



Meeting Minutes

Rare Disease Advisory Council (RDAC) Meeting

Date: Monday, April 17, 2023

Time: 12:00 PM – 1:00 PM EST

Microsoft Teams Video Conference

| Member Name | Member Seat | Present | Absent |
|----------------------------|--|---------|--------|
| 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 | |
| Jon 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 | |

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| 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. | | |
| Vacant | A representative of the Office of Insurance Regulation. | | |

Guests: Kelly Rogers (Florida Department of Health), Tara Cockman (Florida Department of Health), Lisa Rawlins, Patrick Flume, Kemi Olabisi, Haley Tobias, Jon Yochum, Maggie Dilger, Fushimi Brent, Shelly Nickerson.

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

The meeting was called to order at 12:02 PM by Melissa Jordan, Council Chair. Roll was taken and a quorum was established.

Approval of Council and Subcommittee Meeting Minutes – Council Members

Kathy Hebda moved for the minutes to be accepted from the October 26, 2022, council meeting. The council unanimously approved the minutes.

Year 1 Objectives Implementation Plan Development Breakout Rooms – Council Members

Council members were broken up into their respective subcommittees to provide final updates of Year 1 implementation plans. Members of the public were moved to the break out room of their choice.

Public Comment – Melissa Jordan, Chair

Fushimi Brent asked the council if it has established how the RDAC will be a voice for rare disease patients. Melissa Jordan provided the information that council meeting minutes are online to provide public insight into council activities.

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

The meeting adjourned at 13:01 PM.