



**NEVADA RARE DISEASE ADVISORY COUNCIL
MEETING MINUTES
January 28, 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:

Lindsey Kinsinger, Manager, Office of Public Health Investigations and Epidemiology (OPHIE); Rex Gifford, Administrative Assistant III; Joseph Filippi, Executive Assistant; Pierron Takes, Deputy Attorney General; Jennie Belka, Administrative Assistant II

OTHERS PRESENT:

Tanner Call; Tyler Shaw

Rex Gifford opened the meeting at 11:01 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.

Joseph Fillippi advised the chair that the meeting was being recorded for members, if she wanted to start with introductions.

Chair Federizo announced they would start with introductions. She began, "My name is Amber Federizo. I am a Family Nurse Practitioner that covers the entire State of Nevada for bleeding disorders. I fly up to Reno, we have a clinic there. I fly to Salt Lake City to fly into Elko. I have driven to Elko and then to Owyhee, which is at the Idaho/Nevada border. I see all patients across the state. We're the only hemophilia treatment center in the entire state, so we do quite a bit of travel. In terms of advocacy and legislative history, I've worked with the National Hemophilia Foundation with their advocacy portion for 8 years. We've traveled the Hill every single year except for this year, which will be virtual. In addition to that we all, within the interim years, met with state legislature to work on policy development. During the on-session, we attended for testimony on certain bills from them. That is me. Shirley is next."

Subcommittee member Folkins-Roberts began, “I am Shirley Folkins-Roberts. I am the Founder and now the Executive Director of the Northern Nevada Children’s Cancer Foundation. I was a volunteer board member, we originally worked without employees for many years. I’ve been working organizations since it started. Two years ago, I became an employee as an Executive Director. We serve all the Northern Nevada children, diagnosed with cancer, and their families. We have about 120 served at any given time. I like to communicate as much as I can with Southern Nevada. My husband has offices in Southern Nevada. Through his development, his Panattoni Development, we’ve gotten to know candle lighters and the players down there. I’ve tried to work in a role in helping our children, as a state, as much as we do from the Northern Nevada standpoint. We help with emotional and financial support, that is our main mission. However, research, advocacy and a cure have always been important to us. As that is the case, in 2006, I started going to the Hill in DC with a national organization and have been ever since. At least once a year to try to get more funding for childhood cancer, more awareness and so on. I’ve also been a volunteer lobbyist, when I wasn’t an employee, and always participated in the state lobby days. Last time, as an employee, I didn’t register. I don’t know if we’re going to have to or not. I think, as long as we’re just testifying, I’m not sure if we’re going to have to or not. But we’ll have to talk about that because they’ve tightened the rules a lot. It used to be a lot easier to go and follow legislation. I’ve done that a lot. I’m actually an attorney. I’m licensed in Nevada and California, I don’t practice. I am a government affairs junky. I look forward to working with you, seeing what we can keep track of and how we can help this rare disease council and population of people.”

Chair Federizo thanked Shirley and announced Kimberly is up next.

Subcommittee member Ortega began, “For me, I sit on this commission with you as a parent representative. I have two extremely rare kids and they are the only ones in the state. They have two different brain genetic syndromes. My daughter is a 2q37 Dilution, she also has – on top of that. My son is 11p Dilution, he had childhood cancer. So a lot of the different areas you talk about, often mine have multiple things. We are also on the spectrum. We’ve dealt with the cancer. Jonathan, with his genetic syndrome has vision loss. We have already had the removal of one eye, so we have blindness that we work with. My daughter has ortho issues, along with IDD. I sit on about 19 different commissions, councils and boards throughout the state. Some are Supreme Court appointed, some are governor appointed and then local. It is across different abilities to juvenile justice, foster care and education. Because I don’t fit in a box, I try to be able to make sure I use my voice. I’ve also worked for Early Intervention, as well as, non-profits down here in the south. I have currently moved to Pahrump, putting me in the rural aspect. On paper, I’m also going to school to get my BA in Criminal Justice, in hopes to practice law. Hopefully in family or juvenile justice education, each one has affected our life. A lot of times, family court does not understand the complexity of medical kids, on top of that IEP, -- orders, visitation and child support. Some of those things are not really put into play and a lot of individuals, working on those cases, whether that is a state identity or a lawyer, don’t understand the complexity or our group. It doesn’t often translate properly when you’re doing legal battles, either. Because of that, we find a lot of our youth in the juvenile system. I currently chair the DD Council, I was just on their policy, so legislation is huge for me. It has long term affects for all of us that most people don’t fully digest or understand. I have a great passion for medical law. However I can help, I’m glad to be able to work with you ladies and gentlemen. However we can be of assistance, I am game to go.”

