

**Rare Disease Advisory Council (RDAC)**

**Location: IDOH Yoho Conference Room**

**Date: August 22, 2025**

**Time: 3:00 – 5:00**

**Facilitator:** Dr. Wade Clapp

**In Person Attendees:** Dr. Wade Clapp, Cory Best, Dr. Michael Busk, Dr. Tara Jellison, Dr. Guy Crowder, Laura McLinn, Mindy Cameron, Carl Ellison, and Eldon Whetstone

**Online Attendees:** Dr. Ty Sullivan

**Absent:** Dr. Douglas Cipkala, Dr. Jodi Skiles, Lucy Paskus, and Dr. Brian O'Neill,

**Guests:** Karly Van Slykes, RN; Brittany Beard, and Patricia Smith

**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 June Minutes:** June minutes were reviewed. Motion to approve the meeting was made and seconded. Motion carried to approve minutes.

**Old Business:**

- a. **Patient Survey:** The patient survey is ready to go, the group discussed having the survey completed through red cap. Mindy would like to work with the person(s) who will be putting the survey in red cap. Discussion followed on who Mindy would be working with to get the survey in red cap. Dr. Clapp will take responsibility to get IRB approval. Discuss followed where the survey will be coming from; i.e. Indiana University School of Medicine. Dr. Clapp is going to ask Nancy and Stephanie to see if they will be willing to work on putting the survey in red cap.

**New Business**

- a. **Representative Julie McGuire:** Representative McGuire was held up in a meeting on a bill.
- b. **Discussion of New Member Nominations (the following information will need to be submitted to the Governor's office for each nominee to Name, Bio, County of Residence, Political Affiliation, and Resume). It was suggested that the statute be changed to increase the number of members of the council. Laura McLinn suggested going back to the original sponsor asking for the expansion.:**

**Biopharmaceutical Representative:**

Patricia Smith (Eli Lilly and Company)  
Dr. Holly Knoderer (Eli Lilly and Company)

**Research University Representative**

Barb Calhoun (Notre Dame)  
Dr. Stephanie Ware

**Health Carrier Representative**

Dr. Julie Keck

**Physician with Experience**

Dr. Nurcieck Padem  
Dr. Mary Cicarelli  
Dr. Stephanie Ware

**Hospital Administrator**

Dr. Marcia Felker  
Maria Niteu

**Rare Disease Patient Organization Representative**

Robyn Spoon  
Mindy Cameron

**Chairperson:** Dr. Wade Clapps name has been forward to the Governors Office for consideration

c. **2026 Topics and Subcommittees:**

Advocacy Subcommittee (right members on the committee, it could be something to consider a pilot project.

Survey Subcommittee

Pilot Project Development Subcommittee

**Public Comment, Time Permitting:** No comments

**Next Meeting:** October 24, 2025 – 3:00 p.m. – 5:00 p.m. – Yoho Conference Room

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