

Rare Disease Advisory Council

Location: IDOH YOHO CONFERENCE ROOM

Date: January 12, 2024

Time: 2:00PM – 4:00PM

Meeting Minutes

Call to Order – 2:06pm: 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, Dr. Joel Feldman, Kian Hoss, Dr. Nancy Swigonski, Dr. Guy Crowder, Corey Bass, Dr. Patrick Milligan, Mindy Cameron and Cynthia Bryant.

Online Attendees: Dr. Santiago Schnell, Eldon Whetstone, Courtney Comer, Dr. Jodi Skiles, Kristi Linson, Heather Garvey, Dr. Michael Busk, Jessica Beckstrand, Robyn Spoon, Lucy Paskus, ND, Tami Barrett, and Dr. Doug Cipkala and a representative of Artia Solutions.

Approval of Minutes: Dr. Clapp – Council Chairman.

Approval of Previous Minutes – 2:11pm.

Reports: None.

New Business: None.

Announcements: Corey Bass is now representing the Department of Insurance in place of Meagan Laird. Perry Genomics Council update: the first meeting is set for Tuesday, January 23rd from 2:00pm – 4:00pm. The President of the Muscular Dystrophy Family Foundation has passed away.

Handouts: EveryLife shared file – in Microsoft Teams folder for review.

Power Point Presentation: Dr. Swigonski – Survey Development.

Roundtable: Review of co-pay accumulators, co-pay cards and co-pay maximizers. Survivorship and EveryLife Foundation cost estimate/policy/rare drug discussions.

Motions: None.

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To Do

Julie will split council members into subcommittees.

Contact providers and talk with them about the semi-structured survey.

Establish RDAC timeline.

Corey will talk to DOI Director about Indiana legislative action regarding copay laws.

Reserve time in the next meeting for subcommittee meetings.

Meeting adjourned at 4:05pm.