Subcommittee member Folkins-Roberts commended Kimberly and stated she works with parents every day. She hopes to give as much support to her and her kids as possible through this work. She asked what the last organization was that Kimberly sat on where she was legislatively involved? To know what kind of resources the subcommittee has.

Subcommittee member Ortega answered Nevada Governor's Development Disability Council, which we call the DD Council. Dr. Rashid is the Counseling Oncologist for that. She's always had Jonathan there, to look at him. I'm looking forward to working with the North for meetings. It is very divided, in some aspects, so I'm glad that we're going to, hopefully, build that bridge and make it a statewide event.

Subcommittee member Folkins-Roberts asked if one of her children have childhood cancer?

Subcommittee member Ortega answered, "Jonathan did, he's in remission right now."

Subcommittee member Folkins-Roberts replied, "That's great." And thanked Kimberly for indulging her questions.

Chair Federizo added she appreciates it too because it does help. It is difficult in the virtual world to especially come together, then know everyone and get to know them.

2. PUBLIC COMMENT

Chair Federizo stated that they would go to the next agenda item, public comment because it is an open meeting. She did not believe there was anyone else signed in, but the council would wait for Rex to confirm that there is nobody for public comment at this time.

Rex Gifford answered that there were some other folks in the meeting, but it is open for public comment.

Chair Federizo asked if there are additional people, did they have public comment?

Rex Gifford stated he did not see any raised hands or unmuting, so he thought they were good on that.

3. INFORMATIONAL: Provide overview of Subcommittee and present upcoming legislative dates – Chair Federizo and Council member Folkins-Roberts

Chair Federizo introduced the third agenda item, the overview of the subcommittee and upcoming legislative dates. She stated that as the subcommittee knows, unfortunately, Nevada only has a 120 day session so it moves extremely quick. From start to finish it moves fast and, unfortunately, they only do it every other year. Their opportunity to go and testify and present, is something that she is really excited that they decided to do a subcommittee so they can be active and do it now. They couldn't have waited until April for the next big council meeting to get together and talk to them because by then most everything has passed or gone through.

4. Discussion regarding scope of committee surveillance and scheduling of public comment/presentation

Chair Federizo stated they will go on to agenda item #4. The discussion regarding the scope of committee surveillance and scheduling of public comment. She asked Kimberly if she would like to share what they had looked at in her other meeting discussions regarding policy?

Subcommittee member Ortega responded, “For the DD Council, in order to present or make it a day for legislation, you have to make an appointment with them to be able to talk to legislation, put stuff out there, share highlights and things of that nature. Because DD month is in March, we have March 16 as DD day. We are putting things together. There are different identities that sit on the DD council. You have UNR that is a part of it and Disability Excellence, we have that director on there. We also work with Nevada Disability Law Advocacy Center (NDALC). The DD council and those two entities are actually federally mandated to be working together. They all have their own BDRs (Bill Draft Requests) they are working on. I know the DD Council posts theirs. I sit on the board of directors of NDALC, I know they put a handful of BDRs. I can double check with the Executive Director for UNR and see if they have compiled anything that they are ready to release. I can share that with this subcommittee to see if there is anything overlying, if it’s disability related. There is nothing really specific to our demographic, at this point, but it touches further out to the different identities that we all have. We were also addressing cyber bullying and things of that nature. That is why, at our last meeting, I said that if we name it Legislation and Policy, that allows us to still have conversations for the next legislative session. The DD Council puts together a position statement, something we work on in between those legislative sessions. What they do is compile some things that they’ll end up issuing out to legislation. A couple meetings back, we approved our mission statements to be released to legislation. It is going to be released digitally since we can’t go in person. We’ve been working on coming up with a facebook badge for DD Day. I know February is where, if we could work with NORD, it has these little things on the side because I’ve done that for mine. That is what the DD Council is working on as well, more outreach, not necessarily all specific to legislation. I can share those BDRs that they are already watching, so we don’t have to worry about wasting our pick with those. We can build off it to see what else is going on.”

