



# Meeting Minutes

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

**Date: Tuesday, September 19, 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: Kelly Rogers (Florida Department of Health), Tara Cockman (Florida Department of Health), Jon Conley (Florida Department of Health), Maggie Dilger (Florida Department of Health), Pradeep Bhide (Florida State University), Cynthia Vied (Florida State University College of Medicine), Crystal Stickle (Vertex Pharmaceuticals and the Florida Medical Association), Corey Reclvohe (Florida House of Representatives),

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

The meeting was called to order at 12:05 p.m., and Representative Adam Anderson was introduced.

Representative Anderson was recently appointed to the Rare Disease Advisory Council by Senate President Kathleen Passidomo, and he represents North Pinellas District 57. Roll was taken, and a quorum was established.

### Approval of Meeting Minutes – *Council Members*

Dr. Rajan Wadhawan moved for the minutes to be approved from the August 15, 2023, subcommittee meeting, and Dr. Divya Patel seconded the motion. The minutes were approved.

### Member Updates – *Council Members*

No member updates were provided.

Maggie Dilger with the Florida Department of Health asked for discussion on information the subcommittee hopes to capture from the list of Florida Geneticists collected in Year 1. Suggestions included:

- Identify specialties
- Identify sub-specialties
- Identify a list of conditions each physician specializes in
- Identify a list of special or particular interests
- If they are accepting new patients
- If they are open to research collaboration
- If any research trials are available through them
- If they have a sub-specialty, a question needs to be added to ensure they approved to have their information posted publicly. Most centers have a centralized scheduling number that could be provided instead of direct contacts if preferred.

Dr. Barry Byrne mentioned that ClinicalTrials.gov should be added to the website. He believes the organization is setting up an option for those who register to be notified regarding specific topics. The website is a database of privately and publicly funded clinical studies conducted around the world. Dr. Byrne explained there is a requirement to list public studies that have open enrollment through ClinicalTrials.gov. Private or single-subject IND studies are not required to be listed. Trials that have a commercial sponsor and are IRB-reviewed must be listed.

Representative Adam Anderson asked how the list of geneticists from Appendix F in the annual report was compiled. Dr. Divya Patel explained the list was compiled by the subcommittee of known, practicing geneticists in the state. Kelly Rogers with the Department suggested the list be cross-referenced with MQA's list of all licensed geneticists. Dr. Byrne explained most care is delivered by related sub-specialists following a diagnosis, with the exception of metabolic specialties, which would require a much broader list than just geneticists.

Jon Conley with the Florida Department of Health mentioned he works with the Physicians Workforce Advisory Council (PWAC) which administers an annual survey every two years upon re-licensure of those physicians. He offered to help with a survey and narrowing down physicians. He mentioned that MQA and the PWAC survey do not capture specialties.

Dr. Patel asked Mr. Conley if a question could be added to the Physicians Workforce Advisory Council survey regarding rare diseases. Jon explained that because it is a statutorily required survey, there is a lengthy rule-making process required, but the subcommittee could make a recommendation for any rare disease questions to be added.

Dr. Wadhawan mentioned there needs to be of a process for keeping the list updated as people are added or removed. Dr. Byrne suggested the survey be distributed to division chiefs at each academic health center or major hospital systems first. Kelly Rogers with the Department noted that cities and counties should also be captured when compiling this data. Tara Cockman with the Department added that once all details are gathered, an interactive map could be introduced to the website for ease of use.

Representative Anderson asked what the workload is for geneticists in Florida. Dr. Wadhawan explained the workload is significant as appointments are time-intensive, and patients must be prioritized. Dr. Byrne echoed this by noting there is a national shortage of those in training and in the profession. Advanced practice nurses and other sub-specialists will have to fill the gap.

Rep. Anderson inquired about what steps should be taken when building out a new college geneticist program. Dr. Byrne explained the hurdles physician providers (not genetic counselors) experience regarding limited fellowships and jobs due to the profession being one of the lowest reimbursed sub-specialties. There is also a shortage of genetic counselors which could offload some of this work from geneticists. Rep. Anderson asked if genetic counselors could be part of a workforce program through local colleges. Dr. Byrne confirmed it is a master's level program. Dr. Wadhawan added that Advent Health University, an Allied Health Sciences university, is in the process of developing a program. There is a market need and jobs should be plentiful.

#### **Future Agenda Items/October Council Meeting Agenda Items Discussion – Council Members**

Further discussion is needed regarding a Florida version of NORD's Centers of Excellence. The subcommittee has a desire to notice rare disease entities that may not have research elements to be considered a NORD Center of Excellence but have clinical abilities to care for the rare disease community. The subcommittee would like a discussion and direction on who would be responsible for overseeing and creating such a designation.

Council members have requested to hear from a Medicaid lead to present on the new law regarding Rapid Whole Genome Sequencing. Specifically, how the new law will be implemented, and funds disseminated. Rep. Anderson mentioned he has been working on this legislation and believes AHCA is still in the planning process. He is hopeful a plan will be fully executed by the October 25 full council meeting.

Rep. Anderson mentioned an appropriation in the state budget for funding a pediatric rare disease grant program. The question was posed if the RDAC would be able to have oversight for the grant funds. Dr. Byrne mentioned there are organizations that review applicants. RDAC could possibly help establish goals, and it was suggested that someone from the Biomedical Research Program be invited to present at a future meeting to present on its process.

#### **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.

### **Meeting Reminders**

The next RDAC Academic Research Institutions Subcommittee meeting is scheduled for Tuesday, October 17; 12:00 – 1:00 p.m. EST.

The next Rare Disease Advisory Council (RDAC) Full Council meeting is scheduled for Wednesday, October 25; 12:00 – 1:00 p.m. EST.