



## Rare Disease Advisory Council

### State Agencies Subcommittee

### Meeting Minutes

**Tuesday, April 8, 2025**

3 p.m. EDT

Virtual

#### **Welcome/Introductions:**

The meeting of the Rare Disease Advisory Council (Council) was called to order at 3:01 p.m. EDT by Melissa Jordan, Assistant Deputy Secretary for Health for the Florida Department of Health. Chair Jordan welcomed everyone and thanked them for joining the meeting.

#### **The following members or designees were in attendance:**

Melissa Jordan, MS, MPH, Florida Department of Health, Chair  
Alexis Bakofsky, MA, Deputy Commissioner, Florida Office of Insurance Regulation  
Eric Biernacki, JD Andrews Biernacki Davis  
Ann Dalton, Assistant Deputy Secretary, Agency for Health Care Administration  
Jonathan Hawayek, MBA, Head State Government Affairs, Spark Therapeutics, Inc.  
Kathy Hebda, Florida Department of Education, Vice-Chair  
Scott McClelland, Sr. Director Pharmacy Operations at Blue Cross Blue Shield of Florida  
Blake Shay, BCPS, Pharmacy Manager, BayCare Health Systems  
Jennifer Sutherland

#### **Guests and Staff:**

Yolanda Bonds, Florida Department of Health  
Kristin Craze, Florida Department of Health  
Kylie Mason, Florida Office of Insurance Regulation  
Jon Conley, Florida Department of Health

#### **Business**

##### **1. Discussion Topics**

###### **a. Recommendations Review**

The Council reviewed each 2024 recommendation to determine if they are still relevant to the Council's work.

#### **Changes/Update for 2025**

##### **Recommendation 1 – Identify data needed to understand the population with rare diseases in Florida.**

###### **Goals:**

- Define the prevalence/incidence of rare diseases in Florida.
- Develop a list of rare diseases and identify the distribution of incidence across the state, beginning with the top 50 most prevalent rare diseases.
- Identify Florida-specific data from national rare diseases using the current available databases in Florida.
- Determine where Florida ranks in comparison to other states regarding rates of rare diseases.

Resources for goal 1-3 will be retrieved from the Florida Community Health Assessment Resource Tool Set (Florida CHARTS) provided by the Florida Department of Health (DOH). Dr. McClelland

suggested the information be used to disseminate data to providers who care for individuals with rare diseases or as educational materials. Chair Jordan suggested compiling and completing tasks to disseminate the top 500 rare diseases by August. To protect individuals, data tables will suppress or collapse cells with very small numbers.

Goal 4 is put on hold. Chair Jordan stated there was no comparison at this time. Florida leads with having the data related to the rate of rare diseases available.

The lead for this recommendation will be Ann Dalton (AHCA), Alexis Bakofsky (OIR), and a DOH representative.

**Recommendation 2 – Identify areas of improvement for disaster preparedness and pandemic response for individuals with rare diseases in Florida.**

There were no updates, resources will be pulled from entities, current programs or documents that currently exist. The council named the Special Needs Shelter Registry, Division of Emergency Management, and DOH Emergency Preparedness & Response as some of the resources they would utilize. Chair Jordan suggested gathering information and existing documents that can be shared through the DOH website if it is made available.

The leads for this recommendation will be Blake Shay (Bay Care), Eric Biernacki, and Jonathan Hawayek. Blake Shay solicited the assistance of Colleen Bartlett who currently serves on the Health Care Providers Subcommittee for the needs assessment.

**Action Item** – Contact Colleen Bartlett to solicit her assistance on the State Agencies Subcommittee.

**Action Item Completed by DOH Staff** – Colleen was contacted to determine if she would like to serve on the State Agencies Subcommittee. She felt her skillset best matched with the Health Care Providers Subcommittee and will assist the State Agencies Subcommittee when needed.

**Recommendation 3 – Identify areas of improvement for the Florida Department of Health on rare diseases.**

**Goal 4 - Publish data on rare diseases through the Department's data portals, such as FLHealthCHARTS.org**

This goal is complete and will be updated as new data become available. Chair Jordan asked that the update with rare disease inquiry to FLHealthCHARTS.org is listed in the 2025 annual report. Chair Jordan mentioned the creation of a needs assessment and training survey on the population with rare diseases that DOH serves. The leads for this recommendation are Blake Shay and Colleen Bartlett, who currently sits on another subcommittee.

**Recommendation 4 – Identify areas of improvement for the Florida Agency for Health Care Administration (AHCA) on rare diseases.**

**Goal 2 – Identify Medicaid programs that serve the population with rare diseases.**

This goal has been satisfied and will not be included on the 2025 recommendations.

**Goal 5 – Research potential opportunities to improve Medicaid programs or services and address barriers and gaps.**

Ann Dalton suggested the Council work with other subcommittees to complete the research to improve Medicaid. She also mentioned the need for the community to know who to contact for services and to continue using the surveys (create a toolkit). Resources will come from Medicaid. Ann Dalton will lead this recommendation.

**Recommendation 5 – Identify areas of improvement for the Florida Department of Education (DOE) on rare diseases.**

**Goal 1 – Develop a resource guide to educate public and private school staff, students with rare diseases, and families on available resources and supports such as Individualized Educational Plans, 504 Plans, and scholarships offered.**

This goal has been satisfied and will not be included in the 2025 recommendations. Kathy Hebda mentioned the need-to-know pamphlet and back-to-school memo that highlights legislative changes and is currently being used at DOE. This document is disseminated to the school districts and Florida college system institutions and typically goes out by the end of July or beginning of August. She also mentioned the inclusion of information for parents of children with rare diseases to know what their students need while they are in school to include three important bullets concerning awareness at school. Kathy Hebda suggested using the information from the need-to-know pamphlet and back-to-school memo to create a webinar series for Department of Education to disseminate. The presenters will be staff from Office of School Choice, Bureau of Exceptional Student Education, Office of Family and Community Outreach, and Just for Teachers.

Chair Jordan also mentioned training school health nurses for the webinar series/resource. The lead for this recommendation is Kathy Hebda (DOE) and Eric Biernacki.

**Recommendation 6 – Identify areas of improvement for the Florida Office of Insurance Regulation on rare diseases.**

This recommendation and its goals are centered around the Office of Insurance Regulation. The lead for this recommendation is Alexis Bakofsky (OIR). Alexis asked for time to research the needs of the Council and the expertise she could bring to the Council. Alexis Bakofsky and Ann Dalton will work together on this recommendation.

**Action Items** – Eric Biernacki asked for information pulled previously: annual report and web resources. Jon Conley mentioned that DOH staff will continue to be the clearinghouse and will forward to the members.

**2. Public Comment**

No public comments were received.

**3. Adjournment**

The meeting was adjourned at 4:02 p.m. EDT by Chair Jordan.