Subcommittee member Folkins-Roberts thought that was a great idea. She stated, as she understood it, part of their mission is increasing awareness, increasing understanding of rare disease. She continued that in the past, there has always been a Cancer Advocacy Day at the Legislature. She knows that the American Cancer Society (ACS) here has this mantle, but that she does not know what is happening with their advocacy this year. She asked, if there is a Rare Disease Day at the Legislature? Should there be one, or should they create one? She would put her effort in that, rather than the cancer day because she is not sure there will be a Cancer Day, any kind of Cancer Advocacy Day, as well. She asked if anyone knew if there had ever been one?

Subcommittee member Ortega responded, “Yes, in the State of Nevada, one of Jonathan’s, one of the wager kids, for Jonathan ---, she went and did a proclamation. I can go and pull exactly what day that is. As we’re speaking, I can go to her facebook page and I know she tagged me on it. I can figure out what day that specifically was for our state.”

Subcommittee member Folkins-Roberts asked if it was a Legislative day, though? She was wondering if they wanted to see if they could get a day at the Legislature to recognize rare disease. She asked if that were the same thing she was referring to?

Subcommittee member Ortega answered that she didn't know if they have a legislative day, but she knows they have a day of proclamation.

Subcommittee member Folkins-Roberts asked that if before they start talking BDRs, was that something they want to consider pursuing? She said she doesn't know how complicated it is to get a day, but they all probably have legislators they know that they could ask or work with on this. Her good friend Jill Tolles is an Assembly Woman. She asked if that was something they want to look in to at all?

Chair Federizo asked if they want to do a day because there are a couple different things? There is the proclamation, which would set that day and be recognized by the state, but there is going on to the Legislature and registering a day to bring awareness and organize like patients and families to come to the Legislature. She is open to both, they would just have to set it on a day where a lot of them could go up there. Or alternatively, they can integrate that into their attendance into each of the individual meetings.

Subcommittee member Folkins-Roberts said she was just wondering if that were something they want to consider in terms of bringing attention to one Legislative day. There are all kinds of days throughout the session, and whether they can even get in at this point.

Chair Federizo stated there are still dates available. They do one for hemophilia and are scheduled to do it virtually, but one can still be scheduled. She said she found that the legislators don't listen well when it is an awareness day. She didn't know what anyone else's experience had been versus the actual hearing day.

Subcommittee member Folkins-Roberts agreed she was right to some degree. She said she has a friend who could do a press release. It gives attention to the subject matter to just be on the legislature. It's typically a day in the Legislature, a lot of times, is on the news. It was her thought, it's up to the subcommittee, if they have too many days... If they've got different disease days already, then maybe they do not need one. Maybe just focus on the days they have already.

Chair Federizo from her view, thought what she would like to do is be able in this and next year... Unfortunately, because of COVID, they got put behind, in terms of being able to build everything up before the Legislative Session. She would prefer that they get their educational information finessed and in 2023 come out solid with a very robust awareness day. She is not even entirely sure how many individuals would be able to go in person, considering the situation is still not that great for this round. She thinks that 2023 would be the aim with a solid registered awareness day in bringing everyone together. That would give them time to talk to the different groups, the cancer groups, hemophilia groups, rheumatology groups, on a care collaborative. Maybe consolidate those to kind of come together, instead of individual groups.

Subcommittee member Folkins-Roberts agreed and thought is a great idea. She stated one thing she saw at the national level was the cancer communities used to be very divided and when they came together were much more powerful.

