



**Rare Disease Advisory Council**  
Academic Research Subcommittee  
Meeting Minutes

**Wednesday, July 30, 2025**

Noon EDT  
Virtual

**Opening Remarks**

Chair Mustafa Tekin welcomed the attendees to the meeting which began at 12:05 pm.

**The following members or designees were in attendance: (Quorum established)**

Mustafa Tekin, MD, University of Miami Miller School of Medicine (Chair)

Rajan Wadhawan, MD, Advent Health

Barry Byrne, MD, PhD, University of Florida Health

**Guests and Staff:**

Janelle Stanton, Postdoctoral Researcher, Florida State University Institute for Pediatric Rare Disease

Yolanda Bonds, Council staff liaison, Florida Department of Health

Jon Conley, Strategic Initiatives Manager, Florida Department of Health

Kristin Craze, Contractor, Florida Department of Health

**Business**

**1. Approval of March meeting minutes**

Due to no initial quorum at the beginning of the meeting, minutes were not approved.

**2. Member Updates**

No member updates were provided.

**3. Discussion Topics**

- Future Steps: Subcommittee Focus and discussion on 2025 annual report**

The subcommittee members reviewed the recommendations from the 2024 Rare Disease Annual Report released in July of 2025 and discussed the recently enacted Sunshine Genetics Act that passed during the 2025 Legislative session. The members were interested in determining if there would be possible duplication of effort or potential opportunities to collaborate with the new program.

Members discussed ways to shift the subcommittee's focus to determine how to be of assistance in gaining traction for all patients with rare diseases. Dr. Tekin also mentioned that with the support Florida will provide the consortium further opportunities may materialize in terms of financial support.

Dr. Wadhawan asked about the thought process of including Nicholas Children's Hospital only when there are seventeen children's hospitals in the state. Due to Rep. Anderson's absence, this question went unanswered.

Members suggested maintaining the recommendations from this year's report around fostering collaboration and funding of rare disease research.

Dr. Wadhawan wanted to know what happens if the recommendation does not get accepted this year. His suggestion is to keep the recommendation in the annual reports and move forward if it continues to be relevant or revise as necessary. The recommendations can stay in the annual report until they are adopted by the Legislature and signed into law. Dr. Wadhawan suggested improving the framework for better consideration.

Staff mentioned the possibility of merging subcommittees to ensure a quorum, to facilitate collaboration, and ensure future recommendations are relevant, or if they could be modified. In response, members discussed the idea of creating fifteen-minute breakout rooms during the full council meetings as a solution to subcommittee quorum challenges. The suggestion was also to reduce meeting frequency.

- **Member updates and observations from the field**

No updates

- **Future topics**

No new future topics

#### **4. Public Comments**

Dr. Janelle Stanton, from FSU, mentioned the Geisinger Healthcare system and Dr. Ledbetter who works with all patients including those with rare diseases. Dr. Stanton mentioned reaching out to the Pennsylvania Rare Disease Advisory Council to mention Florida's intention of creating a website of flow through data and links.

Next meeting is scheduled for August 27, 2025.

#### **5. Meeting Adjournment**

The meeting adjourned at 12:43 p.m. EDT.