

RDAC November 8, 2024

Meeting Minutes



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

Date: November 8, 2024

Time: 3-5 pm

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

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. Wade Clapp, Dr. Brian O' Neill, Eldon Whetstone, Laura McLinn, Cory Best, Mindy Cameron, Dr. Tara Jellison, Dr. Guy Crowder, Dr. Jodi Skiles, Dr. Douglas Cipkala, Dr. Michael Busk, Dr. Joel Feldman

Online Attendees: Amanda Moore, Speaker; Carl Ellison; Dr. Ty Sullivan; Lucy Paskus; Dr. Santiago Schnell

Introductions and Roll Call: Introductions and Roll Call was completed.

Angelman Syndrome Foundation Speaker Amanda Moore: This month's speaker was Amanda Moore she gave a presentation on Angelman Syndrome. Ms. Moore shared slides which will be available for review.

Approval of July and August Minutes: August minutes were reviewed. Since no extra work has been done regarding categories related to the resource list. Laura McLinn asked that this be stricken from the minutes. With this correction minutes were approved by all.

Old Business

- a. **Clinical Survey Update: Pediatric Cancer** – Dr. Clapp shared slides that review the survey responses. Results will be available. Will continue to try and get 100% response.
- b. **Rare Disease Survey** – All discussed the Rare Disease Survey
- c. **Resource Website Discussion** – Due to time constraints this was tabled until the next meeting.

New Business

- a. **NORD Update** – Mindy Cameron shared information regarding the NORD Survey. There are many things that she must figure out, such as taking the survey. The survey results will belong to NORD, but Mindy is hoping that the results will be shared.
- b. **Subcommittee Formation** – At this time no subcommittee's formed.

Public Comment, Time Permitting – There was no public comment.

Adjourn – Cory Best made a motion the meeting be adjourned and Mindy Cameron seconded. Motion carried with all in favor.

Next meeting will be January 10, 2025, from 3-5 pm.

Power Point Presentations: Amanda Moore: Angelman Syndrome (have requested from Ms. Moore)

Action Items	Owner(s)	Deadline	Status
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