Chair Federizo also agreed and thought then, they could have their materials together.

Subcommittee member Ortega added that what they had done with the DD Council, in the past, before she was involved, was to color code or come up with one united thing. Even if they had a different cancer center, the different clinics and organizations, either around Valentines Day or Halloween, they would take group office shots. If they were able to do something like that in between for the next round, they could add those pictures and integrate with the material they create in the long term. Then it would show unity and they was why they came up with the colors. If the legislators keep hearing the same story, when they see the large color related, but united, organizations, they would know here comes that voice. She did agree it might be premature if they try to do something this year. They don't have enough content, enough to say, enough in place or enough time to make a huge stance. She agreed if they move this in the next round and have some solid information, they could definitely make a point.

Subcommittee member Folkins-Roberts agreed. One thought that came to mind was if they have the opportunity. If they were advocating for rare diseases, but more specialty items, should they share their mission statement? Or should they share something with the legislature integrating the rare disease, as a whole, into things they're saying? She thought maybe they should try to develop a couple talking points that integrate the whole subject into what...

Chair Federizo agreed. She was thinking the Health and Human Services Committee will start meeting on Tuesdays and Thursdays at 3:30. The Senate stuff on the Senate side, and on the Assembly side, the Committee on Weighs and Means, theirs aren't scheduled yet. Even if they can attend that first meeting to say, in general, some of the BDRs may impact rare disease and ask if they could run anything that might impact the RDAC Legislative Subcommittee by the committee. That could be an introduction into the Legislature, so A) They know that the committee exists, even though they voted for it to exist. She thinks there are still some who don't know the committee exists. B) Get the message that the committee is here together to help them on these legislative BDRs as they progress from the beginning. She continues that even though they don't know what that language is, because the dates for them to submit that language, she believes is either February 8 or 9, they wont even see the text of some of them. But at least they can show up as that introduction of "We are the Rare Disease Council. We would like to let you know this is our mission. This is what we are looking to do. We're looking to help you in any way to progress these BDRs to make sure the rare disease in this community is covered during this time." She said she realizes there is COVID 19, but something as an introductions in the back of their mind as these BDRs evolve. They would already be thinking, "How is this going to impact rare disease?"

Subcommittee member Folkins-Roberts suggested that they may be able to take some cues or develop off the national organization. If the subcommittee want to put together some points, they have their mission, but that might be helpful. Since they are so new and don't have a lot of their own information available here with this commission, they could look at what the national organization has and make that a starting point.

Chair Federizo agreed.

Subcommittee member Porter said "Good morning, this is Valerie Porter, I signed in late."

Chair Federizo let her know we are at agenda item #4 and gave her a brief summary of the discussion so far.

Subcommittee member Folkins-Roberts asked if all the meetings would be virtual?

Chair Federizo reported there is some discussion, she believed, regarding whether or not the legislators may become vaccinated. She didn't know if this would change things. But to her knowledge, as of right now, all of the meetings would be virtual. She said she knows Northern Nevada is used to being virtual because they usually have to video conference in to Southern Nevada anyway. She said being virtual does kind of change things a bit in terms of how much passion. She thinks it is much more passionate in person. That is the thing that is going to be a bit different.

Subcommittee member Folkins-Roberts wanted to offer, since she is in Northern Nevada, when they do start meeting in person, she is 20 minutes away and she can be visible, physically if needed.

Chair Federizo stated if she got any information that they might go that way, they may have to tap into that because it would be more meaningful in person.

Subcommittee member Ortega added that something they were doing for the DD Council was trying to be there. She thought they might attempt to set up Zoom meetings with specific content and bringing on that audience instead of it being too big. They were trying to hit different legislators in those different areas that were backing up bills in the past. Then currently addressing the bills that are on the table now. That might be something they could entertain, even if it were a small audience. At least we had something on record in regard to the dialect and content. She said, in her office, she has a lot of different pictures of things going on with her kids in the past. She suggested they talk about creating a logo. She has a NORD button with the caption "Alone we're rare, but together we're strong" and it has hands on top of each other. It shows the unity. Even with the rare gene, has a blue jean and a ribbon, even if that was just a logo with material. She suggested they might dive into coming up with something that could be addressed visually, as a logo.

