



**NEVADA RARE DISEASE ADVISORY COUNCIL
MEETING MINUTES
February 12, 2021
11:00 am**

Meeting Locations:

Pursuant to Governor Sisolak's March 22, 2020, Declaration of Emergency Directive 006, the requirement contained in NRS 241.023(1)(b) that there be a physical location is suspended in order to mitigate the possible exposure or transmission of COVID-19 (Coronavirus). Accordingly, all members of the public were encouraged to participate by using the web-based link and teleconference number provided in the notice.

1. Introduction and Roll call – /DPBH Staff/Amber Federizo, Chair

SUBCOMMITTEE MEMBERS PRESENT:

Amber Federizo, DNP, APRN, FNP-BC (CHAIR); Shirley Folkins-Roberts; Kimberly Palma-Ortega; Valerie Porter, DNP, BSN, MBA (Quorum = 3)

COUNCIL MEMBERS ABSENT:

Brynlin Thornley;

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:

Rex Gifford, Administrative Assistant III; Joseph Filippi, Executive Assistant; Julia Peek, Deputy Administrator; Melissa Yerxa, Developmental Specialist 3; Jennie Belka, Administrative Assistant II; Pierron Takes, Deputy Attorney General;

OTHERS PRESENT:

None

Rex Gifford opened the meeting at 11:05 am. Roll call was taken and is reflected above. It was determined that a quorum of the Rare Disease Advisory Council (RDAC, the Council) Legislative Subcommittee was present.

2. PUBLIC COMMENT

No public comment provided.

3. FOR POSSIBLE ACTION: Consideration and Approval of previous Rare Disease Advisory Council Legislative Subcommittee Minutes from January 28, 2021 – Chair

Chair Federizo introduced the third agenda item, to approve the minutes of the past meeting. She motioned to approve the minutes. This motion was seconded by Subcommittee member Ortega. A verbal vote was taken, and the motion passed to approve the minutes of January 28, 2021.

4. POSSIBLE ACTION: Bill Draft Requests (BDRs) to follow and committee assignments

Chair Federizo presented agenda item #4. POSSIBLE ACTION: Bill Draft Requests (BDRs) to follow and committee assignments. She noted there have been some updates since the last BDR list was sent out. There are quite a few new ones, unfortunately there haven't been a whole lot of individuals who have updated the text, but there have been a lot more submissions from the last one. She asked if everyone had that list of the BDRs that are healthcare related, that have a healthcare title. She said she had condensed them for everyone. The members confirmed receipt of the list.

Chair Federizo stated, the bill she thinks will be substantial for both this committee and the council in general is Senate Bill (SB) 40. They have released that full text. Senate Bill 40 was presented by the Patient Protection Commission. The bill itself appears to entail many of the things the council members had talked about in terms of things that they would need to identify. Such as, what is their prevalence and what is their incidents of rare disorders cost entailing? This bill does structure it as going after the payor side. The one gap in this bill that she could see is, it will be a little bit difficult without the reporting institutions to get the entirety of the numbers. It is a step in the right direction because this would create a data base from all payors to the Department of Health of what this looks like for all disorders. This would be a global repository for the state. It would still have gaps, but in terms of overall comprehensive nature of this bill, she really feels like it is headed in the direction, that they as a council, have discussed on their own. Chair Federizo added she doesn't want to do duplicative efforts. This is the one bill that she thinks needs to be followed at the highest level. She is not sure how it will eventually evolve into how these sections will be met, but much of this bill does go through the things they, as an overall council, have talked about. Of what this might look at in terms of payor claims data base and trying to find this information. She understands they are going to have issues in rare disorder because some of their rare disorders do not have ICD 10 codes, but this bill would allow them to potentially, as a Rare Disease Advisory Council, to request through the Patient's Protection Commission access to this data in addition to the limited data that we as a council can find within our own institutions. SB40 is from the Patient Protection Commission and is not actually specific to any bill committee. It is sponsored by the Committee on Health and Human Services. Usually when it's a Committee on Health and Human Services, it's typically not just one legislative sponsor, those bills typically have a better shot at, actually, making it all the way through. This one, she thinks, would have the most power. This will also come up in the agenda later today, but I think it would be in our best interest to have the Executive Director of the Patient Protection Commission come to our next meeting, if I can get that arranged with them, to talk about more of what this would look like and maybe some of the gaps that we could assist in shoring up before this goes all the way through, I think it would be beneficial. There is a section in this bill that talks about the Patient Protection Commission working on not having so many other commissions and councils duplicating efforts. She agrees because many of the things they are trying to do are things that the council is trying to do, but they're not talking to each other. Chair Federizon asked how do we advise the Patient Protection Commission on subjects specific to rare disorders as a source of a sub-advisory to the Patient Protection Commission as they are tasked with protecting everyone, but within that things specific to our council? She thinks that it would be of benefit to meet with them to see if the Executive Director has time to come to this committee, or if they decide whether they as a subcommittee feel that it would be valuable to have the Executive Director come speak to the general council. The Chair asked if the subcommittee members agreed with that idea? The subcommittee members agreed with the idea. Chair Federizo discussed the Bill Draft Request (BDR) list and assigned the list to the subcommittee members for monitoring as follows:

