



Rare Disease Advisory Council
State Agencies Subcommittee
Meeting Minutes

Thursday, August 14, 2025
12:00 p.m. EDT
Virtual

Welcome/Introductions:

The meeting of the Rare Disease Advisory Council (Council), State Agencies subcommittee was called to order at 12:00 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. She provided a brief overview of the agenda.

The following members or designees were in attendance: (Quorum established)

Melissa Jordan, MS, MPH, Florida Department of Health, Chair
Amy Hardee delegate for Alexis Bakofsky, MA, Deputy Commissioner, Florida Office of Insurance Regulation
Eric Biernacki, JD, Managing Shareholder, 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

Guests and Staff:

Yolanda Bonds, Council staff liaison, Florida Department of Health
Kristin Craze, Contractor, Florida Department of Health
Crystal Stickle, Magnolia Advocacy, LLC
Jon Conley, Strategic Initiatives Manager, Florida Department of Health

Approval of Past Meeting Minutes

Chair Jordan asked for a motion to approve minutes from previous subcommittee meetings. Jonathan Hawayek made a motion, to approve the meeting minutes from August 15, 2024, September 18, 2024, January 29, 2025, and April 8, 2025, seconded by Kathy Hebda, and approved by the members.

Business

1. Define subcommittee roles and operations – Purpose of subcommittees

Chair Jordan explained how some of the subcommittees have not been meeting quorum which effects the effectiveness of the subcommittees work. The Rare Disease Advisory Council has three subcommittees which includes the Academic Research subcommittee, Healthcare Providers, and the State Agencies subcommittees. These smaller groups provide guidance and support for the Council based on member expertise which aligns with the statutory requirements for the Council. Staff suggested that subcommittee members determine their purpose and review roles and operations or to combine subcommittees allowing more participation to meet quorum. Member suggestions included:

- Explain in detail the importance of attendance
- Inviting ad hoc members who aren't voting members
- Members reach out to staff regarding attendance or send a delegate who will come prepared to engage in conversation with thoughts and ideas.

2. Observations from the 2025 Annual Report

Chair Jordan provided an overview of the information that was included in the annual report, which include successes throughout the state. Chair Jordan mentioned identifying areas for improvement in future reports. Improvements are noted as gaps the council can focus on to assist in preparing future council meetings. Chair Jordan asked for topics that could be used to invite specific presenters to future meetings. Members asked Chair Jordan about the annual reports and the next steps to showcasing the work the council has done. Members suggested:

- Ask Representative Anderson if there would be opportunities for the council to showcase the work to the legislature.
- Use of the Florida Channel or other informational interview sources
- Forward the annual report to different advocacy and rare disease groups within the state
- Share information on listserv
- NORD through the Florida connect

Eric Biernacki shared a story about his role in assisting someone with information to help their severely autistic child. Although autism is not considered a rare disease, the father was unaware of the Step-Up scholarship and other resources to assist his family. Eric Biernacki would like the council to address ways to disseminate resources to families in the upcoming year.

3. Resources for the website – i.e. links, data

Chair Jordan agreed that the web repository would be a great way to inform families of the information received from DOE about where to start in a school district, how to go through the process of getting assistance, how to maneuver the insurance process, which include private paying or Medicaid recipients. Chair Melissa mentioned the website being a priority, Department of Health is still looking into ways to accomplish completing the process.

Questions regarding the website ensued, such as:

- What are you looking for to build the website?
- Does the Department of Health have to build the website, or can a third-party assist?
- What are the criteria/specs for a third party to build the website?
- Is the Department looking to complete this at a low-cost/no cost?

Chair Jordan and staff explained to the council that there are specifications that must be adhered to for Department of Health to access and monitor if an external/contractor builds the website. They are exhausting every avenue to get a website built with little to no cost. Jonathan Hawayek and Kathy Hebda both requested the information on criteria/specifications for the website. They will speak with external sources in getting this project started. Updates on the website repository will be presented in future meetings.

4. Member Updates

- Kathy Hebda from the Department of Education shared the news of the back-to-school memo being sent to all superintendents in Florida. The memo included a resource link from the National Organization for Rare Disorders (NORD) which offers a database of rare diseases, educational tools and patient support services as mentioned in a previous meeting.
- Jonathan Hawayek mentioned several updates:
 - Inquired about the correspondence he received regarding a lack of participation at National Organization for Rare Disorders (NORD). Jon Hawayek was assured that Florida Rare Disease Advisory Councils (RDAC) will be represented. The Chair and one staff will represent Florida's RDAC at the 2025 NORD summit.
 - New Jersey RDAC along with a geneticist counselor (graduate student) reviewed surveys from different state RDACs to revise and create a survey that would be useful to the data they were trying to collect from patients. The graduate student in the genetics

department used the data in her thesis as well as to create QR codes on the New Jersey's RDAC website. The document will be placed in doctor's offices to collect information from patients, in hopes to publish information that shows similarities in genetics.

- Chair Jordan was asked by Jonathan Hawayek to attend the New Jersey RDAC meeting to discuss best practices on different topics on October 6, 2025, at 2:15 pm. along with Representative Anderson.

Public Comment

No public comments were received.

Adjournment

The meeting was adjourned at 12:39 p.m. EDT by Chair Jordan.

DRAFT