Chair Federizo agreed and suggested if Kimberly wanted to put together some draft logos, then it could be added as an agenda item for the large council. It would have to be put up for a formal vote on the agenda, but they could be developing it. And offered, as she had said before, that just because they wouldn't have certain things available for this session, doesn't mean the next session, they would have everything together.

Subcommittee member Folkins-Roberts commented it sounded like they were going to try to develop some talking points, something to present to the committee, as a kick off. Then integrate throughout, any time any of them are going to look at a specific bill or testifying. She asked how they want to go about monitoring legislation? What are people already doing? Kimberly is already monitoring certain segments that are going to be relevant to them. Do they want to divide and conquer or do they want to figure out what people are already doing?

5. Discussion regarding Subcommittee's proposed plan for Bill Draft Request (BDR) surveillance of legislation relating to rare diseases during the upcoming Legislative Session and proposed approach for providing recommendations

Chair Federizo moved to agenda item #5. Discussion regarding Subcommittee's proposed plan for Bill Draft Request (BDR) surveillance of legislation relating to rare diseases during the upcoming Legislative Session and proposed approach for providing recommendations

Chair Federizo reported she did go through the currently published BDRs that are out there. There are some she thinks they should be following. There are some that are not going to be applicable to them. She said she could send these out as a list, but right now Senator Spearman has 140-5 that revises provisions relating to healthcare. There is no text, so it is a really open ended BDR. Again, she has 138-6 that revises provisions relating to aging persons. Assemblywoman Neal has one governing the provision of care for Lupis, which is BDR #8. Assemblywoman Krasner has BDR #13, which is revising provisions governing healthcare for women. Assemblywoman Tolles has 53-32, which will revise provisions governing in-home service providers, home nursing. Senator Cancela has 54-34 which revises provisions relating to healthcare. Senator Brooks has BDR 50, which revises provisions relating to older persons. Senator Scheible has quite a few in, which is great because the Senator is in her district. 57-54 revising provisions relating to insurance. 55 revises provisions related to Medicaid, eligibility to children for Medicaid in 56. Assemblywoman Benitez-Thompson has 54-61 which revises provisions regarding prescriptions. Senator Spearman has 40-62 which makes changes concerning disparities in healthcare including, without limitations, disparities relating to support of mental health and emotional wellbeing. Hardy also has 57-71 for prescription drugs. Orenthall has a healthcare and Medicaid, which is 43-88 and Senate 89. Those were the ones that she had taken a look at and from a healthcare standpoint or from a rare disease standpoint she thought they should be on the lookout. She noted they are only titles at this point, but she thought they should monitor those when the text finally goes out. She thought they could maybe start having those individual conversations, such as meeting with Senator Spearman. They could have the Subcommittee meet separately with Senator Spearman to discuss or help revise or finesse some of those BDRs to be inclusive or supportive of rare diseases without potentially having budgetary impact.

Subcommittee member Ortega reported she also sits on the Medical Chair Advisory Committee, which is Medicaid. The BDRs the chair mentioned, the Medicaid committee had talked about in their last meeting. Dr. Azzam also sits on the committee, as well. She had brought up the rare disease to them, so they understood that. They might want to pull together with some collaborative efforts. Their demographic is the demographic that the RDAC is serving too. Some of those they are serving, use that as an insurance base. She suggested either getting more recipients on board or bringing more attention to some of the areas would be good. A lot of their different abilities group are in the foster care system also. She suggested they list the things they are doing and that they might be able to blend and mesh with the other players who are looking at the same BDRs. She said it works with the DD Council quite a bit, knowing there are more players than just the ones they're specifically working on. It is more than just one issue that filters into a multiple – of others. She would be able to assist in facilitating that as well.

