

Rare Disease Advisory Council (RDAC)

Location: Yoho Board Room

Date: April 17, 2026

Time: 3:00 – 5:00

Facilitator: Dr. Wade Clapp

In Person Attendees: Dr. Wade Clapp ,Cory Best, Carl Ellison, Laura McLinn, Dr. Guy Crowder, Eldon Whetstone, Mindy Cameron, Robyn Spoon, Barbara Calhoun, and Dr. Douglas Cipkala

Online Attendees: Patrica Smith, and Lucy Paskus

Guest Online: Dr. William (Billy) Bennett, Faculty Member, at School of Medicine and Health Services Research

Absent: Dr. Michael Busk, and Dr. Tara Jellison

Open Door Law Message: Eldon read the Open-Door Law Messaging that is required at the beginning of each meeting.

Introductions and Roll Call: Introductions and Roll Call were completed.

Approval of February Minutes: February minutes were reviewed. Motion was made to approve the minutes and seconded the motion. Minutes were approved by all.

Old Business:

- A. Council Vacancies Update - Eldon Whetstone:
 - a. Hospital Administrator possible member was submitted to the Governor's Office; however, they did not want to move forward a Hospital Administrator is still needed for that role. If you have a recommendation for the Hospital Administrator, please let Eldon know.
 - i. Question: Does it have to be a current Hospital Administrator can it be a retired Hospital Administrator? Eldon wasn't sure, but he will check.
 - b. Insurance Representative is still needed. Dr. Clapp has given Eldon a name and he will be following up.

New Business

- A. Patient Survey Update – Mindy Cameron, Robyn Spoon, and Dr. Billy Bennett
 - a. Survey was reviewed. Two additional questions were added.
 - i. 15. Title: Predictability of symptoms and care. Question: How predictable are you or the person you care for symptoms and care needs from day-to-day. Answers on a Likert scale from not at all to extremely predictable.

- ii. 16. Title: Complexity of daily management. Question: How complex is the day-to-day management of you or the person you care for condition?
Answer: Consider the number and intensity of daily tasks, for example, medications, monitoring appointments, self-care, personal hygiene, dressing, eating, transferring, toileting, incontinence, or procedures on a Likert scale from not at all complex to extremely complex.
- iii. At the end we have an open-ended text box that allows feedback
- iv. Dashboards have also been developed.
- v. Motion to adopt amended patient survey including addition of questions, 15 and 16 Dr. Cipkala moved for the approval Laura McLinn second motion was unanimous.

B. NORD Update – Robyn Spoon and Patrica Smith

- a. Start a quarterly meeting for RDAC, some of the topics will be leadership, best practice, and who can testify in front of legislators
- b. Knowing what your threat landscape is, who's a skeptic who's an advocate, showing how rare disease affects constituents and RDAC value.
- c. Developing a crisis response protocol. A 72-hour response would be approved through a process outline. Who has what responsibilities on the committee, who has what specialties.
- d. Efficiencies for how to survive. How valuable are those rare disease connections that would be able to also help if there were something to come about from a legislative standpoint that we would be able to help.

C. Other

- a. Annual Report - Get drafting started so that on June 5, 2026; review annual report draft and vote.
- b. Guest Speaker -- Mindy Cameron will invite the guest speaker from Minnesota for the June 5, 2026, RDAC meeting.

Public Comment, Time Permitting: No comments only committee members attended the meeting.

Adjourn – Motion was made to adjourn. Motion carried.

Next Meeting: June 5, 2026 – 3:00 p.m. – 5:00 p.m. – Yoho Conference Room, 3rd Floor