

**Rare Disease Advisory Council (RDAC)**

**Location: IDOH Yoho Conference Room**

**Date: October 24, 2025**

**Time: 3:00 – 5:00**

**Facilitator:** Dr. Wade Clapp

**In Person Attendees:** Dr. Wade Clapp, Cory Best, Patrica Smith, Robyn Spoon, Tara Jellison, Dr. Guy Crowder, Laura McLinn, Mindy Cameron, and Eldon Whetstone

**Online Attendees:** Dr. Ty Sullivan, Dr. Michael Busk, Dr. Douglas Cipkala, and Lucy Paskus

**Absent:** Carl Ellison

**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 August Minutes:** August minutes were reviewed. Minutes were approved.

**Old Business:**

- a. Patient Survey Update:** Mindy Cameron gave an update on the Patient Survey. Mindy met with Billy Bennett, Stacy Keffer and Stephen McKee from IU to discuss and develop the survey. The link for the survey was sent to Mindy, and she took the survey in ten minutes; however, the questions were very familiar to her so someone not familiar with the question might take a few more minutes. Discussion followed of who the survey would come from, the concerning being if it came from the Indiana Department of Health those filling out the survey might feel the state is tracking them. It was discussed that maybe the survey should be sent through IU Health. The doctors will send emails to their patients. Eldon will email the survey to the RDAC, and the council members need to send their feedback to Eldon by the end of the day on Friday, October 31, 2025. How to avoid duplicate responses was discussed. Robyn Spoon made the motion and Corey Best seconded to proceed with patient survey review. Finalizing a format and then distribution throughout the state.
- b. Council Vacancies Update:** Eldon Whetstone updated the Council on the vacancies. Our newest members are Patricia Smith filling number 9 representing the biopharmaceutical industry and Robyn Spoon filling number 7 representing rare disease organization. Additional Dr. Clapp has been reappointed by the Governor as the Chairman. Remaining spots are number 4 hospital administrator, number 3 physician licensed under Indiana Code 25-22 with experience treating a rare disease, number 10 representative of health carrier, and number 11 research physician. Dr. Clapp has recommended Dr. Stephanie Ware as that council member for number 11 research physician. Dr. Clapp has sent out messages to different hospital administrators outside of Indianapolis.

## **New Business**

**a. NORD Update:** Mindy shared information from the NORD Annual Meeting via slides. NORD does have an RDAC portal, but they mentioned that it isn't used very much.

**b. 2025 - 2026 Objectives:**

Government Affairs and Legislative Coordination subcommittee (subcommittee to report to council before the next meeting) -- The subcommittee will be made of Laura McLinn, Robyn Spoon, and Patrica Smith.

Survey subcommittee (help with the execution of the survey) -- The subcommittee will be made of Dr. Clapp, Tara Jellison and Robyn Spoon.

Grant subcommittee – This subcommittee would supply awareness of grants that are accepting applications. This subcommittee is tabled until additional vacant council positions are filled.

Additional subcommittees to be discussed at the December meeting.

Motion was made and second for the Government Affairs and Legislative Coordination Subcommittee and Survey Subcommittee. Motion carried with all in favor.

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

**Next Meeting:** Date and time undetermined as we explore legislator availability

**Adjourn** – Dr. Busk made a motion to adjourn the meeting seconded by Cory Best and Carl Ellison. Motion carried with all in favor.