Amber Federizo

40-5 Senator Spearman - Revises provisions relating to health care –
38-6 Senator Spearman - Revises provisions relating to aging persons
8 Assemblywoman Neal - Makes various changes governing the provision of care for lupus.
13 Assemblywoman Krasner - revises provisions governing health care for women
53-32 Assemblywoman Tolles - Revises provisions governing in-home service providers
54-34 Senator Cancela - Revises provisions relating to health care (expect this to be dead as Cancela was pulled to work in the Biden administration).
50 Senator Brooks -Revises provisions relating to older persons.
57-54 Senator Scheible -Revises provisions relating to insurance.
55 Senator Scheible - Revises provisions relating to Medicaid
56 Senator Scheible - Revises provisions relating to the eligibility of children for Medicaid

Shirley Folkins-Roberts

54-61 Assemblywoman Benitez-Thompson - Revises provisions governing prescriptions
40-62 Senator Spearman - Makes changes concerning disparities in health care including without limitation disparities relating to services to support mental health and emotional well-being.
57-71 Assemblywoman Hardy - Revises provisions governing prescription drugs.
43-88 Senator Orenschall - Revises provisions regarding health care
S89 - Senator Orenschall - Revises provisions relating to Medicaid
40-192 – Senator Settlemyer
49-229 – Assemblywoman Alexis Hansen

Valerie Porter

40-239 – Assemblywoman Flores
251 – Senator Canizzaro
252 – Senator Canizzaro
40-478 – Senator Gansert
38-522 – Peters
541 – Orentlicher
54-632 – Settelmeyer
654 – Assemblywoman Hardy
40-655 – Hansen
40-747 – Leavitt

Kimberly Palma-Ortega

771 – Duran
823 - Ratti
57-848 – Senatory Hardy
866 Assemblyman Hafen
876 – Pickard health care workforce readiness
57-543 – Senate Committee on Commerce and Labor
40-288 AB 35 – text available related to aging and medications

38-449 – Requires Medicaid coverage of services provided by community health workers
38-452 – Medicaid coverage of pregnant women
54-456 – revises provisions governing health records

Everyone

40-415 SB Text available registry and data PPP

54-457 – provides for the collection of certain data concerning providers of health care

614 – Senator Hardy – makes various changes to expand access to and improve the delivery of health care in Nevada

710 – Assemblywoman Gorelow establishes a health care clinic pilot program

756 – Assembly Committee on Health and Human Services

903 – Senate Minority Leader

913 – Assembly Minority leader

914 – Assembly Minority leader

Chair Federizo motioned to approve the BDR list that they would watch and narrow between now and the next meeting. Subcommittee member Ortega seconded the motion. A verbal vote was taken and the motion passed.

5. POSSIBLE ACTION: Talking point leave behind/testimony awareness language.

Chair Federizo moved to agenda item #5. POSSIBLE ACTION: Talking point leave behind/testimony awareness language.

Chair Federizo discussed potentially modifying the NORD documents that they utilize to fit the needs of the Rare Disease Advisory Council in Nevada. In this way, they would not have to start from scratch to come up with a leave behind for the council.

Chair Federizo suggested they defer this to a vote until the subcommittee members can review the document and see how they would want to revise it to their needs.

The subcommittee members agreed to defer this item to the next meeting agenda.

6. Discussion of future agenda items – Subcommittee Members

Chair Federizo moved into agenda item #6. Discussion of future agenda items.

Chair Federizo stated she will reach out to the Exec Director of the Patient Protection Commission, to see if they are available.

Chair Federizo motioned that we reach out to the Executive Director and recommend that they present at their next meeting, if feasible. Subcommittee member Ortega seconded. A verbal vote was taken and the motion passed in favor.

Chair Federizo stated that in addition they will have the deferred agenda item of reviewing and modifying the NORD handout, to modify it specific to NV, so they don't have to build that from scratch and make it more applicable to their own. That will be agenda item #2.

Chair Federizo motioned that the NORD handout revision will be agenda item #2. Subcommittee member Porter seconded. A verbal vote was taken and passed in favor.

Chair Federizo continued, the 3rd agenda item will be discussion for the paired down and narrowed BDR list.

Chair Federizo motioned that the discussion for the paired down and narrowed BDR list would be the 3rd and final agenda item for the next meeting. Subcommittee member Ortega seconded. A verbal vote was taken and passed in favor.

Chair Federizo asked if anyone had any agenda items that they missed or they thought they needed to consider for the next meeting? She is trying to keep the subcommittee meetings short so that they only run to about an hour.

Subcommittee member Folkins-Roberts stated, she didn't have any more agenda items, but she had a couple of comments / questions, when the time is right.

Chair Federizo thought they could do that within this section because it is discussion of any agenda items, questions and comments they might have.

Subcommittee member Folkins-Roberts stated she has been in touch with Carrie Harrington, who is the Executive Director for the Nevada Cancer Coalition, and she will be working with her to follow relevant legislation, as well as, the cancer community because she is tapped into that. At this point there is only one bill she found that looked real relevant to them. It was a step therapy bill and she is not sure it's covered in any of the bills they covered, but she'll check. Additionally, there is usually a cancer day and there isn't this year, but there is a children's week, March 8,9,10 and 11. She wasn't sure if they wanted to get involved in that at all.

