



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

Friday, August 16, 2024

12:00 p.m. EST

Virtual

### **Welcome/Introductions:**

Jon Conley with the Florida Department of Health welcomed everyone and began the meeting at 12:05 p.m. EST.

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

Rep. Adam Anderson

Dr. Barry Byrne

Dr. Mustafa Tekin

Dr. Rajan Wadhawan

### **Guests and Staff:**

Yolanda Bonds, Florida Department of Health

Jon Conley, Florida Department of Health

Maggie Dilger, Florida Department of Health

Anna Grace Lewis, Metz, Husband & Daughton, P.A.

Lee Willer-Spector, caretaker and VHLA's Board of Directors

### **Business**

#### **1. Approval of Meeting Minutes:**

A quorum was not established at the beginning of the meeting. Approval of meeting minutes will be moved to the next subcommittee meeting.

#### **2. Pre-discussion for Hybrid Meeting in October:**

Maggie Dilger with the Department reminded the council that the scheduling survey would close on August 16, and emphasized how results would help schedule upcoming meetings. Staff will update and confirm an October meeting of the full council soon. The meeting is tentatively planned to be hybrid (in-person at FSU Discovery Days and virtually via Microsoft Teams). Council members were asked to provide their availability for October 7 and October 8.

#### **3. Target Priorities for the Year:**

The subcommittee reviewed last year's recommendations and the following priorities were discussed.

- The subcommittee should investigate ways to better support universities including assisting with collaborations within the state's research institutions.
- A future website should promote research in Florida to match clinical trials with patients.
- Connecting/collaborating with research students at Florida universities to help with accomplishing the goals of the council.

#### **4. Next Steps**

Selection of a subcommittee chair will occur at the next subcommittee meeting.

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

No public comments were received.

**6. Adjournment:**

Representative Anderson motioned to adjourn. Dr. Barry Byrne seconded. The meeting adjourned at 12:48 p.m. EST.