



## Rare Disease Advisory Council Academic Research Institutions Subcommittee Meeting Minutes

Friday, September 20, 2024

12:00 p.m. EST

Virtual

### Welcome/Introductions:

Jon Conley with the Florida Department of Health welcomed everyone and began the meeting at 12:00 p.m. EST.

### The following members or designees were in attendance:

Rep. Adam Anderson  
Dr. Barry Byrne  
Dr. Divya Patel  
Dr. Mustafa Tekin

### Guests and Staff:

Yolanda Bonds, Florida Department of Health  
Jon Conley, Florida Department of Health  
Maggie Dilger, Florida Department of Health  
Leslie Dughi, Metz, Husband & Daughton, P.A.

### Business

#### 1. Approval of Meeting Minutes:

Representative Adam Anderson motioned to approve the March and August 2024 Meeting Minutes. The motion was seconded by Dr. Mustafa Tekin. All approved.

#### 2. Selection of Chair

Representative Anderson nominated Dr. Tekin as the Chair of the Academic Research Institutions Subcommittee. Dr. Barry Byrne seconded. All were in favor and Dr. Tekin accepted.

#### 3. Member Updates

No member updates were provided.

#### 4. Discussion Topics

- a. **Hybrid Meeting on October 7, 2024:** The next meeting of the Rare Disease Advisory Council is scheduled for Monday, October 7, 2024, from 12:00 – 1:00 p.m. EST. The meeting will be a hybrid format via Microsoft Teams and at Florida State University's campus. Further details and meeting materials will be shared on the council's webpage and shared via email.
- b. **Goals of a Future Survey:** Discussion was had regarding the goals of the subcommittee and if any members could utilize their organizations resources to create, disseminate, and analyze a survey.
- c. **Collaborative Resources for Website and Survey:** Mr. Conley provided an update and explained resources provided in previous years would need to be revisited to ensure accuracy before posting.
- d. **Conquering Tasks of the Subcommittee:** Discussion on the future of the subcommittee and its work with the chair to ensure the work of the council and provide meaningful presentations.
- e. **Next Steps/Future Subcommittee Meeting Dates**
  - Moving forward the Academic Research Institute Subcommittee plans to meet every other month.
  - Full Council meets October 7, from 12:00 – 1:00 p.m. EST

- Next Subcommittee Meeting is scheduled for November 14, from 12:00 – 1:00 p.m. EST
- Tentative Full Council Meeting and State RDAC Roundtable on December 11 from 11:00 a.m. – 1:00 p.m. EST.

**5. Public Comments/Open Discussion:**

No public comments were received.

**6. Adjournment:**

Representative Anderson motioned to adjourn. Dr. Tekin seconded and all were in favor. The meeting adjourned at 12:55 p.m. EST.

DRAFT