Chair Federizo answered, she thinks the best thing they can do for that one is to send that information to the council as a whole and then have the individual members represent their individual entities to participate.

Subcommittee member Folkins-Roberts asked about the restrictions on lobbying and advocating? She is not registered as volunteer or a lobbyist this session. She doesn't think she needs to be nor should she be, from the regulations she has read. It would be more informational testimony on behalf of her organization and if she does that she would just note that she is on the rare disease council. Her understanding is if they want to provide and testimony on behalf of the rare disease council, it has to be authorized by the council prior, is that her correct interpretation?

Chair Federizo answered that is the correct interpretation. She didn't know before they voted in the subcommittees, that during that subcommittee vote that she would also have to have that vote to authorize them to do any kind of presentation on behalf of the subcommittee. That leaves them with two options, she can either call and enter a meeting of the entire council to set forth the authority to have one of us on the subcommittee to present. Which means they would have to move up the April 9, 2021 meeting. She would have to see if the members can reach quorum for that meeting. Or the other alternative is through the subcommittee, they as individual entities, are allowed to state that they are part of the RDAC, but that their information is not reflective or responsible for that. They can present this information, but they cannot link it back to the council. She asked the members what the plan forward might be? She can go

ahead and try to convene a meeting before April 9. They could follow the BDRs and see how they kind of progress toward April 9. She thinks that they would still have time. She just doesn't know what the bill hearings would be for senate bill 40.

Subcommittee member Folkins-Roberts asked what's the notice you need to convene a meeting? How far in advance?

Chair Federizo answered, just to get it approved by the Attorney General's office, we need 3 days, but honestly, they need 2 weeks in advance, because often times the AG's office will have clarifying language in regard to the way that they are wording some of the things. That adds a couple days. Just to get this meeting we had to clarify several of the wordings, just to make sure it was accurately reflecting the meeting. She would definitely want to give them enough time and days to be able to do that.

Subcommittee member Folkins-Roberts stated in her experience with the legislative session is you don't know what you've got until the very end. It is hard to know, it really changes. She doesn't know how this session will be because it's so different and remote. She asked if they can just put a meeting on the calendar so they have it at their disposal if needed?

Chair Federizo answered, we can definitely do that, but for the larger council, she would have to reach out to them to see what that would look like. I guess the question would be, do they think that they can afford to wait until the April 9 meeting to ask the council at that time give the subcommittee specific authority. In the meantime, until that point in time, if something comes up, they're going to have to address this as individual and separate entities from this council.

Subcommittee member Porter asked, she knows this is an appointed council and everything, but if they couldn't get the group together, or they didn't feel like waiting until April 9, is it possible to send out the information and have a voting button? Would that count or not?

Chair Federizo answered, you can't because you have to have public notice. Then you have to have verbal voting to confirm that those names amongst the council reached quorum to sufficiently address it. She was thinking along the same lines as Ms. Porter. Because of open meeting law, the restrictions they have, the process has to be followed for every single decision. She felt responsible, too, because she didn't have that foresight when they created the subcommittees, to have that in the last major council meeting to specifically identify from the council to give them that permission. There is always that chance that the larger council does not feel that the subcommittee would accurately reflect their opinion. There is the chance the larger council could come back and say, no, we don't want you to specifically represent. Or they could come back and say, we agree, but this is restricted to only this. If that makes sense?

Subcommittee member Porter replied, it does, she was just trying to think outside the box. Just trying to see how we get done what they need to get done and keep it not too tedious for everyone.

Chair Federizo said she is leaning toward keeping the April 9 complete council meeting and watching the Senate Bill 40 really take shape by then. Then for that agenda, for the larger council, implementing the pieces for discussion, presenting their final narrowed BDR list. Then this committee will have an idea of what specific BDRs and what it is that they think as a council they should advise on. The members cannot testify as approving or in support of or not in support of, all we can do is testify and be neutral. By then they will have a better idea of their specific asks, as a council, and how they will represent those items if

they need to, as they come up. The only risk they have is if there is a meeting held in regards to these BDRs before that meeting. All they can do is watch them or speak as an individual entity in regards in support of not support of, but separate from the council. Which, she thinks, is still an okay path, it just does not have the force of the council itself. She asked what the members thought of about just leaving the main council meeting at April 9 and just keeping their meeting?

The members agreed that would be fine.

Chair Federizo continued the next thing they would be discussing is their own subcommittee meeting date and time.

7. Discussion of future meeting dates and times – Subcommittee Members

Chair Federizo stated the next discussion will be formally #7, which will be their next subcommittee meeting. Dates and times were discussed and the date of March 10, 2021 at 12:00 pm was decided upon by the members.

8. Adjournment – Chair

Chair Federizo moved to adjourn the meeting at 12:05 and reminded the Council of the next meeting scheduled for March 10, 2021 from 12pm-1pm. She thanked everyone for their time.