

**Rare Disease Advisory Council (RDAC)**

**Location: IDOH Yoho Conference Room**

**Date: June 6, 2025**

**Time: 3:00 – 5:00**

**Facilitator:** Dr. Jodi Skiles in Dr. Wade Clapps Absent

**In Person Attendees:** Dr. Jodi Skiles, Cory Best, Dr. Guy Crowder, Laura McLinn, Mindy Cameron, Carl Ellison, and Eldon Whetstone

**Online Attendees:** Dr. Wade Clapp, Dr. Tara Jellison, Dr. Douglas Cipkala, Lucy Paskus, and Dr. Ty Sullivan

**Absent:** Dr. Brian O’Neill, Dr. Michael Busk, and Dr. Santiago Schnell

**Guests:**

Allison Chizum – Nurse Case Manager for the Indiana Pregnancy Promise Program

Amanda Hankins – Clinical Nurse Specialist for Franciscan Health in the Central Indiana Region

Julie McGill – Family Solutions Home Care

Kimberly Wallace –

Garnette Cox –

**Introductions and Roll Call:** Introductions and Roll Call was completed.

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

**Old Business:**

- a. **None**

**New Business**

- a. **2025 Report Preparation:**

Discussed the cover of the 2025 Report. Public Affairs supplied a couple of additional options for the cover. Mindy would like to see a young adult in a wheelchair (young women not a child). Eldon will have Public Affairs look for additional pictures.

The introduction will be updated as necessary.

Letter from the Rare Disease Advisory Council (RDAC) Chairperson Dr. Clapp will state the recommendation that the Council make in the 2025 Report.

The same introduction will be used as last year with change to the last paragraph. Eldon asked if everyone was okay with the introduction. Everyone was okay with the introduction.

The Membership Section will remain the same with the following updates:

Health Carrier Representative – Vacant

Physician Relevant Experience -- Vacant

Additional, Eldon is check with Dr. Brian O'Neill – Biopharmaceutical Representative this will be update accordingly.

Summary of Activities and Progress update and reviewed. Each recommendation and each bullet point was reviewed, if necessary revised ,and additions were made if necessary. Recommendation 1 was accomplished. Recommendations 2 -5 were reiterated, and Recommendations 6 was added to seek legislation for an exception to open door law for the RDAC that requires five (5) council members be present in-person.

The appendices for the RDAC Annual Report were reviewed.

Carl Ellison moved that the Council vote on moving forward with the report as it was reviewed today Laura McLinn second. Voting as follows:

**Yes:**

Dr. Jodi Skiles

Carl Ellison

Lucy Paskus

Laura McLinn

Dr. Tara Jellison

Mindy Cameron

Dr. Douglas Cipkala

**Abstain:**

Cory Best

Dr. Ty Sullivan

**New Members and Vacant Positions:**

Eldon talked to the Indiana Department of Health Chief Operations Officer, and he said that the governor's office has new forms. If you have anyone you want to recommend for the vacant positions or those term ends these are the things we need:

Name

Brief Bio

County of Residence

Political Affiliation

Resume or CV

Eldon believes there is an actual form, however, he hasn't gotten the form. When he gets the form, he will circulate it to everyone. Forms would be completed by the person being recommended to the Council once the forms are completed, they would be returned to Eldon, and he would forward them to Office of Legal Affairs.

Discussion on possible Council members followed.

**Other:**

Eldon will check with legal to see what is needed to get an exception to the Open Door Law for RDAC.

Discussed inviting Legislators to the RDAC meetings.

The scheduled July meeting was rescheduled to August 22, 2025. There are no meetings scheduled after August 22, 2025.

Invite Legislators on the Healthcare Committee to the August 22, 2025, meeting. The items suggested for this meeting were:

- Briefly review the Annual Report
- Waivers
- Education

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

**Next Meeting:** August 22, 2025 – 3:00 p.m. – 5:00 p.m. – Yoho Conference Room

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