

Rare Disease Advisory Council

Location: IDOH Yoho Conference Room

Date: March 14, 2025

Time: 3:00 – 5:00

Facilitator: Dr. Wade Clapp, Chairperson

In Person Attendees: Dr. Wade Clapp, Cory Best, Mindy Cameron, Dr. Guy Crowder, Laura McLinn, Dr. Tara Jellison, Dr. Jodi Skiles, and Eldon Whetstone

Online Attendees: Dr. Lucy Paskus, Dr. Brian O'Neill, Dr. Santiago Schnell, Carl Ellison, and Dr. Ty Sullivan

Guests: Robyn Spoon, Mary Foster, Sara Burnett, Laura Ball, and Chris Roberson

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

Approval of February Minutes: February minutes were reviewed and approved with the correction that Dr. Joel Feldman was not in attendance.

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Old Business: None

New Business

- a. **Rare Disease Survey:** Was moved to item b. **Pediatric Cancer Legislation Letter:** Was moved to item a. The Pediatric Cancer Legislation Letter was reviewed by each individual attending the RDAC Meeting. Attendees reviewed the letter together and Eldon Whetstone made the recommended changes to the letter. After the letter was revised attendees reviewed the letter. Mindy Cameron made a motion to vote on the approval of the letter. Dr. Jellison second the motion. Each council member was asked to vote on the letter Dr. Sullivan, who abstained from voting, everyone else approved the letter. Attendees discussed who the signatory should be of the letter. It was decided that Dr. Clapp as the Chairman of RDAC would sign the letter. Once the letter has been signed Eldon Whetstone will start the letter through the chain of command to Representative Timothy O'Brien.
- b. **Indiana Rare Disease Advisory Council (I-RDAC) Rare Disease Patient Needs Assessment Survey** – Attendees reviewed the survey. Eldon Whetstone made changes as each question was reviewed. The group was only able to reach question 27 before running out of time.
- c. **2024 Report Preparation** – Not Addressed
- d. **2025 Meeting Dates** – Not Addressed

Next Meeting: Since all items weren't addressed the Council decided a meeting was needed in April. Eldon Whetstone will send out a doodle poll to see what date the best date for everyone

would be to attend. There is a meeting scheduled for May 9, 2025. A meeting may also need to be scheduled for June.

Public Comment, Time Permitting – There was no public comment.

Adjourn – A motion to adjourn the meeting was made seconded. Motion carried with all in favor.

Next Meeting in April to be determined

Location to be determined

Time to be determined