

# Rare Disease Advisory Council

**Location: IDOH YOHO CONFERENCE ROOM**

**Date: June 14, 2024**

**Time: 2:00pm – 4:00pm**

## Meeting Minutes

**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, Eldon Whetstone, Cory Best, Dr. Joel Feldman, Dr. Guy Crowder, Dr. Lucy Paskus, Mindy Cameron, Dr. Tara Jellison, Jake Torre, Dr. Michael Busk, Dr. Doug Cipkala, Dr. Brian O’Neill and Cynthia Bryant.

**Online Attendees:** Dr. Ty Sullivan, Robyn Spoon, Jill Gard, Jessica Beckstrand, April – Representing Dr. Jodi Skiles, Heather Garvey.

**Approval of Minutes:** Not Applicable.

**Approval of Previous Minutes** – May and June minutes and notes are to be reviewed and approved during July 12th meeting.

**Reports:** June 7th draft of Rare Disease Council Annual Report.

**New Business:** None.

**Announcements:** None.

**Handouts:** Indiana Family to Family flyer.

**Power Point Presentations:** None.

**Roundtable:** A review and revision of the six report recommendations, and the final report. Laura McLinn’s letter to the FSSA will be added to the annual report as Appendix 1.

**Motions:** 3:45 – Motion to Approve Report Amendments and Final Report: 11 approved and 1 abstained.

**3:52:** Public welcomed to comment.

**3:56pm** – The meeting was adjourned.

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## To Do

Resource Editing  
Discussion – Laura  
McLinn – On July's  
meeting agenda.

Begin new  
session/fiscal year  
with Genomics  
and Newborn  
Screening  
Programs.