



# Meeting Minutes

## Rare Disease Advisory Council (RDAC) Meeting

Date: Thursday, February 17, 2022

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 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, Jhoanny Cardenas (NORD RareAction Network), Leslie Dughi (Metz, Husband & Daughton, P.A.), Linda Ebelini, Tameka Footman (Florida Department of Health), Casey Omeke (Florida Department of Health), Kelly Rogers (Florida Department of Health), Emily Reeves (Florida Department of Health), Anne Rugari (NORD RareAction Network), Gillian Sapia, Haley Tobias

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

The meeting was called to order at 11:05 AM 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 November 2, 2021, meeting. The council unanimously approved the minutes at 11:08 AM.

**Rare Disease Day Event – Jhoanny Cardenas, Florida RareAction Network**

Jhoanny Cardenas from the National Organization for Rare Diseases (NORD) Florida RareAction Network (RAN) provided an overview of what Rare Disease Day is and extended an invitation for council members and members of the public to attend the Florida Rare Disease Day virtual event being held on February 25, 2022 and the national Rare Disease Day virtual event being held on February 28, 2022.

Council member Zana Dupee shared about the BioFlorida Legislative Affairs Committee Meeting that occurred on February 7, 2022, in which Kelly Rogers, RDAC coordinator, presented at on the RDAC.

Additionally, Zana provided information on the Rare Disease Day proclamation sponsored by Senator Baxley, which will be formally read before the legislature on February 28, 2022.

**Overview of Florida’s Newborn Screening Program – Emily Reeves, Florida Department of Health**

Emily Reeves, Program Director of the Florida Newborn Screening Program, presented on the Florida Newborn Screening Program, including the purpose of the Newborn Screening Program and the Genetics and Newborn Screening Advisory Council, the conditions included in the newborn screening, locations of referral centers, information on the screening process and how newborns are identified and provided services after being screened.

## **Legislative Annual Report Draft Recommendations – Council Members**

Council members gave an overview of all drafted recommendations that have been developed during their individual subcommittee meetings. Members of the council provided feedback and discussion on the recommendations that were presented.

Council members agreed that the March council meeting should be cancelled to provide additional time for subcommittees to meet to work on how recommendations should be formatted into a timeline to be accomplished over the coming years.

## **Public Comment – Melissa Jordan, Chair**

A member of the public shared a personal story of their child who was diagnosed with rare disease. Additionally, they shared information on resources related to rare disease empowerment and advocacy, including the EveryLife Foundation for Rare Diseases and the Haystack Project.

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.