Chair Federizo agreed and thought it would be good if they can consolidate voices and get them together so that they are saying the same thing. She stated the BDRs start off in language that they don't end up in because each individual fragmentation of those discussions is piecemeal, people are not on the same page and then the bill dies. She thinks it would be immensely helpful. They could then coordinate with them and let them know. If they are going to be there in the meeting for these BDRs, as well, they would like to talk with them and put the two views together and testify for each other.

Subcommittee member Ortega offered that she could do some E-greets to some of the other Chairs to the other things she is working on. She could give the Chair a list of the groups she sits on and the Chair could let her know if she wanted her to facilitate them. Or the Chair could send that to anyone else and if someone is sitting on something, she can assist with an E-greet for that as well.

Chair Federizo thought that would be great to have that first introduction. In this way, all of the different councils would be formulated and could work together on these BDRs so no one would be in a position where they would have to oppose something because there wasn't something thought of weeks ago.

Subcommittee member Folkins-Roberts thought it a great idea, using everyone's experience and work efficiently. She said she was going to reach out to the cancer community, Nevada Cancer Coalition and what remains of C.A.N., and see what they are up to this session. She said she usually touches base with them at this time anyway and can look into that part. She noted that Kimberly was really active with the state and other mission and they could use that work to make the subcommittee more efficient. She asked where do they go from here? Do they give the Chair a list of things they are already involved in to figure out how to best be efficient? What were they thinking in terms of best way to do things for this session?

Chair Federizo suggested as far as right now, is reaching out to those other groups, the other councils, to get a temperature on what it is they're looking at. She knows it is difficult now because the language of the BDRs is not out. Once that happens, in future to have those conversations, it would be an amazing thing to have them be introduced to everyone so they could talk with each other and see where they could partner versus each working individually or testifying individually on only one thing.

Subcommittee member Folkins-Roberts asked if she wanted them to reach out to any particular legislators because she knows Lisa Krasner. She could see what her thoughts are with her BDR and wanted to know if it is premature to do any of that?

Chair Federizo answered that it would be premature only because her bill doesn't have text right now. Once it does that is an opportunity for them as a council to reach out to any other councils who may be looking at the same bill and set up a separate meeting with Krasner. That is what they have done in the past, set up separate meetings from a hemophilia standpoint to meet with the legislators individually about their BDRs and modification of changes to language. They could set it up together once the language is out there.

Subcommittee member Folkins-Roberts asked if the Chair wanted them to come back to her with the list of organizations they're working on that could be used as resources? Any one of them in particular could be following BDRs? How do they want to go about that monitoring piece?

Chair Federizo said she would see how many BDRs are out there because there is a limit to how many you can follow when you register.

Subcommittee member Ortega stated it is 10. She suggested that she could send her what she has from the different organizations she works with and then they could see what mirrors the different ones that she currently has. They could compile the ones they know they could send it out, this way everyone would know what is going on and they could do just a handful of them. She could look into BDRs the Chair is not following, that maybe are not being addressed. She asked if they would agree that doing some E-greets, send out the BDRs they have, compile a list that points to the rare for the next meeting and ask that from the rest of the council, considering there are other professionals who might extend even further and make a national front? She suggested they could compile a statewide list and a national list.

Chair Federizo agreed because there are 15 on this list which may impact. Sometimes the test comes out and it is completely not what the title suggests. If there were ones, 3 or 4, where your other groups were saying these are the ones we're going to focus on, these would be the 3 or 4 the committee would want to monitor and provide surveillance. Then each of the members could follow the 3 or 4 other ones and give an update whether they think it is going to be something they need to follow or not.

Subcommittee member Ortega added that maybe putting a list of not only the boards or councils that they sit on, but maybe a list of legislators that they have connections to would be good. In that way, they could reach out and they could co-work with another legislator if they did have connections with certain people. That way, they would know who they have to work with versus trying to knock on a door they're unfamiliar with. With the E-greet or E-bridge, they could address those that they might not have that same familiarity with.

