



Meeting Minutes

Rare Disease Advisory Council (RDAC) Meeting

Date: Tuesday, November 2, 2021

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	X	

	funding for research regarding rare diseases.		
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: Nancy Bryan (BioFlorida, Inc.), Kory Gehring, Patricia Greene, Bethany Linderman (Florida Blue), Casey Omeke (Florida Department of Health), Emily Reeves (Florida Department of Health), Kelly Rogers (Florida Department of Health)

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

The meeting was called to order at 11:00 AM by Melissa Jordan, Council Chair. Roll was taken and a quorum was established. John Hawayek, recently appointed to the council by Governor DeSantis, provided a brief introduction.

Approval of September 29, 2021 Meeting Minutes – Council Members

Melissa Jordan moved for the minutes to be accepted from the September 29, 2021 meeting at 11:02 AM. The council unanimously approved the minutes at 11:03 AM.

**National Organization for Rare Disorders (NORD) Presentation – Annissa Reed, MPH Policy Director,
Eastern Region, National Organization for Rare Disorders**

Annissa Reed provided a presentation on NORD. This presentation gave an overview of the needs of the rare disease community along with resources NORD has developed to support the work of RDACs.

Legislative Report Development Process – Melissa Jordan, Chair

Melissa Jordan provided an overview of the three main objectives of the Legislative Report required in statute that need to be addressed within the first Report. These objectives include:

- Developing recommended strategies for academic research institutions in this state to facilitate continued research on rare diseases;
- Developing recommended strategies for health care providers to be informed on how to more efficiently recognize and diagnose rare diseases in order to effectively treat patients. The advisory council shall

provide such strategies to the Department of Health for publication on the department's website; and

- Providing input and feedback in writing to the department, the Medicaid program, and other state agencies on matters that affect people who have been diagnosed with rare diseases, including, but not limited to, pandemic or natural disaster preparedness and response.

Council members discussed each of these objectives of the Legislative Report in depth and volunteered to work in subcommittees to assist in developing information and recommendations under the objectives.

- Dr. Byrne, Dr. Tekin, and Dr. Wadhawan volunteered to work on the first objective.
- Dr. Davis, Rebekah Dorr, Zana Dupee, Dr. McClelland, and Jessica O'Reilly volunteered to work on the second objective.
- David Altmaier, Ann Dalton, John Hawayek, and Jennifer Sutherland volunteered to work on the third objective.

Public Comment – *Melissa Jordan, Chair*

No public comment was provided.

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

The meeting adjourned at 12:15 PM.