

Rare Disease Advisory Council

Location: IDOH YOHO CONFERENCE ROOM

Date: July 12, 2024

Time: 3:00 p.m. – 5:00 p.m.

Call to Order – 3:00 p.m.: 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, Cory Best, Laura McLinn, Dr. Jodi Skiles, Dr. Joel Feldman, Dr. Guy Crowder, Jake Torrie, and Mindy Cameron.

Online Attendees: Dr. Michael Busk, Dr. Tara Jellison, Dr. Santiago Schnell, Lucy Paskus, Dr. Ty Sullivan, and Dr. Brian O'Neill

Approval of Minutes May 10, 2024: Motion was made to approve the May 20, 2024, minutes and seconded. Roll was call and minutes were approved unanimously.

Approval of Minutes June 14, 2024: Motion was made to approve the June 14, 2024, minutes and seconded. Roll was call and minutes were approved unanimously.

Old Business:

- **Link to Report:** Everyone can see the report, thorough the link <https://www.in.gov/health/cdpc/files/RDAC-2024-Report-6.14.24.pdf>
- **Bylaws Review:** Following corrections were requested:
 - **Article IV Duties:**
 - Number 1 under c
 - 6) should be D
 - 7) should be E
 - 8) should be F
 - 9) should be G
 - 10) should be H
 - Number 2 stick When appropriate and change Committee to Advisory Council
 - Number 3 becomes Number 8 under Article 3
 - **Article V: Voting:**
 - Number 3 at the end add (only applies to three (3) positions).

Motion was made and seconded to approve the changes above. Roll was called and the Bylaw Revision was approved unanimously.

New Business

- 2025 Goals and Objectives

- Survey – Possible adapting a survey on Cancer, Children, Rare Cancers. Of course this be adapted to Rare Disease. Get final approval so it can be sent out. Send out the Survey before the September meeting.
 - Intellectual Disabilities – Mindy Cameron will make some calls about the Task Force, what their charge is and what sort of relation we should have.
 - DDRS – Laura McLinn will contact DDRS to see what their charge is and what sort of relation we should have.
 - Broad Input from
 - ✓ Families
 - ✓ Caregivers
- Report – Will we ever hear back with regard to this report.
- Increase Legislative Engagement around Healthcare (Work on Relationship Building) – Not much action until after the election. Committees are appointed in December (Senate – Committee on Health and Provider Services, and House – Committee of Public Health. Senate Committee on Family and Children Services and House Family Children and Human Affairs) – Jake Torrie would be happy to walk Council Members through the General Assembly website. Jake will do a 15-minute presentation at the next meeting.
- Speakers (if you are getting a speaker make sure you get back with the Council)
 - Insurers – Dr. Feldman will work on a speaker for Insurers.
 - Pharmaceuticals – Dr. O'Neill will work on identifying a speaker for pharmaceuticals. There are a range of topics (pricing, therapy, distribution {People need to understand what a high-level delivery looks like in this country it's very complex.})
 - Legislators
 - Transition of Care from Children to Adults – Dr. Clapp will contact Mary Ciccarelli
 - Monitoring the Landscape for Whole Genome Sequencing and Genetic Testing (Genetic Testing and Screening) – Dr. Clapp recommended Stephanie Ware from the School of Medicine – Dr. O'Neill also suggested Doctor Suri.
 - Dr. Sullivan can probably find somebody from FSAA to talk about the waiver, but it probably won't be in August and the person would just be able to outline the changes but won't be able to answer the why. Looking forward to December.
- Resource Website – Update – Laura McLinn -- What I really would like to talk about before we do that is we still have this long weird, you know website link, it's how gender, the cancer, it's very long. We've talked about this like the web. The link itself to our page and UM. I still don't feel like I have a direct person to report to, to, like, get things added and as new one comes in, I thought we should talk more about the process versus just adding stuff. We can certainly take a vote today on adding a few. I hate doing it just to check a box and I hate putting a lot of work into something that won't get used, so I would like to spend more time as a committee talking about what are we going to do with it and how will people know it's there. Discussion followed with some of the following comments:
 - Even though it's a long address for our website. The SCO's been optimized so when it first, even if you go to Google and there's any interviews, advisory

council that comes up right away. So, the overall length for the address matters very little in the FBO setup properly, which is like it is.

- Discussed concern about able to find the Resource Website. Community would educate (doctors, nurses, social workers, individuals who also have the rare disease).
- Each resource website will have to be voted on (Yes, we add it. No, we don't.) before it can be added to the list.
- We talked about seeing what we have and then seeing how they naturally start to cluster together.
- Do we want to establish some criteria as a Council, or do we just want to say, we like that one or now, we don't like that one.
- We need to build a structure and it should be Indiana specific.
- NORD, I think we can all agree should be on our website. NORD is a national organization for disorders. Maybe we have a State Specific Section and a National Section.

At this point, because of the time left, what would probably be easier and compile them all on one list and send them out to the Council early next week? That gives the whole Council 3 1/2 weeks, 4 weeks and then next meeting we should all have a chance to look at it.

Laura asked who she should be sending the email to. The 15 on the Council plus Dr. Crowder, Jake Torrie, and Eldon Whetstone.

Laura formally requested that Resources be added to the August agenda.

Question doesn't the state have a Webmaster that can help with this and to help organize it? IDOH doesn't have a Webmaster on retainer. Our Public Affairs Office handles web pages.

Laura, so next time we come together I have 10 this who should I given them too. Dr. Crowder replied. Eldon Whetstone.

Public Comment, Time Permitting – Public Attendees

There wasn't any Public Attendees, and there wasn't any time for public comment.

Next Meeting

August 9, 2024, at the Indiana Department of Health in Yoho Conference Room from 3:00 p.m. to 5:00 p.m.

Adjourn