:30 PM.