

Rare Disease Advisory Council (RDAC)

Location: Training Room 5T

Date: December 8, 2025

Time: 3:00 – 5:00

Facilitator: Dr. Wade Clapp

In Person Attendees: Dr. Wade Clapp, Cory Best, Patricia Smith, Robyn Spoon, Dr. Guy Crowder, Laura McLinn, Dr. Michael Busk, Lucy Paskus, Barbara Calhoun, Dr. Michael Busk, and Eldon Whetstone

Online Attendees: Dr. Ty Sullivan, Dr. Douglas Cipkala,

Public Online: Chris Mitchell, and Mindy Cameron

Public In Person: Representative Ryan Lauer

Absent: Tara Jellison, and 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 October Minutes: October minutes were reviewed. Minutes were approved.

Old Business:

- a. Patient Survey Update:** At the last meeting we agreed to send the survey out for some additional review. We had Patricia and Robyn join the Council. Laura, Robin and Patricia came back with some great additional feedback and some questions that they would like to see included. Mindy felt the additional questions were a significant departure from what the Council had agreed too. So, before reaching out to the Redcap team at IU Health to help get the survey reformatted, Mindy wanted the Council to look at some of the additional questions. Since that time Mindy discovered that the state of Indiana is reconsidering all of their waiver programs. The plan is to implement these changes in 2027. With that in mind, being able to data from the rare disease population in Indiana would really help the Council inform how waiver changes may affect rare disease patients. Since we are doing this survey anyway why not include a few questions specifically about what people are getting and what they need versus what they need? So even though these questions represent a departure from what we had agreed upon as a Council, and they are pretty inconsistent with other states. We have an opportunity and it is something we should really consider. Mindy was asked to go back and explain to everybody just to bring everyone up to speed what the intention of this survey was and why is RDAC compelled to do such a survey. Who were we trying to get information from. The Rare Disease Advisory Council was set up in different

states, one of the first tasks that most of them do is a survey of their rare disease population. In Indiana we don't know the prevalence, and nobody can tell you how many patients living with rare diseases actually in the state. So, it's hard to implement and ask for policy changes without data for back-up. The surveys serve as a way to get data from rare disease patients and families on prevalence, how they receive medical care, if they're experiencing any challenges in accessing medical care, if they're experiencing challenges getting access to medical care, and how many patients are qualifying for Medicaid? What kind of service do they need. Can non RDAC Council Members participate? Yes, they can. Eldon asked Mindy to send the survey to Barb Calhoun to review. Survey needs to take no longer than 5 – 15 minutes. What is the timeline needed in order to help inform the legislature? Survey needs to be ready to be sent out by the end of January 2026. Survey results and data are needed by June or July 2026 to be given to the legislators. Dr. Clapp will have his Administrator send out a doodle poll in early January for the committee to have a zoom meeting.

b. Council Vacancies Update: Eldon gave the Council Vacancies Update. 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 us with 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 care for 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. Subcommittees and 2026 Goal Discussion:

1. Survey and External Communication Subcommittee (name changed from Survey Subcommittee) (Dr. Clapp, Tara Jellison, Robyn Spoon new members Chris Mitchell and Mindy Cameron)
2. Government Affairs and Legislative Coordination Subcommittee (Laura McLinn, Patricia Smith, and Robyn Spoon) – Goals:
 - a. Keeping tabs on bills. The best opportunity is with survey data and getting a plan together before session and talking to our representatives, so they craft legislation in a way that addresses our issues. We can advocate for that beforehand because during the session, mines have already been made-up.
 - b. Reports – Nice bullet list in the front that has a very tight highlight reel to make it easy.
3. Grant Subcommittee
4. Outreach Subcommittee

b. HB1453 -- Pediatric Cancer Research Fund: This is legislation that passed last session that created the pediatric Cancer Research Fund. Robyn indicated that there are some groups interested in donating to that fund. Dr. Crowder and Eldon talked with our State

Budget Agency contact about how that actually gets created. Receiving a donation would prompt the State Budget Agency (SBA) to create the fund. If you have some entities that wish to donate, the donation would be submitted to SBA, and a fund would be requested.

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

Adjourn – Cory Best made a motion to adjourn, Dr. Busk second, motion carried.

Next Meeting: will find a date agreeable with the Council