



Meeting Minutes

Rare Disease Advisory Council (RDAC) State Agencies Subcommittee Meeting

Date: Thursday, August 17, 2023

Time: 12:00 PM – 1:00 PM EST

Microsoft Teams Video Conference

Member Name	Member Seat	Present	Absent
Vacant	A representative of the Office of Insurance Regulation.		
Eric Biernacki	An individual who is, or was previously, a caregiver for individuals with a rare disease.	X	
Ann Dalton	A representative of the Agency for Health Care Administration.	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	
Jennifer Sutherland	An individual who is a caregiver of an individual with a rare disease.	X	

Guests: Kelly Rogers (Florida Department of Health), Tara Cockman (Florida Department of Health), Maggie Dilger (Florida Department of Health), Jon Conley (Florida Department of Health), Nicole Perez (Blue Cross Blue Shield), Morgan Elaina (Florida Senate), Leslie Dughi (Metz, Husband, & Daughton, P.A.).

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

The meeting was called to order at 12:00 PM. Roll was taken, and a quorum was established.

Approval of Subcommittee Meeting Minutes – Council Members

Jon Hawayek moved to approve the meeting minutes from the July 20, 2023, meeting. Dr. Scott McClelland seconded the motion, and the July 20, 2023, meeting minutes were approved.

Year 2 Objective Implementation Plan – Council Members

Ann Dalton with the Agency for Health Care Administration (AHCA) provided an update regarding the Data Use Agreement (DUA) and Medicaid data. A new DUA is required to move forward with sharing AHCA's Medicaid data, and AHCA is currently working on completing that document.

AHCA did pull Medicaid claims data (single individual per year from 2018-2022) – both fee for service and managed care – for the list of top 50 rare diseases. Those findings showed total prevalence for all 50 diseases was less than one percent of the entire Florida Medicaid population. Of that one percent, thirty-three percent were diseases of the blood, and sickle cell accounted for twenty-five percent. Jon Hawayek asked if the Medicaid data mimicked the national data shared by Artia Solutions. Tara Cockman with the Florida Department of Health explained that the formatting of data from Artia Solutions needs attention in order to properly cross-walk. The Department will work with the data team and Jon, if necessary, to format the data in a way that is useable for completing the objective.

Jon Hawayek and Eric Biernaki have completed their assessment of Florida advocacy/patient groups and they plan to have a compiled spreadsheet by the next subcommittee meeting.

Kathy Hebda with the Florida Department of Education (FDOE) asked for clarification on FDOE recommendations regarding communications and if there were any suggestions.

Jennifer Sutherland suggested an educational scholarship improvement and expressed concern with funding after a person graduates high school under the Gardiner Umbrella (Step Up). Ms. Hebda explained the Gardiner scholarship is for K-12 and expansion would require new legislation and additional funds. There are other services for post-secondary students – including the Office of Vocational Rehabilitation. Ms. Sutherland suggested resources to notify parents of what is available – there is a gap in knowledge of resources as the student is aging out. Mr. Biernacki noted how difficult it is to navigate resources and mentioned listing resources on RDAC's website in the future. Kelly Rogers with the Department explained that the goal of the website is to get information out to the rare disease community, and that funding options/logistics are being researched to build the website and create communication plans to publicize once up and running. Ms. Hebda mentioned FDOE has a fairly standard plan for email blasts and asked if there is a timeline for the website and what funds are needed. Kelly explained that the Department is working with state partners to identify resources to be able to move forward since the RDAC is not funded.

FDOE shared a collection of resources for the 2022-2023 Legislative Report, and it was suggested the list be redistributed prior to the next meeting. If any additional resources should be added, the group can report back.

Tara Cockman provided an overview of what the Department is doing to review resources and identify gaps in services within the Department. Internal and collaborative meetings are being scheduled with other divisions/departments within the Department (Early Steps, Chronic Disease, Birth Defects, CMS, Brain and Spinal Injury Program, Healthy Start, School Health Programs, Medical Marijuana, WIC, County Health Systems, Office of Minority Health). The Department hopes to be able to report back in the coming months on its findings (how programs are identifying individuals with rare diseases, how they serve those persons, who qualifies, how they qualify, etc.) The Department is also researching website creation for the future. Ann Dalton recommended reaching out to the Agency for Persons with Disabilities once the Department has completed its internal review.

Public Comment – *Maggie Dilger, Florida Department of Health*

No public comment was made.

Adjournment – *Maggie Dilger, Florida Department of Health*

The meeting adjourned at 12:35 PM.

Meeting Reminders

The next RDAC State Agencies Subcommittee meeting is scheduled for Thursday, September 21; 12:00 – 1:00 pm EST.

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