

# Rare Disease Advisory Council

**Location: IDOH YOHO CONFERENCE ROOM**

**Date: November 13, 2023**

**Time: 8:00AM – 10:00AM**

## Meeting Minutes

**Call to Order – 8:04 am:** 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, Dr. Doug Cipkala, Lucy Paskus NP, Julie Gries, Dr. Joel Feldman, Ann Alley, Allison Forkner, Kristi Linson, Dr. Nancy Swigonski, Kendra Harper and Cynthia Bryant.

**Online Attendees:** Dr. Santiago Schnell, Dr. Ty Sullivan, Meghann Leaird, Amy Beard, Dr. Jodi Skiles, Carl Ellison, Leigh Denny, Rachel Swartwood, Robyn Spoon, Tami Barrett.

**Approval of Minutes:** Dr. Clapp – Council Chairman.

**Approval of Previous Minutes – 10:21am.**

**Reports:** None.

**New Business:** None.

**Announcements:** None.

**Handouts:** House Enrolled Act No. 1201, by Dr. Nancy Swigonski.

**Power Point Presentations:** Amy Beard : Indiana Department of Insurance, Kristi Linson: Children’s Special Health Care Services, Allison Forkner: Genomics and Newborn Screenings.

**Roundtable:** Kendra Harper explained the Open Door Law for Council meetings. Dr. Nancy Swigonski explained how to construct survey questions. She used the House Enrolled Act handout survey examples as a base to build upon. She also gave the council homework: review the handout to create survey questions, make suggestions and give feedback. Also, weigh the survey question burden.

**Motions:** Motion One- 10:15 am: There was a unanimous vote that the survey questions will be used to develop a series of surveys for pediatric cancer. Those results will be applied to rare diseases and learning more about non-malignant rare disease. Motion Two – 10:21 am: The meeting minutes were approved and edit recommendations were requested.

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## To Do

By law Review.

Review possible partnership with CSHCS for focus groups and survey questions. Consult Mary.

Create public polls. Insert questions in appropriate areas depending on subcommittees.

Ask Mr. Ellison about available/alternate voices for surveys.

Mr. Ellison will ask for a sample survey for upcoming meeting with the Rare Disease Diversity Coalition.

Meeting adjourned at 10:25am.