



Meeting Minutes

Meeting of the Rare Disease Advisory Council (RDAC) Health Care Providers Subcommittee

Date: Wednesday, September 20, 2023

Time: 12:00 PM – 1:00 PM EST

Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
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	
Jessica O'Reilly	An individual who is 18 years of age or older who has a rare disease.		X
India Steinbaugh	An individual who is 18 years of age or older who have a rare disease.	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), Eric Martin (Pfizer's State Government Relations Division), Crystal Stickle (Vertex Pharmaceuticals and the Florida Medical Association)

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

The meeting was called to order at 12:05 p.m., and roll was taken. A quorum was established.

Approval of Meeting Minutes – Council Members

A motion was made by India Steinbaugh to approve the July 19, 2023, meeting minutes. Dr. Anita Davis seconded, and the meeting minutes were approved.

Member Updates – Council Members

Jon Conley with the Florida Department of Health updated the group that administrative responsibilities will be transitioning under the Division of Public Health Statistics and Performance Management from the Division of Community Health Promotion.

Dr. Anita Davis has been collecting information from colleges and universities on what is being taught as it relates to rare diseases. Working from a list of schools that graduate physical therapists, she has already received responses from 50 percent of the schools she has contacted. She also reached out to several medical schools in the state to collect curriculum information. Her next step is to reach out to the Deans of Curriculum and Deans of Academic Education.

Maggie Dilger with the Florida Department of Health reminded the subcommittee there is a need to request the Agency for Health Care Administration (AHCA) to include a question on holistic care in their survey. She asked the subcommittee for questions to send to AHCA, and what data the group wishes to capture.

Maggie Dilger and Kelly Rogers with the Department provided an update from last month's joint meeting with the Academic Research Institutions Subcommittee. During that meeting members commented they were unaware of a universal list of screening tools. Genome sequencing is used but can be costly depending on whether testing is concluded in-patient/out-patient. There has been a request from the Academic Research Institutions Subcommittee to ask for a Medicaid presentation on the new genome sequencing law during the October full council meeting. Dr. Davis mentioned listing NORD's Centers of Excellence for patients to contact regarding screening and noted having genome testing information and where to direct health care providers for details on cost/coverage on the website.

An objective under Recommendation 3 is to identify current medical practices and specialists who accept both pediatric and adult individuals with rare diseases. The next action step is to coordinate with the Office of Insurance Regulation and AHCA to survey insurance plans on health care providers that accept both pediatric and adult individuals with rare diseases. A question was posed as to additional options to garner this information through other surveys being utilized. Jon Conley explained that some of the statutory surveys in place could be a more complicated venture.

Future Agenda Items Discussion – Council Members

The group was asked to provide suggestions for upcoming agenda items or subject matter experts they wished to hear from. No comment was provided, and members were encouraged to submit suggestions via email to Maggie Dilger with the Department.

October Council Meeting Agenda Items Discussion – Council Members

The group was asked to provide topics they wished to cover during the October Full Council meeting. No comment was provided, and members were encouraged to submit suggestions via email to Maggie Dilger with the Department.

Public Comment – Members of the Public

No public comment was made.

Adjournment – Maggie Dilger, Florida Department of Health

The meeting adjourned at 12:34 p.m.

Meeting Reminders

The next RDAC Health Care Providers Subcommittee meeting is scheduled for Wednesday, October 18;

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.