



Meeting Minutes

Rare Disease Advisory Council (RDAC) State Agencies Subcommittee Meeting

Date: Tuesday, February 21, 2023

Time: 12:00 PM – 1:00 PM EST

Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Vacant	A representative of the Office of Insurance Regulation.		
Eric Biernacki	An individual who is, or was previously, a caregiver for individuals with a rare disease.	X	
Ann Dalton	A representative of the Agency for Health Care Administration.	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 representative of health insurance companies.		X
Jennifer Sutherland	An individual who is a caregiver of an individual with a rare disease.	X	

Guests: Rebekah Dorr (Health Care Providers Subcommittee), Marci Perkins (Florida Department of Health)

Call to Order, Member Roll Call– Vera Beloshitzkaya, Florida Department of Health

The meeting was called to order at 12:03 PM. Role was taken, and a quorum was established.

Approval of Subcommittee Meeting Minutes – Vera Beloshitzkaya, Florida Department of Health

Kathy Hebda moved to approve the meeting minutes from the January 17, 2023 meeting. Eric Biernacki seconded the motion to approve. The meeting minutes from the January 17, 2023 meeting were approved. Eric Biernacki moved to approve the meeting minutes from the December 14, 2022 meeting. Kathy Hebda seconded the motion to approve. The meeting minutes from the December 14, 2022 meeting were approved.

Discussion of Joint Objectives – Rebekah Dorr, Healthcare Subcommittee

Rebekah Dorr discussed overlapping objectives of both, the State Agencies Subcommittee and the Health Care Providers Subcommittee. Rebekah Dorr identified the need to survey the providers and patients on their needs and experiences. Melissa Jordan and Ann Dalton will explore the possibility of such surveys by the next

meeting. FDOH will also explore how other states approach this task. Rebekah Dorr also mentioned that more standardized protocols are available for genetic diseases than autoimmune diseases.

Discussion of Council Member Questions – Vera Beloshitzkaya, Florida Department of Health

Vera Beloshitzkaya reviewed Dr. Mustafa Tekin’s question of whether Florida is doing anything on the Consolidated Appropriations Act of 2023, which President Biden signed on December 23, 2022. The State Agency Representatives noted that Florida is aware of the CMS guidance and the work is happening.

Vera Beloshitzkaya reviewed Jon Hawayek’s question asking if it was possible for Florida to share the data mining parameters that the ACHA Medical Director had mentioned on the last call. Ann Dalton will take this question back to AHCA.

Year 1 Objectives Implementation Plan Updates and Next Steps – Vera Beloshitzkaya, Florida Department of Health

The Subcommittee continued the discussion of the updates for the Year 1 Objectives Implementation Plan. Council members provided status updates for the action steps on the Recommendations and Objectives they are responsible for.

Public Comment – Vera Beloshitzkaya, Florida Department of Health

No public comment was provided.

Adjournment – Vera Beloshitzkaya, Florida Department of Health

The meeting adjourned at 12:56 PM.