



Meeting Minutes

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

Date: Tuesday, November 14, 2023

Time: 12:00 PM – 1:00 PM EST

Microsoft Teams Video Conference

Academic Research Institutions Subcommittee:

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), Pradeep Bhide (Florida State University)

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

The meeting was called to order at 12:05 p.m., Roll was taken, and a quorum was not established.

Member Updates – *Council Members*

Dr. Barry Byrne shared that he met with Dr. Pradeep Bhide of Florida State University (FSU) to plan ongoing interactions between FSU and the University of Florida (UF) as FSU begins its infrastructure and collaborations for its pediatric rare disease institute.

There was conversation regarding newborn screening in Florida and around the nation as additional diseases are being added that will provide early detection and treatment. The discussion moved to creating a patient registry from diagnosis through treatment in an effort to understand risk factors for better outcomes. It was noted that New York has a similar registry as a reference. The group expressed the importance of health

outcomes data and sharing the economics of treated patients versus untreated patients with policymakers as there is value to the state in identifying and tracking health results. UF's Health Outcomes and Biomedical Informatics (HOBI) team could be a resource.

The group brainstormed ideas to engage the RDAC with other advisory councils, subject matter experts, and patient-centered organizations to continue the work of the council.

Future Agenda Items Discussion – Council Members

Possible collaborations or presentations:

- Newborn Screening Advisory Council
- Dr. Chris Cogle, Chief Medical Officer for Florida Medicaid, Agency for Health Care Administration
- Genetic counselor to discuss the process of diagnosis through treatment (for full council meeting)

Public Comment – Members of the Public

No public comment was provided.

Adjournment – Maggie Dilger, Florida Department of Health

The meeting adjourned at 12:57 p.m.