Chair Federizo thought that sounded good, because sometimes it is easier to get appointments for people when they are your district representative that doing it as a council. She asked that whoever has connections to send them. Once they had taken a look at those, she would send out summaries to them as to which have any kind of reference in terms of healthcare or any kind of related changes to insurance that may affect rare disorders in the state. Then they could piecemeal it from there as it would not require a formal vote procedure. They would just be assigning people, after the fact, of who's going to watch because they are not making any decisions in terms of it until they come together again to decide how they're going to approach it.

Subcommittee member Folkins-Roberts asked if she wanted them to send her a list of anything they have a connection to in terms of the BDR or the sponsor, or which?

Chair Federizo, answered the sponsor or the BDR. She would send out a list of the summarized BDRs, today, with the name of the representative, so if they live in the district or they have connections to then through another council or through another avenue, they could emphasize those are the people they want to follow the BDRs. Some of the BDRs are going to fall off and some die pretty early, but it they're ones where they can help them tack on their ideas in terms of insuring whatever they come up with that doesn't impact the rare disease community negatively. This session will be hard because a lot of people will look at things and say, "we cant do this because of budgetary reasons", but it doesn't mean that language that is in place can't impact us, even if there is no budgetary involvement now. Some of the laws passed have unintended consequences. Just to be able to review that language or add language is an action for the rare disease council community as a whole.

Subcommittee member Folkins-Roberts said she thought what they need to do is to do something as a talking point or take their mission or something. That they would want to do that sooner rather than later, something that they can use this session.

6. Discussion regarding the development and adoption of legislative informational document to provide talking points on rare disease policy

Chair Federizo stated that is on the agenda item #6. The development and adoption of the legislative informational documents to provide talking points on rare disease policy. She said they could take a look at what NORD (National Organization on Rare Disease) already has. She asked that the four of them on the committee come together in terms of what they would want to see in an informational talking point pamphlet. They could come together with what they would formally come out and publish or print, bring all four ideas together in a coherent legislative informational document. She thought that would provide them with that basis. Even if, for whatever reason, they cannot attend a meeting, they can put those talking points in place so they have that awareness that they do need to speak to them before any final hearing is made on the floor.

Subcommittee member Ortega reported that one thing they had done is highlight members. Maybe if, they were able to have someone allow them to send a small snippet of who the council is and a picture, it might help with adding a face to the name, so that when they're back, going through some of the dialect, they know who they're working with and what is going on. She asked if that were something they could do? She continued, if she could show her kids, or Brynlin shows her family, especially with that rare disease, that might be some additional clipart they can put on their face to the purpose. Or if certain organizations have families or things they wanted to highlight, they could use clipart that way, building different pieces for documentation for the future, as well. She asked if that were something that they might want to add to this agenda item?

Chair Federizo responded they needed to touch base because Tara Van Order's internship ran out. She is no longer working on the council and she was putting together bios and pictures from the individual committee members. She would need to follow up with the person who has replaced Tara to see if they would have the information to share, with not just the committee members, but also there would be a network to put it in the public website, so the people are aware of them and of who the council are. She continued she was going to have to go back and see if Tara sent that or she may have to have the council resubmit those.

Subcommittee member Folkins-Roberts asked if Kimberly was thinking of pictures of, for instance, the kids in her organization or impact pictures of her children?

Subcommittee member Ortega replied correct, if they gave them the opportunity, she has herself and her kids, where they've done certain things that puts a face to the individuals, one. And two, to the impact of why this personal committee is good. If we allowed how a bucket where you were able to pull content at any given time, for different pieces or educational, things of that nature. She has pictures of her son trying to do writing or whatever because he is visually impaired. She can send them for an educational piece. That is a clipart that is personal, not something they just pulled and added. It would actually have something to do with someone from our state. She continued that since they do have the ability and organizations on board, they would be able to highlight them. She stated that Jonathan had been on

certain cancer flyers and she has kept those. They are something that highlight his, as they call them VI.P. moments. Their families now get to share, so there is extended awareness that people will share because their child got highlighted. They're part of informational resources. It may be premature her now, but maybe later on that might be of use. If the council were able to add that while it has their attention and everyone is still fresh and ready to go, it might be of use, if the council feels that would be a good place to start.

