



Meeting Minutes

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

Date: Tuesday, March 26, 2024

Time: 12:00 PM – 1:00 PM EST

Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Representative Adam Anderson	An individual who is a caregiver of an individual 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	
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: Jon Conley (Florida Department of Health), Maggie Dilger (Florida Department of Health), Brielle Dozier (Artia Solutions), Leslie Duhi, Holly Murphy, Kemi Olabisi, John Omick, Corey Recvlohe,

Call to Order and Member Roll Call – Maggie Dilger, Florida Department of Health

The meeting was called to order at 12:02 p.m. Roll was taken, and a quorum was established.

Approval of Meeting Minutes – Council Members

Rep. Adam Anderson motioned to approve the January meeting minutes, Dr. Rajan Wadhawan seconded. The motion carried and the minutes were approved.

Discussion of Work Plan – Council Members

Florida Department of Health staff reviewed the subcommittee’s work plan and explained the council’s Annual Report is due by July 1. Due to the routing process, the report should be completed in April. Staff indicated that the council would have an opportunity to review the document at the April 24, 2024, RDAC meeting. The subcommittee reviewed the plan and was asked by staff to updates.

Members suggested changing Recommendation 1 from “Support Research Institutions in Florida” to “Identify and Support Rare Disease Research Institutions in Florida”.

Other members inquired about the identification of rare disease research institutions in the state. Staff explained that information was gathered using NORD’s criteria for a Center of Excellence. A subcommittee member noted that few institutions in Florida meet these criteria but suggested recognizing organizations that do not fully comply. The proposed designation would recognize both academic research and clinical rare disease institutions, pending further direction on the designation process.

Another subcommittee member suggested that organizations could submit lists of their rare disease research support, which could serve as a metric for assessing research involvement. It was also noted that NORD’s Centers of Excellence collaborate regularly, and Florida’s designations could have similar work groups.

Staff mentioned a list of geneticists created by the subcommittee, which showed 60-70 medical geneticists from state data. Concerns were raised about the accuracy of this list, prompting further research and discussion.

The subcommittee was asked about additional sources for identifying research institutions. It was suggested to use the NIH reporter to find institutions receiving state or federal funding.

Representative Anderson requested a funding target recommendation for the pediatric rare disease grant, suggesting a multi-year grant and financial range to be included in the Annual Report. Prioritizing grant spending was also discussed, with supplemental recommendations to be emailed to council staff for the next meeting.

Representative Anderson asked about restructuring the council to allow more researcher-oriented appointments, noting current vacancies are hard to fill due to the rarity of the positions.

Member Updates – Council Members

No member updates were provided.

Future Agenda Items

There was no discussion of future agenda items.

Public Comment

No public comment was made.

Adjournment – Maggie Dilger, Florida Department of Health

Representative Anderson motioned to adjourn, and Dr. Patel seconded. The meeting adjourned at 1:00 p.m.