

Rare Disease Advisory Council

Location: IDOH YOHO CONFERENCE ROOM

Date: May 10, 2024

Time: 3:00pm – 5:00pm

Meeting Minutes

Call to Order – 3:00pm: 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, Eldon Whetstone, Cory Best, Dr. Joel Feldman, Dr. Guy Crowder, Dr. Doug Cipkala and Cynthia Bryant.

Online Attendees: Dr. Santiago Schnell, Dr. Laura Paskus, Dr. Ty Sullivan, Robyn Spoon, Mindy Cameron, Dr. Nancy Swigonski, Dr. Michael Busk, Dr. Brian O'Neill, Courtney Comer and Tami Barrett.

Approval of Minutes: Dr. Clapp – Council Chairman.

Approval of Previous Minutes – 3:05pm, unanimous vote..

Reports: None.

New Business: None.

Announcements: None.

Handouts: Report Recommendations for Review and Voting, the RDAC Agenda.

Power Point Presentations: None.

Roundtable: A review and revision of the six report recommendations and public comments.

Motions: Seven motions/votes on recommendation revisions. A detailed listing of motions are in the meeting notes.

5:23pm – The meeting was adjourned, unanimous vote.

Rare Disease Advisory Council

Location: IDOH YOHO CONFERENCE ROOM

Date: May 10, 2024

Time: 3:00pm – 5:00pm

To Do

Have the second draft of the RDAC Annual Report ready for review by May 31st.

Work on amendment language between now and June 14th.

Eldon will forward survey comments to Dr. Swigonski.

Robyn will provide wording regarding genetic counseling recommendations.

Dr. Clapp will discuss recommendation 4 with Robyn.

Rare Disease Advisory Council

Location: IDOH YOHO CONFERENCE ROOM

Date: May 10, 2024

Time: 3:00pm – 5:00pm

Final vote of
annual report and
submission to the
Legislative Council.

Next Meeting:
June 14, 2024