Meeting Minutes

Rare Disease Advisory Council (RDAC)
Kick-Off Meeting

September 29, 2021
12:00 PM – 1:00 PM EST
Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Melissa Jordan, Chair	A representative of the Department of Health.	X	
Kathy Hebda, Vice-Chair	A representative of the Department of Education.	X	
David Altmaier	A representative of the Office of Insurance Regulation.	X	
Ann Dalton	A representative of the Agency for Health Care Administration.	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	
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 the biotechnology industry.		
Vacant	A representative of health insurance companies.		
Member Name	**Member Seat**	**Present**	**Absent**
Dr. Barry Byrne	A representative from an academic research institution in Florida, which receives grant funding for research regarding rare diseases.	X	
Dr. Anita Davis	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	

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	
Member Name	**Member Seat**	**Present**	**Absent**
Rebekah Dorr	A representative of organizations in this state which provide care or other support to individuals with rare diseases.	X	
Jessica O'Reilly	An individual who is 18 years of age or older who has 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	

Guests: Jhoanny Cardenas (Florida Rare Action Network, NORD), Leslie Dughi (Metz, Husband & Daughton, PA), Kara Godwin (UF Health), Javonni Hampton (The Florida Channel), Bethany Linderman (Florida Blue), Linda McMullen (Florida Department of Health), David Ogman, Casey Omeke (Florida Department of Health), Portia Palmer (Florida Department of Education), Kelly Rogers (Florida Department of Health), Kristin Strobel (BGR Group)

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

The meeting was called to order at 12:00 PM by Melissa Jordan, Council Chair. Roll was taken and a quorum was established with all council members present. Welcome and introductions were made by both the Chair and Vice-Chair.

Council Member Introductions – *Council Members*

Each council member provided a brief introduction that included member background as it relates to rare diseases, role on the council, and location.

Florida Sunshine Law Presentation – *Linda McMullen, Assistant General Counsel, Florida Department of Health*

Linda McMullen provided a presentation on section 286.011, Florida Statutes and Sunshine Law, including public records. The presentation addressed communication requirements pertaining to boards and commissions within state agencies or elected officials.

Overview of Council – *Melissa Jordan, Chair*

Melissa Jordan provided an overview of section 381.99, Florida Statutes, Rare Disease Advisory Council. Melissa explained that the RDAC is statutorily required to have 20 council members, representing individuals with rare disease, caregivers of those with rare disease, health care providers, researchers, and various organizations. The roles of the council as outlined in statute were reviewed, specifically highlighting the requirements of the council to:

- Consult with experts on rare diseases and solicit public comment to assist in developing recommendations on improving the treatment of rare diseases in this state.
- Develop recommended strategies for academic research institutions in this state to facilitate continued research on rare diseases.
- Develop 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.
- Provide 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.
- By July 1 of each year, beginning in 2022, submit a report to the Governor and the State Surgeon General which describes the activities of the advisory council in the past year and its findings and recommendations regarding rare disease research and care.

It was shared that with the report deadline of July 1, 2022 will require the final draft report to be completed by May 15, 2022 in order for adequate time for routing for review and approval. Council members discussed identifying subject-matter experts and/or organizations that could be invited to present at future council meetings to facilitate discussion and assist in meeting the councils' goals.

Future Meeting Dates/Times – *Council Members*

Council members discussed the frequency and length of future meetings. Based on the timeline for the legislative report, members recommended monthly meetings that last one and a half hours each.

Public Comment – *Melissa Jordan, Chair*

No public comment was provided.

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

The meeting adjourned at 1:00 PM.