

**Rare Disease Advisory Council (RDAC)**

**Location: Yoho Board Room**

**Date: February 2, 2026**

**Time: 3:00 – 5:00**

**Facilitator:** Dr. Michael Busk

**In Person Attendees:** Dr. Michael Busk, Cory Best, Carl Ellison, Laura McLinn, Lucy Paskus, Dr. Guy Crowder, Eldon Whetstone

**Online Attendees:** Dr. Douglas Cipkala, Tara Jellison, Barbara Calhoun, Patrica Smith, Robyn Spoon, Mindy Cameron and Dr. Wade Clapp

**Public Online:** Chris Mitchell

**Absent:**

**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 December Minutes:** December minutes were reviewed. Dr. Jellison made a motion to approve the minutes, and Patrica Smith seconded the motion. Minutes were approved by all.

**Old Business:**

- a. **Patient Survey Update:** Robyn Spoon shared a link so everyone could access the link <https://docs.google.com/document/d/1ly4Y-Vm8SVnf69DqO-Zl6ZlKwHcj0jSIM42HVBbyzsA/edit?tab=t.0#headin...> the link is live and is updating as changes are made. Robyn Spoon and Mindy Cameron worked through what they did and how the survey got to this point. Dr. Busk asked if we could run through the survey. Laura McLinn moved to approve the survey as written, Barbara Calhoun second the motion. Roll Call was taken to vote on the motion. Vote was unanimous to approve the survey as written.
- b. **Council Vacancies Update:** Eldon Whetstone gave the Council Vacancies Update. Mindy Cameron is back on the council. Dr. Cipkala switched his role to a physician treating a rare disease which allowed Mindy Cameron to fill the role of patient living with a rare disease. Barbara Calhoun is the newest RDAC member and introduced herself. Barbara fills the position previously occupied by Doctor Schnell, which was a member of the scientific community, who is engaged in rare disease research. That leaves three vacant spots:
  1. Physician with experience treating rare disease – We have a couple of leads and are pursuing these possibilities.

2. Hospital administrator from hospital licensed that provides cared individuals diagnosed with a rare disease – We have a couple of leads and are pursuing these possibilities.
3. Representative of the health carrier (insurance type company) –No leads at this time, however, Mike Smith is helping look for someone.

## **New Business**

### **a. Survey Distribution and Analysis:**

1. Robyn Spoon and Barbara Calhoun talked about the distribution of the Patient Survey and the analysis of the Patient Survey. Robyn Spoon deferred to Mindy Cameron who has been working with IU on the distribution. As far as distribution we had agreed we would use our own outreach and channels through our various foundations. There was a lot of talk about IU providers sending this out to patients, this would be the biggest way we were going to get the survey distributed. Robyn Spoon suggested see if somebody from Peyton Manning Hospital would also consider putting this out amongst their groups. The question is how long it takes IU to get through the IRB process because they're going to have to evaluate the questions. How do we make sure that the team at IU has a copy of this, that they get moving forward on it? When we find out approximately when they're going to get it back so that we all have some kind of knowledge about when we can push it out. For the timeline Elden could you remind us of when the report from the RDAC needs to be submitted to legislature? The report needs to be completed and approved by RDAC by June 30, 2026. Dr. Cipkala noted the patient survey would also have to be routed through Peyton Manning Hospital IRB process and volunteered Lucy Paskus for that challenge. Dr. Jellison mentioned that there are some disclaimers that you can put at the beginning of the survey that would then be distributed to the other organizations that are distributing on behalf of the RDAC, and they shouldn't have to get additional IRBs. Dr. Jellison also mentioned that she would love to be able to give the survey to genomics providers and pediatric cancer providers as well, but she is going to need something that says this is the RDAC and we're doing this study disclosure. Robyn Spoon indicated that language has already been written it just want on top of the survey that was reviewed. Mindy Cameron hasn't reached out to the Red Cap team but predicts they'll have this back within a week. Mindy asked if the survey was underway in June if it couldn't be like a rolling report and report what information has already be received; however, the survey is still on going. Robyn Spoon indicated you could do it like that; however, sometimes it's better to do it in cohorts because of the windows of time. Dr. Busk indicated that IRBs can be completed quickly. Robyn Spoon indicated that the survey committee meet again and start writing. Robyn Spoon is willing to start putting together a basic outline. Mindy Cameron brought up that the letter accompanying the survey needs to be completed. Dr. Clapp suggested that if deeper details are back by the September or October RDAC meeting a handout could be organized for the Committee for the Council and a legislator could be invited to the meeting. The next session is going to be a budget session, and it will start in November. Dr. Clapp gave the Patient Survey subcommittee the authority to make any changes requested by the IRB. Survey will be distributed:
  - a. Physicians
  - b. List of Rare Disease Patients at different Medical Centers
  - c. Foundations

d. Every county in Indiana

Discussed having legislators come maybe Representative Lauer, Cindy Ledbetter, and there are few others. Set a date for the October meeting.

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

**Adjourn** – Motion was made to adjourn. Motion carried.

**Next Meeting:** April 17 , 2026 – 3:00 p.m. – 5:00 p.m. – Yoho Conference Room, 3<sup>rd</sup> Floor