

Rare Disease Advisory Council

Meeting Minutes



Location: Yoho Conference Room, IDOH

Date: August 9, 2024

Time: 3:00-5:00

Facilitator: Dr. Wade Clapp, Chairperson

In Person Attendees: Dr. Wade Clapp, Eldon Whetstone, Laura McLinn, Cory Best, Dr. Jodi Skiles, Dr. Brian O'Neill, Jake Torrie, Dr. Guy Crowder, Dr. Michael Busk

Online Attendees: Joel Feldman, Santiago Schnell, Robyn Spoon, Mindy Cameron.

Approval of Minutes: Adaptions to July 12, 2024 meeting minutes.

Mindy Cameron mentioned that she was not listed as in-person attendee on July 12, 2024, meeting. There was a reference to the speaker that Mindy was providing has been moved over to the presentation about the General Assembly website. Changes need to be made regarding the language in July 12, 2024, meeting minutes. Unclear on the state of the dollar amount mention in last months meeting minutes. Eldon will make these corrections on previous meeting minutes

As discussed in the last meeting on July 12, 2024, we did receive the final approval for the survey on pediatric cancer patients. Dr. Nancy Swigonski sent out the surveys to the physicians to send out. Dr. Nancy Swigonski will have a draft for comment, for nonmalignant conditions at the next meeting. It would be useful to the people who are not completely familiar on what we do to have a definition of what DDRS is. It could be useful to be more specific on which report we are talking about when discussing "will we ever hear back with regards to this report". Currently, we are talking about the year-end report that we recently submitted. It was shared the report is posted on the website.

Old Business: There is no old business currently.

New Business: Resource website discussion

Thank you to Laura McLinn and Lucy Smith for providing an extensive resource list. RDAC is a part of our website Department of Health. Anything added to the website must get reviewed and approved by our Office of Legal Affairs and Public Affairs. This is an ongoing process as they go through the list and examine each resource to see what is in compliance and what is appropriate. In part of review, Legal Affairs looked back at the Statue to remind us that it specifically states what is to go on this list of resources that includes four (4) categories: research, diagnosis, treatment and education relating to rare disease.

Laura McLinn mentioned that she has had many resources sent to her. After many hours of hard work, she now has hundreds of resources that she worked on categorizing into the four (4) categories. Laura McLinn sent an email two (2) weeks ago to council and thought there would be voting on these twenty (20) resources today before being sent to legal for final approval. There was a misunderstanding on the process order to get these resources approved. The resources must go through the internal team, legal and then comes back to the committee for approval. Mindy Cameron asked what is the internal team? The internal team is public Affairs that included Chief Communications Officer and her team, our Legal Team, and Dr. Clapp and Eldon Whetstone review the process. There was discussion on the number of resources that should be on our website and what other state RDAC websites show per categories.

There was discussion over the list of resources that Laura McLinn sent in an email on July 18, 2024. There was a mention that if there is a fund raising attached to the resource, that resource may be denied. The State Agency cannot put anything on website that could be asking for donations. It was brought up that maybe RDAC would have its own website for next year. At this point, moving forward with resources for our website will be put on hold until next meeting. This will give us time to hear back from legal on what will be approved and denied for resources.

Legislation 101- Jake Torrie

Jake Torrie handed out a resource called "HOW A BILL BECOMES A LAW" that can be found on the House Republican caucus web page. Jake walked us through the General Assembly website that can be found on <https://iga.in.gov>. This is where you can find legislation for committees and individual legislator information. The following information can be found: legislative sessions, senate sessions, how to find your state representative, and state senator.

Standing committees meet during regular sessions. There is standing committees in both the Senate and the House. Health related legislation can be found in Family and Children Services, Health and Provider Services, Commerce and Technology, and Insurance and Financial Institutions. 2025 sessions schedule should update around the end of November 2024 to early December 2024.

Long Sessions Vs. Short Sessions:

A long session is a budget session- when they are discussing the budget only on odd number years.

We are going into 2025 – budget session will run first week of January through end of April (April 27th). A short session is non- budget session on even number years. Generally, starts first week of January through the middle of March (March 17th). It was discussed how to start a bill and the process. Taking a legislator whether they are a representative or a senator, they can start a bill in either chamber. It must start in the Chamber in which you sit.

Ex. If you're a representative and you file a bill, it will start in house. Then if you pass it out of the house, it goes to the Senate and process starts itself.

Specific Bill:

Here is where you will find bills that were filed for both Senate and House (about 300-400 bills). If the text is in blue means that the bill passed, and if the text is in gray means the bill died. Only about 10% pass. In this area the important tabs are latest version and bill action. In the Bill Action you can follow along as the bill goes through the process. A collection of laws in Indiana is called Indiana Code. To look up an Indiana Code, go to Laws, Indiana Code, type in search bar (ex. Rare Disease).

Public Comment, time permitting- Public attendees

Mindy Cameron has an update on a task for this meeting. She did reach out to Intellectual and Development Disabilities task force that is headed by Lieutenant Governor Crouch. This might be on hiatus. She has an email to her office and has been very responsive in the past, so she does anticipate a response. Mindy feels this task force discusses many issues of interest to rare disease patients including tying Medicaid funding to patient, employment opportunities, and housing opportunities. Mindy mentioned maybe having RDAC members could sit on this task force.

Mindy also mentioned the new CMS Rule that came out in April 2024 about Medicaid having every state having to incorporate what they are calling a Beneficiary Advisory Committee. She will keep her eyes on this and hopefully get some clarity from Ty Sullivan, about where the State of Indiana is on this. Mindy mentioned that maybe a RDAC member could sit on this committee. Currently, it is not possible for an RDAC member to serve on those committees because the membership positions are statutorily created. However, just like our meetings they are open to public. Mindy asked if the statute could get amended because our Rare Disease group is new and accommodate these new changes. It would take legislation action to amend that current list.

Robin Spoon asked if there was a way of tracking legislation edits as the language changes with bills. Is there any record of changes made to language. Jake Torrie explained that it doesn't specifically say it's been edited. There is a button called Bill Version, you would need to keep an eye on the bill and have several copies of said bill to compare line by line. Robin asked if the report that was presented to Legislative Counsel and the Governor was available. You can find the RDAC annual report on the main page of RDAC website, at the bottom of the page called annual report.

Next Meeting September 13,2024
3-5pm