

Eric J. Holcomb
Governor

Lindsay M. Weaver, MD, FACEP
State Health Commissioner

RDAC Meeting Minutes
February 9, 2024, 2 to 5 p.m.
Yoho Conference Room, Teams Meeting

Call to Order – 2 p.m.: A meeting of the Rare Disease Advisory Council was held at 2 N. Meridian St, in the YOHO Conference Room on the third floor.

In Person Attendees: Dr. D. Wade Clapp, Laura McLinn, Dr. Tara Jellison, Julie Gries, Mindy Cameron, Dr. Jodi Skiles, Dr. Brian O’Neil, Eldon Whetstone, Amy Kent, Jake Torrie, Cory Best, Kian Hoss and Cynthia Bryant.

Online Attendees: Dr. Santiago Schnell, Dr. Doug Cipkala, Eden Bezy, Dr. Ty Sullivan, Carl Ellison, Courtney Comer, Dr. Nancy Swigonski, Robyn Spoon, Kristi Linson, Lucy Paskus NP, Dr. Patrick Milligan, and Tami Barrett.

Approval of Minutes: Dr. Clapp – Council Chairman.

Approval of Previous Minutes – 2:13 p.m.

Reports: None.

New Business: None.

Announcements: Dr Brian O’Neil has been chosen as the representative for Eli Lilly.

Handouts: A Caregiver Waiver Proposal Letter by Paskus and recommendation drafts from Skiles, Cipkala, Paskus, and Clapp.

Roundtable: Timeline construction; Bill 1386 is dead, so the Council will work on the Council Report to submit in June so it may be reviewed for legislation for next year. The final draft, vote and approval are due in May.

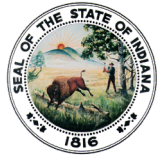
Motions: Motion One- 2:20 p.m.: A bylaw change for the appointment of a vice chairperson to oversee meetings during Dr. Clapp’s leave of absence. Motion Two – 3:33 p.m.: Lucy’s recommendation be submitted to the General Assembly. Motion three – 3:35 p.m. the subcommittees were reduced to two. The permanent names will be Pediatric Cancer and Non-Cancerous Rare Disease as of this meeting.

Record of Votes on Motions:

Meeting minutes approved with changes. 14 Ayes/ 0 Nays

Bylaw change to have an appointed vice chair 14 Ayes/0 Nays

Send letter supporting responsible individual to serve as a medically fragile child’s personal care attendant from the RDAC. 12 Ayes/0 Nays/2 abstained (Sullivan and Feldman)



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3:45 p.m. – Council split into subcommittees.

4:30 p.m. – The Non-Cancerous Rare Disease subcommittee returned to the YOHO conference room.

5:05 p.m. – The meeting was adjourned.

Action Items

- Paskus will refine and finalize her letter; McLinn will send it to the FSSA for review during the public open comment period.
- Cipkala and Feldman will brainstorm and refine prior authorizations proposal.
- The Pediatric Cancer Subcommittee will work on the survey and present it to the full Council.
- Skiles will present a proposal for children's future fertility protection after chemo/radiotherapy treatments.
- The Non-Cancerous Rare Disease Subcommittee will create a resource tree document for the RDAC website.
- Notre Dame students will help with resource tree document. McLinn will email Barb Calhoun for assistance. McLinn will travel to Notre Dame to work with the students.