



Meeting Minutes

Rare Disease Advisory Council (RDAC) State Agencies Subcommittee Meeting

Date: Thursday, July 20, 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), Marci Perkins (Florida Department of Health), Maggie Dilger (Florida Department of Health), member of House Appropriations Committee

Call to Order and Member Roll Call – Marci Perkins, Florida Department of Health

The meeting was called to order at 12:05 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 February 21, 2023, meeting. Melissa Jordan seconded the motion, and the February 21, 2023, meeting minutes were approved.

Year 2 Objective Implementation Plan – Council Members

Melissa Jordan welcomed the group and mentioned the 2022-2023 Legislative Report was emailed out and posted to the website. The next full council meeting for the RDAC will be October 25, from 12:00 – 1:00 pm.

There was discussion regarding the Medicaid data use agreement (DUA). The agreement has been executed, and Tara Cockman with the Florida Department of Health is going to ask that the information be forwarded to Ann Dalton with the Agency for Health Care Administration (AHCA). After AHCA has received the DUA, the completed Medicaid data analysis can be presented to the subcommittee. Ms. Dalton mentioned a member of the data team would be needed when the findings were presented to the committee. Any additional data usage agreements that could be required or are in progress will be tracked on the subcommittee's implementation plan.

Tara Cockman is researching the process and dissemination of completed data use agreements. Ann Dalton will explore the necessity of additional agreements regarding sharing information with the Florida Department of Health and in discussions with the RDAC.

Tara Cockman reviewed the Year 2 Implementation Plan with the subcommittee. Each of the six recommendations and the accompanying objectives were reviewed. Year two objectives were assigned to department/council leads.

Upon reviewing Year 1, Recommendation 1, questions were presented regarding the statuses of Objectives 1.1 – 1.4. Details are being confirmed, and RUSP was recommended to be used as a reference for Newborn Screenings.

Regarding Recommendation 1, Objective 1.5, there was discussion of preparing a process map by age to help illustrate services offered to the rare disease community (emergency preparedness, scholarships, and additional resources).

Members of the subcommittee discussed data collection from numerous state agencies, and the group is hopeful there will be an appointment to the RDAC from the Office of Insurance Regulation. Once data is collected from Florida, it can then be compared to national data.

Jon Hawayek mentioned Recommendation 1, Objective 3.1 (2024-2025 goal) "to develop a list of rare diseases with an overlay of distribution across the state, using the top 500 most prevalent rare diseases nationally," could possibly be completed this fiscal year.

Melissa Jordan requested that the Department of Health hold meetings with internal staff prior to monthly subcommittee calls to work on each of its recommendation responsibilities and identify departments that could present at future meetings to discuss services offered. Each agency has been invited to use the implementation plan to do the same. The subcommittee's Year 2 Implementation Plan will be forwarded to members prior to the August meeting.

Public Comment – *Melissa Jordan, Florida Department of Health*

No public comment was made.

Adjournment – *Marci Perkins, Florida Department of Health*

The meeting adjourned at 1:01 PM.