



Eric J. Holcomb
Governor

Lindsay M. Weaver, MD, FACEP
State Health Commissioner

RDAC Minutes
March 26, 2024 – 1 to 3 p.m.
YOHO Conference Room, Teams Meeting

Call to Order – 1 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. Wade Clapp, Laura McClinn, Dr. Brian O’Neill, Julie Gries, Guy Crowder, Dr. Doug Cipkala, Jessica Faser, Cory Best, Eldon Whetstone, Dr. Nancy Swigonski, Jake Torrie.

Online Attendees: Lucy Paskus NP, Mindy Cameron, Dr. Michael Busk, Amy Beard, Holly Lambert, Carl Ellison, Tara Jellison, Dr. Jody Skiles, Dr. Ty Sullivan, Courtney Comer, Robin Spoon.

Approval of Minutes: Dr. Wade Clapp, Laura McClinn, Ty Sullivan, Cory Best, Amy Beard, Lucy Paskus NP, Dr. Michael Busk, Tara Jellison, Carl Ellison, Mindy Cameron, Dr. Jodi Skiles, and Dr. Ty Sullivan. 12-Ayes, 0-Nays

RDAC went over the Mock-up Report planning and timeline. RDAC has accomplished a lot since September 2023. Any comments or ideas are welcomed that may want to be added for next year. There are two meetings before this is due June 15, 2024. The team will need to approve the draft in May to have it ready to submit. Currently there are four recommendations. These were provided at the February meeting. The report includes documentation of activities and will include the required assessment of funding in Indiana. Dr. Clapp will have a draft of the cancer allocations in the state for research by the next meeting. Reminder that the report can only be 20 pages long.

The abstract that Dr. Clapp submitted to the NORD meeting was discussed. It shows the importance of preclinical work and integration for rare disease. Before preclinical work and integration, there had been 14 clinical trials for patients with the debilitating and ultimately

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lethal cancers called Plexiform develop fibromas. Zero out of 14 trials had no success at all. With Integrated models, 3 out of 3 have been successful with a possibility of a fourth on the way.

There was a motion to make a sub-committee to be called Resources. This will replace the current non-cancer rare disease committee. The motion was passed with 12 Ayes, 0 Nays.

The two committees will be called Cancer sub-committee and Resource sub-committee. The Resource committee members: Laura McClinn, Mindy Cameron, Dr. Santiago Schnell, Lucy Paskus NP, and Dr. Doug Cipkala in virtual meetings. Resource Website needs to be more accessible, and easier to find. (ex: in.gov/rdac). The Resource committee members were updated.

There was a conversation about rules for notification. Kendra Harper will provide updated information on meeting rules with the change from the legislative session.

The mock survey was originally sent to five people, and the results showed a range of 10-11 minutes to complete the survey. Changes have been made to the survey by previous recommendations.

RDAC discussed the benefit of leaving names on the survey for tacking purposes, to help get 100% participation. The survey will need to go through the process IRB for finalization, then it goes to OPA-Team for proofreading. This should be done as quickly as possible. The surveys will be sent electronically. The goal is to have these sent out in the last two weeks in April.

Work on sending to pediatric oncologist we know across the state, primarily at Riley, Peyton Manning group in Fort Wayne and South Bend. It was discussed maybe targeting some Illinois oncologist who may be outlined boarder Indiana towns. Dr. Clapp and Dr. Cipkala will be distributing these surveys at staff meetings to get a better response rate.

All resources need to be sent to Laura. The Resource Committee will need to reach out to social workers at Peyton Manning that can give us more resources. The resource committee will invite family to family for additional resources and explore ways that they could partner.

Subcommittee meetings met separately and reports on progress were given to the entire team.



An update on the perinatal and genomics committee was provided by Laura McClinn.

Julie urged everyone to let her know if they were coming in person. We need a third of the members to have a meeting. Otherwise, it will be cancelled.

The next meeting April 12, 2024, from 2-5.