

Rare Disease Advisory Council (RDAC)

Location: Yoho Board Room

Date: June 5, 2026

Time: 3:00 – 5:00

Facilitator: Dr. Wade Clapp

In Person Attendees: Dr. Wade Clapp ,Cory Best, Laura McLinn, Eldon Whetstone, Robyn Spoon, Dr. Michael Busk, and Dr. Douglas Cipkala

Online Attendees: Carl Ellison, Mindy Cameron, Patrica Smith, and Barbara Calhoun

Guest Online: Dr. William (Billy) Bennett, Faculty Member, at School of Medicine and Health Services Research, Megan Smithhart, Treana Payton and Kimberly Compton

Absent: Lucy Paskus, and 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 April Minutes: April minutes were reviewed. Remove council position listed as Child with Special Health Care Needs. Cory Best moved that the correction be made and minutes approved, Laura McLinn second the motion. Minutes were approved with the above correction.

Old Business:

- A. Patient Survey Update and Distribution – Barbara Calhoun, Robyn Spoon, and Dr. Billy Bennett – Dr. Bennett shared the dashboard for the survey (Cohort I). Fourteen people have responded to the survey. Dr. Bennett also shared a flyer that has been developed and is being sent out. The survey hasn't been sent out to everyone it is being sent in phases. Dr. Bennett will email the flyer to the Council so it can be shared with others, and the flyer does have a QR code and link so people can take the survey. Distribute in close Facebook groups. Robyn will email the spreadsheet address to Dr. Busk to review and see if there are additional entries to email. Dr. Busk will be able to edit the list. An end date for the survey was discussed. It was suggested that a reasonable amount of time would be two to three months. Data analysis was discussed. Robyn would like to talk with Dr. Bennett regarding data analysis. Discuss how often the survey should be done, once the survey is completed then it can be determined how often the survey needs to be completed. Dr. Cipkala, how many surveys the council is expecting, Dr. Bennett would like to see 1,000. The council discussed what would be done to help with survey completion. Staff on Dr. Bennett's team and the RDAC shouldn't complete the survey.

New Business

- A. Annual Report Outline and Section Assignment – All
 - a. Survey
 - b. Funding
 - c. Other
- B. Drafts due Friday, June 12, 2026

The Annual Report will be sent to everyone for review. A motion was made and second that the Annual Report be approved once reviewed and any questioned addressed, all were in favor of this motion.

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

Adjourn – Motion was made to adjourn. Motion carried.

Next Meeting: August 28, 2026 – 3:00 p.m. – 5:00 p.m. – Yoho Conference Room, 3rd Floor