



# Meeting Minutes

## Rare Disease Advisory Council (RDAC) Academic Research Institutions Subcommittee Meeting

**Date: Thursday, February 23, 2023**

**Time: 12:00 PM – 1:00 PM EST**

**Microsoft Teams Video Conference**

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. 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	
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: 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 12:05 PM. Role was taken, and a quorum was established.

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

Dr. Mustafa Tekin moved to approve the meeting minutes from the January 26<sup>th</sup> meeting. Dr. Rajan Wadhawan seconded the motion to approve. The meeting minutes from January 26<sup>th</sup> were approved. Dr. Rajan Wadhawan moved to approve the meeting minutes from December 19<sup>th</sup> meeting. Dr. Divya Patel seconded the motion to approve. The meeting minutes from December 19<sup>th</sup> were approved.

### **Discussion of Overlapping Priorities with Health Care Providers Subcommittee Members** – Vera Beloshitzkaya, Florida Department of Health

The Subcommittee reviewed overlapping priorities with Health Care Providers Subcommittee Members.

The Subcommittee would like to move towards promoting advancements in the process of achieving a diagnosis for rare disease. The subcommittee stated that there are thousands of rare diseases. Screening is different for them. Protocols will be different for them. Strict follow-up protocols exist for conditions on the newborn screening. Other protocols will take a long time to develop. Autoimmune diseases are multiple. It is not possible to develop a single screening tool or treatment protocol for all rare diseases.

The Subcommittee also recommended to focus on developing a broad list of signs and symptoms that can possibly be a rare disease to be shared with providers. CME's can be developed to educate providers on recognizing a rare disease condition. Providers can also be given resources on where to refer patients with a suspected rare disease. FDOH's website may be a good place to post information on rare diseases and resources. Discussion elaborated on the need to develop appeal mechanism in case of insurance denial and how to advocate for patients to get treatment. The Committee emphasized that every disease is different. It is more important to educate primary care providers on how to get patients to the right providers and resources than to focus on identifying screening tools. Protocols for each disease will require expert guidance and time for development. Alternatively, a state registry for the rare diseases can be created, so when a physician makes a diagnosis, the case is reported to the registry (similar to the Uterine Fibroids Database).

**Review Resources**– *Vera Beloshitzkaya, Florida Department of Health*

The Subcommittee reviewed resources. The Subcommittee members reviewed NORD's Rare Disease Centers of Excellent Scoring Criteria. They decided to use this framework as their starting point as they develop Florida-specific framework on how to designate Rare Diseases Centers of Excellence. The Council reviewed the draft list of Florida Geneticists. The Subcommittee also discussed and analyzed the SB 0616.

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

The Subcommittee continued the discussion of the Year 1 Objectives Implementation Plan. Council members provided status updates for the action steps on the recommendation 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 1:02 PM.