



Rare Disease Advisory Council

State Agencies Subcommittee

Meeting Minutes

Wednesday, January 29, 2025

Noon EST

Virtual

Welcome/Introductions

The meeting was called to order at 12:06 p.m. EST, by Melissa Jordan, MS, MPH, Assistant Deputy Secretary for Health for the Florida Department of Health (Chair). Chair Jordan thanked the members for their work in 2024 and welcomed them into 2025.

The following members were in attendance: (Quorum was established)

Melissa Jordan, MS, MPH, Assistant Deputy Secretary for Health, Florida Department of Health (Chair)

Kathy Hebda, Chancellor, Division of Florida Colleges, Florida Department of Education (Vice-Chair)

Eric Biernacki, JD, Managing Shareholder, Andrews Biernacki Davis

Ann Dalton, Assistant Deputy Secretary for Medicaid Policy and Quality, Agency for Health Care Administration

Jennifer Sutherland, Caregiver

Jonathan Hawayek, MBA, Director, State and Local Government Affairs, Spark Therapeutics, Inc.

Guests and Staff

Yolanda Bonds, Health Services and Facilities Consultant, Florida Department of Health

Kim Witte, Director, National Accounts, Krystal Biotech, Inc.

Lisa Rawlins, The Garner Group

Jon Conley, Strategic Initiatives Manager/Operations Manager, Florida Department of Health

Business

1. Approval of Meeting Minutes

Chair Jordan cast the vote. Eric Biernacki approved the minutes from September 18, 2024, seconded by Kathy Hebda.

2. Member Updates

Chair Jordan announced that the Rare Disease Advisory Council (Council) has a new member, Alexis Bakofsky (not in attendance), who will represent the Office of Insurance Regulation (OIR). She added that representation from the OIR will be helpful in meeting the goals and objectives of the Council's State Agencies Subcommittee (Subcommittee).

Ann Dalton introduced a new statewide managed care program effective February 1, 2025, maintained by Florida Agency for Health Care Administration (AHCA). The new managed care program references services and benefits available which were identified as Medicaid conflicts that created barriers for patients to access. Information will be disseminated to members either by chat or by staff.

The Chair mentioned that data on rare conditions is now available through the Florida CHARTS (FLHealthCharts.org) website and shared with members how to obtain the information for research. The Council expressed a desire to promote the availability of the data broadly.

Before continuing with the Subcommittee discussions, Jonathan Hawayek shared research performed by his organization that was commissioned to identify up to 500 rare diseases based on ICD-10 codes to be used by Florida to broaden its understanding of rare disease.

3. Discussion Topics

a. Insights from December 11, 2024 – Other States' RDACs

The Subcommittee discussed and shared their thoughts on the material shared from other states' Rare Disease Advisory Councils (RDACs). Members expressed their appreciation in learning from the other states. They recommend future discussions with other state RDACs in the future.

b. Recommendation Review

Subcommittee members reviewed previous annual reports. The reports assisted them in editing, revising, or extracting goals that they determined were unachievable or completed. The information would then be used to complete the 2024 annual report.

Ann Dalton mentioned how the data from the research performed by Jonathan Hawayek can be overlaid with data from the Medicaid program. She would like all data to be included in the report. Ann Dalton gave an example of data that would show action, such as pulling information that shows the number of children who transitioned out of a nursing facility. Ann Dalton will take the information back to ensure data is pulled that will be meaningful and helpful to the state.

Jonathan Hawayek asked how transportation, mental health, and tutoring can be included in the Medicaid benefits. Ann Dalton spoke on the new out of state travel stipulation in the managed Medicaid policy but indicated it may be case specific. She mentioned a few of the expanded benefits that will assist the rare disease community such as non-medical transportation, travel to clinical trials in other states and tutoring to not only the patient, but also the caregiver. She will gather information and share with the members in a future meeting.

Kathy Hebda provided insight on broadened scholarship plans. She will assist with getting the information to the institutions, advisory groups, and others regarding the shortages and workforce issues. Kathy Hebda recommends the Council include available scholarships on the website.

c. Next Steps/Future Subcommittee Meeting Dates

The Chair mentioned again that a representative from the OIR had recently joined the Council and requested that staff provide onboarding sessions for new members.

Jonathan Hawayek shared observations about troubling trends and indicated it might be helpful to hear from the OIR on these trends, related to how Blue Cross Blue Shield commercial plans will not cover drugs and therapies that receive accelerated approval from the Food and Drug Administration (approval can be on hold for up to 18 months in cases where there is a lack of acknowledged clinical benefit, which often includes rare disease cases.)

He mentioned a possible solution worth exploring would be to provide an adjustment or add-on, which references additional coverage options that can be added to basic insurance policies for an extra premium cost. He acknowledged this is expensive and could introduce an obstacle to care. He also suggested assisting the OIR representative to expound on this subject at a future meeting.

The Chair asked members for other suggestions for future agenda items.

Ann Dalton volunteered AHCA to present the overview of the new Streamlined Modular Certification program which includes certifying discrete Medicaid information technology systems used to manage, monitor, and administer their Medicaid program.

Eric Biernacki asked about the status of the Pediatric Rare Disease Grant process and applications. The Chair indicated there were approximately 13 Letters of Intent received, and the Florida Department of Health expected to start receiving applications in the coming weeks.

The Chair also shared information pertaining to the application window and the Council's involvement in the process.

The Chair closed this portion of the agenda by mentioning that at the next Council meeting, sometime in mid-April or early May, the Council would be reviewing the grant applications and finalizing the work for the annual report. She indicated that staff would be forwarding a survey to the members to determine availability for future meeting dates.

4. Public Comment

No comments from the public were given.

5. Meeting Adjournment:

The meeting adjourned at 12:56 p.m. EST.