Chair Federizo replied they could do it now because if they're even developing, like a trifold, it is more tactful to have pictures than just simply words.

Subcommittee member Folkins-Roberts agreed. She said they have always tried to show photographs and video, whatever they have and that she has plenty of that.

Chair Federizo asked if they could send her what their idea is of what the pamphlet would be? She thinks it would be more impactful if they had the pictures with the different text. Then they could formulate it and kind of get the final version, then bring it together for the next meeting they have for the final approval.

Subcommittee member Ortega offered that once they were done here, she would go back and figure out what the confirmation day is for rare day in Nevada because she knows that exists. Once she does that, she'll send them a copy of it and they can tailor that to add highlights. If they end up getting facebook up and running, or if they end up adding it to the state's website, at least they have the highlight copy so they can address some things. Or if they did write ups for just the council members themselves or self-advocates, there is another avenue for you. Right now we can work on the policy aspect that at least we can address to as another component.

Subcommittee member Folkins-Roberts asked if they were talking about a pamphlet or a leave behind because she has a document she could send them? The front has a collage of pictures of their kids, inside it talks about cancer facts and their mission and that sort of thing. It could be one or two page thing. It's also something we could use electronically. She asked if they want her to send that copy to see if it is something they would want to model after? She said she likes it because right off the bat they've got all of the beautiful pictures of people and children.

Chair Federizo answered yes because it would have to be a leave behind for them once they are spoken to. At this point, they are going to have to send things virtual to them anyway. She stated she thought it speaks more than the informational pieces, having pictures.

7. Discussion of future agenda items – Subcommittee Members

Chair Federizo moved into agenda item #7, what she will include for the next meeting. She stated they wouldn't schedule it right now to give them time to get the information together. Once they have it together, they can schedule the meeting. Future agenda items will include: the vote in terms of the final leave behind information of what they will move forward with; the vote on which BDRs they will follow. Those will be the two for the next agenda items for the next meeting. Taking it to a vote is finalizing it to that leave behind information of what they will be using and how they will be assigning people and moving forward, in terms of legislative BDR following and introduction. A lot of the other things will happen informally because they're not taking any action or anything, it is just information. She reminded

them they can send it to her. She can send it the them, but they can't send it to each other. She asked they send it to her and she will communicate between everyone, in terms of how they are getting to the finalized piece. Then they will put together another public meeting to get the finalized information out, the public hearings may take longer.

Subcommittee member Folkins-Roberts confirmed to only send to the Chair. She asked how often they would be getting together, at this point? Or when do they want to get back together?

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

Chair Federizo answered at this point, she wants to get that information together. She thought they would have to get together perhaps the week of February 8 because February 8 is when the BDRs are due. She hoped they would be posted, but there is a chance they wouldn't be.

Subcommittee member Ortega asked, regardless of what day they choose, they might want to run it past the AG if they have enough time to post it because it has a time limit of when it has to be posted?

Chair Federizo answered correct, as long as we're a week out, we can do it. It is a lot of emails back and forth on my end. If they have an idea of a date, from today and they already have those agenda meetings, they can already be drafting that from today. The question is whether or not, even if the BDRs are not fully there, what days are good for them in February?

Subcommittee member Folkins-Roberts stated she has additional fundraising events, but that February 12 was good for her.

Subcommittee member Ortega stated she would adjust her meetings as needed.

Chair Federizo stated the 12th should work well because the BDRs should be published and should they should have an opportunity to have full language they are trying to follow. The time was set for February 12, 11:00 am -12:00 pm.

9. PUBLIC COMMENT

Chair Federizo moved to the next agenda item #9, Public Comment. She asked if there were any public comments? She said she didn't think there were any public comments unless they saw any raised hands. There were none.

10. Adjournment – Chair

Chair Federizo moved to adjourn the meeting at 12:01 and reminded the Council of the next meeting scheduled for February 12, 2021 from 11am-12pm. She thanked everyone for their time and said she looked forward to working with them.