



Meeting Minutes

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

Date: Tuesday, March 21, 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: Tara Cockman (Florida Department of Health), Haley Tobias (Standing in for Crystal Stickler, Lobbyist group)

Call to Order, Member Roll Call– *Marci Perkins, Council Coordinator, Florida Department of Health*

The meeting was called to order at 12:05 PM. Role was taken. There were not enough subcommittee members present for a quorum to be established. Marci Perkins moved for the meeting minutes from the February 23, 2023, Subcommittee meeting to be tabled for review and approval at the next subcommittee meeting.

Review of Resources – *Marci Perkins, Council Coordinator, Florida Department of Health*

The Subcommittee reviewed the information from Emily Reeves (Program Director of Newborn Screening Follow-up Program, Division of Children’s Medical Services of the Florida Department of Health) regarding newborn screening questions and answers.

Dr. Wadhawan presented a list of Florida pediatric rheumatologists and a framework for Florida Rare Disease Centers of Excellence. The subcommittee discussed what should be mandatory and what should be optional. Some institutions are patient oriented. There is no way of judging their expertise because their experience is unknown. Some things are

recommended and are not needed. The subcommittee would like to see Social Worker or Program Coordinator added to the criteria which would be optional. The subcommittee mentioned there needs to be similar mechanism for scoring as to the ones on the NORD sites. The Subcommittee will look at the list of Florida Pediatric Rheumatologist more in depth to see if the list can be expanded.

Year 1 Objective Implementation Plan Updates and Next Steps– *Marci Perkins, Council Coordinator, 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 – *Marci Perkins, Council Coordinator, Florida Department of Health*

No Public comment was provided.

Adjournment – *Marci Perkins, Council Coordinator, Florida Department of Health*

The meeting adjourned at 12:42 PM.