



Meeting Minutes

Rare Disease Advisory Council (RDAC) Meeting

Date: Wednesday, October 25, 2023

Time: 12:00 PM – 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), Kelly Rogers (Florida Department of Health), Maggie Dilger (Florida Department of Health), Gabrielle O’Sullivan (Florida Department of Health), Matthew Cooper (Florida Agency for Health Care Administration), Olivia Chiarelli (Minnesota Rare Disease Advisory Council), Leslie Dughi, Thomas Perkins, Lilly Erickson, Pradeep Bhide, Nicole Perez, Eric Martin, Carol Kelly, Matt Harju, Holly Murphy, Kemi Olabisi, Tim Melancon, Dr. Hannah Ehrli

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

The meeting was called to order at 12:02 p.m. by Melissa Jordan, RDAC Chair. Roll was taken and a quorum was established.

Ms. Jordan introduced the RDAC’s newest member, Representative Adam Anderson. Representative Anderson serves the 57th District and was elected to the Florida House in 2022. He has worked extensively on behalf of the rare disease community, establishing the Andrew John Anderson Rapid Whole Genome Sequence Grant Program and securing funding for launching FSU’s Center for Pediatric Rare Disease Research.

Ms. Jordan provided an overview of the inaugural National RDAC state meeting hosted by the Nation Organization for Rare Disease (NORD) which included RDACs from around the country sharing what their states are doing to improve services for the rare disease community.

Approval of Council and Subcommittee Meeting Minutes – Council Members

Melissa Jordan moved for the minutes to be accepted from the following meetings:

- May 8, 2023, council meeting;
- August 17, 2023, State Agencies Subcommittee meeting;
- September 19, 2023, Academic Research Institutions Subcommittee meeting;
- September 20, 2023, Health Care Providers Subcommittee meeting;
- September 21, 2023, State Agencies Subcommittee meeting.

The meeting minutes were approved unanimously.

Future Website Discussion – Florida Department of Health

Jon Conley with the Department explained options to create a Florida RDAC website and provided an outline for what the site would showcase. Mr. Conley showed the members the Florida Department of Health's Office of Medical Marijuana Use's (OMMU) website (knowthefactsmmj.com) as a reference to a possible model. He explained the development and maintenance of a website similar to OMMU's would be cost-effective and easy to maintain.

More information will be gathered and presented in the next quarterly meeting after the Department has met with the web team that is responsible for OMMU's site. The Department will review resources, screening tools, and treatment information gathered previously by the RDAC to identify areas that may need additional detail to launch the site. Ms. Jordan encouraged the members to research other websites as possible models and to share any findings with the RDAC staff.

It was noted that advocacy groups could also be listed on the website and information will be gathered and added over time as more resources are identified.

Top 50 Prevalence Data Discussion – Florida Agency for Health Care Administration

Matthew Cooper with the Florida Agency for Health Care Administration provided an overview of the Medicaid data recently shared with the Florida Department of Health for the RDAC. He mentioned that 5 million people receive Medicaid coverage, and the data identified by diagnosis of those with a rare disease (top 50 diseases provided by SPARK. Note: Jon Hawayek shared with the group that SPARK Therapeutics will be able to provide a list of top diseases from 51-500 in the future.).

The Medicaid data covered five calendar years (2018-2022) with disease occurrences of 15 or more individuals. Mr. Cooper explained that when reviewing the data over the five years, some patients would show up yearly since the numbers provided rely on claims data, e.g. the same patient could appear yearly

for a disease such as sickle cell anemia.

A question was asked as to why cystic fibrosis had a large increase in one year of the data provided. Mr. Cooper explained it could have been a programmatic change but was unsure of the cause. The AHCA team will research to see if there is a clear explanation as to why there was such a dramatic increase.

Further data variables will be discussed in the future, and Ms. Jordan mentioned researching additional data sources (Newborn Screening, new Sickle Cell registry) as well.

Rapid Whole Genome Sequencing Medicaid Coverage Discussion – Florida Agency for Health Care Administration

Ann Dalton with the Florida Agency for Health Care Administration provided an update on recent legislation passed that requires Medicaid coverage for Rapid Whole Genome Sequencing (rWGS). She said AHCA was directed to add coverage of rWGS to the Medicaid benefit specific to enrollees who:

- Are 20 years of age or younger;
- Have a complex or acute illness of unknown etiology that has not been caused by environmental exposure, toxic ingestion, an infection with normal response to treatment, or trauma; and
- Are receiving inpatient treatment in a hospital ICU or high-acuity pediatric care unit.

Rulemaking and public meeting workshops have been and are being held, and AHCA is updating two rules:

- 459G-4.190 which is the laboratory services policy; and
- 59G-4.150 which is the inpatient hospital services coverage policy.

Additional public meetings will be scheduled soon to begin finalizing the rules and then AHCA will establish specific billing codes for rWGS. Meeting attendees were encouraged look for future rulemaking workshops regarding this topic.

Rep. Anderson mentioned issues other states are facing that he hopes Florida will be able to avoid. These issues included direct billing from labs and billing should be to the mom, not the child since the child would not have a Medicaid code at birth.

Ms. Dalton noted that AHCA is still working on establishing these rules and will ensure that there are no barriers to access. Details are still being finalized. More to come.

Subcommittee Updates Discussion – Melissa Jordan, Chair

Maggie Dilger with the Department gave a brief update on recommendations for each subcommittee and opened the floor for discussion.

The subcommittees were encouraged to share/create questions they had for other subcommittees and agencies before the next quarterly council meeting.

Public Comment

Dr. Hannah Ehrli mentioned a need for research regarding specific treatments for disorders that could be shared with providers and patient support.

Adjournment – *Melissa Jordan, Chair*

The meeting adjourned at 1:02 PM.