



Meeting Minutes

Rare Disease Advisory Council (RDAC) Meeting

Date: Wednesday, February 7, 2024

Time: 11:00 AM – 1:00 PM EST

Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Rep. Adam Anderson	An individual who is a caregiver of an individual with a rare disease.	X	
Eric Biernacki	An individual who is, or was previously, a caregiver for individuals 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	
Ann Dalton	A representative of the Agency for Health Care Administration.	X	
Dr. Anita Davis	A representative of organizations in this state which provide care or other support to individuals with rare diseases.	X	
Rebekah Dorr	A representative of organizations in this state which provide care or other support to individuals with rare diseases.		X
Zana Dupee	An individual who is a caregiver of an individual with a rare disease.	X	
Jon Hawayek	A representative of the biotechnology industry.		X
Kathy Hebda, Vice-Chair	A representative of the Department of Education.	X	
Melissa Jordan, Chair	A representative of the Department of Health.	X	
Dr. Scott McClelland	A representative of health insurance companies.	X	
Jessica O'Reilly	An individual who is 18 years of age or older who has a rare disease.		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	
India Steinbaugh	An individual who is 18 years of age or older who have a rare disease.	X	
Jennifer Sutherland	An individual who is a caregiver of an individual with a rare disease.		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
Vacant	A geneticist practicing in this state.		
Vacant	A registered nurse or advanced practice registered nurse who is licensed and practicing in this state with experience in treating rare diseases.		
Vacant	A hospital administrator from a hospital in this state which provides care to individuals diagnosed with rare diseases.		
Vacant	A pharmacist who is licensed and practicing in this state who has experience with drugs that are used in the treatment of rare diseases.		
Vacant	A representative of the Office of Insurance Regulation.		

Guests: Jon Conley (Florida Department of Health), Maggie Dilger (Florida Department of Health), Roger Allen Andrews (Florida Department of Health), Daniel Leyte-Vidal (Florida Department of Health), Jon Feazell (Florida Department of Health), Kelly Rogers (Florida Department of Health)

Call to Order, Member Roll Call – Melissa Jordan, Chair

The meeting was called to order at 11:00 a.m. EST by Melissa Jordan, RDAC Chair. Chair Jordan provided an overview of the upcoming Rare Disease Day on February 29, 2024. Representative Adam Anderson noted he would be presenting the Rare Disease Day Resolution on the House floor on February 28, 2024. He mentioned there would be a press conference to honor the event and all are invited to participate. Representative Anderson also expressed wanting to invite a resident who has a rare disease, has been cured of a rare disease, or is undergoing treatment in order to create awareness and shed a positive light on the work that is being done within the rare disease community.

Chair Jordan discussed the Pediatric Rare Diseases Research Grant Program. Applications are due at 5:00 p.m. EST on February 16, 2024, and the anticipated date of award announcements is March 29, 2024. She noted the application would be peer-reviewed and clarified that there would be no conflict of interested if any institutions represented on the RDAC wished to apply. Represented Anderson suggested the RDAC make a recommendation on the amount of funding for the grant program moving forward.

After the welcoming remarks and discussion, Maggie Dilger with the Florida Department of Health took roll and announced a quorum had been established.

Chair Jordan introduced Jon Feazell to the council meeting. Mr. Feazell is from the University of Kentucky

College of Medicine on a public health leadership residency away rotation with the Florida Department of Health. He is a former Naval Officer and current fourth-year medical school student going into internal medicine.

Approval of Council and Subcommittee Meeting Minutes – Council Members

Chair Jordan asked for a motion for the following meetings minutes to be approved:

- October 25, 2023, RDAC meeting;
- November 15, 2023, Health Care Providers Subcommittee meeting;
- November 16, 2023, State Agencies Subcommittee meeting.

A motion was made by Vice Chair Kathy Hebda and seconded by Representative Anderson. The meeting minutes were approved unanimously.

Florida Sunshine Law Review – Florida Department of Health

Roger Allen Andrews with the Florida Department of Health provided an overview of Florida's Government in the Sunshine Law, found in [Chapter 286](#), Florida Statutes, and [Article I, Section 24](#), of the Florida Constitution which provides a right of access to governmental proceedings of public boards and commissions. The Sunshine Law applies to any board or commission of any state agency. This includes advisory boards and committees.

