

RDAC April 12, 2024

Meeting Minutes



Location: TEAMS Meeting and YOHO Conference Room, 2 North Meridian St. Indianapolis, IN

Date: April 12, 2024

Time: 2-5 pm

Facilitator: Dr. Wade Clapp, Chairperson Rare Disease Advisory Council

Call to Order – 2:00pm: 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, Robyn Spoon (not council member), Mindy Cameron, Dr. Brian O'Neill, Cory Best, Dr. Joel Feldman, Dr. Michael Busk, Dr. Doug Cipkala

Online Attendees: Dr. Santiago Schnell, Dr. Laura Paskus, Dr. Ty Sullivan, Dr. Jodi Skiles, Dr. Tara Jellison

In Person Staff Support: Cynthia Bryant, Guy Crowder, Julie Gries, Jake Torrie, Eldon Whetstone

Approval of Minutes: Dr. Clapp – Council Chairman.

Approval of Previous Minutes – 2:10pm, unanimous vote.

Reports: The second mock annual report.

New Business: None.

Announcements: The draft survey has been completed and submitted for IRB review. After approval, it will be sent to IDOH for OPA review. Next meeting of the Perinatal Genomics Committee is scheduled. Representative will report at next meeting.

Handouts: Open Door Law update, Pediatric Cancer Subcommittee Legislative Recommendations, Educational Engagement Proposal, Report on item #7 – Funding on pediatric cancer research, Pediatric Cancer Legislative Recommendations – Prior Authorizations, PHO Study Categories and RDAC upcoming meeting dates.

Discussion: Updates on the survey and the Perinatal Genetics and Genomics Advisory Committee were given. There was significant discussion of the annual report. A second mockup was shared. Dr. Clapp had sent a written draft

concerning the status of cancer research in the state. He asked that any additional research that wasn't in the plan be sent to him for inclusion.

This year's report will be drafted and sent to council members for further edits. This will need to be approved at the May meeting for time to send through OPA before being submitted to the Governor and legislators.

There was discussion of existing recommendations in the plan. It was requested that when appropriate, rare diseases be added to the cancer recommendations. One of the recommendations on pre-authorizations will be replaced with what was sent April 11 by Dr. Cipkala and Dr. Feldman.

There was significant discussion on the recommendation about Medicaid waivers. Dr. Feldman offered to run data on MHS to assess Medicaid costs for pre-authorization and share with the group. Although not representative of all insurance costs, it will provide some information. RDAC members were to provide Dr. Feldman with a list of rare diseases.

It must be submitted by June 14th and a draft will be sent for review by council members. Because there was written verbiage and the pediatric cancer/survey subcommittee submitted recommendations, there is a cancer Presence in the plan. Others are welcome to submit additional recommendations. It was requested that rare diseases be included in existing recommendations when appropriate. The council will need to discuss direction for next year's annual report. Genomics was suggested.

Ms. McLinn shared some of the resources that she had explored and received from committee members. She suggested that all review the Minnesota RDAC website and the NORD website. She shared her activities of meeting with Family to Family and with Notre Dame. Family to Family is probably not a good source for the website since it is for families and children and rare disease is bigger than that. Although the student project cannot occur this semester, it is very promising that Notre Dame students will be able to contribute to the council's activities.

There is an ability to do a vanity name for the RDAC. It would still be attached to the existing website. RDAC would like a more extensive website for the resources. Ms. McLinn asked that her role be changed on the RDAC website.

There was a request to begin considering how to structure the meetings in the upcoming year. RDAC members will discuss further.

A correction was made. Monthly meetings will continue through September. RDAC will then go to an every other month format. A standing time of the second Friday of the month from 2-4 will be set for meetings after the June meeting.

Final discussion and approval of the annual report will occur at the May 10 meeting. Next meeting will be May 10, 2024, from 3-5 pm.

Power Point Presentations: None.

Action Items	Owner(s)	Deadline	Status
Revise the current waiver legislative recommendation with recommended and viable language.	RDAC Committee	May 8, 2024	
Revise RDAC 23-24 Legislative recommendations to include cancer and submit any additional waivers to all.	RDAC Committee Jullie Gries	May 8, 2024	<p>Additional recommendation came in from Pediatric cancer subcommittee and has been added.</p> <p>Julie deleted the previous prior authorization recommendation and replaced it with two from Drs. Cipkala and Feldman.</p> <p>Julie added rare disease to two recommendations (fertility preservation and learning specialist.)</p>

Provide list of rare diseases and run MHS data to compare cost of treatment and prior authorizations	RDAC committee Dr. Feldman	May 10, 2024	
Assess website status	Julie Gries Eldon Whetstone	Ongoing	Titles have been revised on existing website.
Review next draft of the annual report	RDAC	May 2-May 8, 2024	Next version will not be sent until May 2, 2024.
Send ongoing meeting invites for July, August, September and then bimonthly	Julie Gries	May 10, 2024	Completed.