



Meeting Minutes

Meeting of the Rare Disease Advisory Council (RDAC) State Agencies Subcommittee

Date: Thursday, September 21, 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), Jon Conley (Florida Department of Health), Maggie Dilger (Florida Department of Health), John Mattson (Agency for Health Care Administration), Eric Martin (Pfizer’s State Government Relations Division), Crystal Stickle (Vertex Pharmaceuticals and the Florida Medical Association)

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

The meeting was called to order at 12:05 p.m., and roll was taken. A quorum was not established.

Approval of Meeting Minutes – Council Members

Approval for the State Agencies Subcommittee’s July 19, 2023, meeting minutes will be moved to the October 18, 2023, meeting.

Member Updates – Council Members

Tara Cockman with the Florida Department of Health updated the group on the DUA. The Department has submitted a new application to the Agency for Health Care Administration for Medicaid data to be shared. Ms. Cockman explained that when dealing with small data numbers that could be personal identifying, data must

be suppressed in accordance with HIPPA law. John Mattson with the Agency for Health Care Administration mentioned aggregate data was just sent to the Department's data team on Tuesday. Tara confirmed the staff member is traveling and will work to obtain the information in chart form to distribute to the group in the near future.

Future Agenda Items Discussion/ October Council Meeting Agenda Items Discussion – Council Members

Melissa Jordan with the Department asked that meeting minutes and work being done by the other subcommittees be shared prior to the full council meeting to help align goals and conversation. The State Agencies subcommittee will provide an update on its progress regarding data. There should be a presentation from the IT department to discuss the future website with possible mockup ideas.

Ms. Jordan also reported she will be attending NORD's upcoming RDAC meeting in early October and reminded the group there is an open spot if a member is interested in attending.

Before the full council meeting on October 25, Maggie Dilger with the Department will send prompt questions along with the agenda.

Public Comment – Members of the Public

No public comment was made.

Adjournment – Maggie Dilger, Florida Department of Health

The meeting adjourned at 12:26 p.m.

Meeting Reminders

The next RDAC State Agencies Subcommittee meeting is scheduled for Thursday, October 19; 12:00 – 1:00 p.m. EST.

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