Legislative Update – Florida Department of Health

Daniel Leyte-Vidal, Deputy Director of Legislative Planning, with the Florida Department of Health gave an overview of bills currently being reviewed during the 2024 Legislative Session. Bills discussed include:

- The Department of Health Bill, HB 1441 – This bill includes the Andrew John Anderson Pediatric Rare Disease Grant Program which is a funding opportunity for research and treatment for rare pediatric diseases in Florida. The inaugural year in the proposal asked for \$500,000 for research projects with hopes that it would become a recurring funding stream in the future. Representative Anderson suggested the RDAC provide a recommendation to help guide the Legislature on prioritizing how the funds could be used and a dollar amount for awards.
- HB 115 and SB 186 – The Progressive Supranuclear Palsy and Other Neurodegenerative Diseases Policy Workgroup Bill requires the State Surgeon General to establish a progressive supranuclear palsy and other neurodegenerative diseases policy workgroup.
- HB 499 and SB 168 – Congenital Cytomegalovirus Screenings (CMV) Bill. This bill requires most newborns to be screened for Cytomegalovirus (CMV) and mandates that the screening, and any necessary follow ups, be covered by Medicaid or insurance. Additionally, it mandates that the child must be referred to a primary care provider and to Children's Medical Services Early Intervention Program to manage the condition.

- HB 349 and SB 552 – This bill requires health care practitioners of medicine to complete education on Sickle Cell Disease care management and treatments as a condition of licensure renewal.

Council Duties and Responsibilities – Florida Department of Health

Chair Jordan gave an overview of the RDAC's previously established recommendations and reminded council members that the RDAC was created to provide recommendations on ways to improve health outcomes for individuals residing in Florida who have rare diseases. She added that a short-term, ad hoc subcommittee with possibly two liaisons from each established subcommittee could be formed to help finalize a web resource.

Jon Conley, Strategic Projects Manager, with the Florida Department of Health explained that council staff had been reformatting the implementation plans to make the recommendations and objectives information easier to digest. The document was presented, and Mr. Conley explained it would be emailed to the council following the meeting. Council members were asked to review the document and provide feedback before and/or during the next month's subcommittee meetings. Members were also asked to volunteer to be leads of the objectives to help meet the established goals and/or make suggestions on new objectives.

Mr. Conley explained that the Department of Health is in the process of an agency website revamp and creating a new website for the RDAC could be delayed. The existing website (<https://www.floridahealth.gov/provider-and-partner-resources/rdac/index.html>) can be used in the interim.

Chair Jordan asked for feedback on ways council staff can help support the cross collaboration of the subcommittees.

Representative Anderson mentioned vacancies on the council and encouraged council members to invite experts in their fields to apply. Chair Jordan asked council staff to send the current roster of members along with vacant positions and requirements to fill those positions to the group.

Eric Biernacki noted a priority of the council is to get the website up and running and agreed it could be helpful to have a specific subcommittee to move that objective along. Ann Dalton also voiced interest in restructuring some of the meetings to ensure goals are accomplished. Chair Jordan reiterated that reorganizing or rotating RDAC meetings could be helpful if the group needed to specifically talk about data, research, the website, etc. She also noted that past full RDAC meetings included subcommittee breakout rooms, and that function could be used again at the next quarterly RDAC meeting. Vice Chair Hebda agreed that separating meetings into task groups (data, research, resources) could be helpful.

Chair Jordan mentioned other state RDACs have surveyed individuals living with rare diseases and their

caregivers and families. Dr. Anita Davis said she liked the idea of addressing the surveys and noted the Health Care Providers subcommittee has not been sure how to create and distribute a survey.

Dr. Davis also noted the RDAC could make short presentations to existing meetings of healthcare providers or interested groups to increase awareness and obtain feedback. Additionally, she suggested having a table or poster at upcoming physical therapy and medical associations' state meetings to possibly build awareness for the council. Chair Jordan asked council staff to research this idea for the future.

Future Agenda Items and Meeting Frequency Discussion – *Melissa Jordan, Chair*

Chair Jordan asked members to think about how often they'd like to meet moving forward and let staff know their preferences. She noted that subcommittees are currently meeting monthly while the full council meets quarterly. She also welcomed members to connect with council staff should they have a member of their team who could possibly help complete objectives.

Mr. Biernacki suggested inviting members from other RDACs to a full council meeting to discuss their successes and to see if any of their ideas could speed up Florida's RDAC's processes.

Chair Jordan mentioned council staff would follow-up after the meeting with the work plans and council vacancies and asked the council to review and provide any updates and agenda suggestions prior to the next meetings.

Public Comment

There was no public comment.

Adjournment – *Melissa Jordan, Chair*

The meeting adjourned at 12:44 p.m.