
NEVADA RARE DISEASE ADVISORY COUNCIL

MEETING MINUTES

April 9, 2021
9:00am – 11:00am

Meeting Locations:

- This meeting was held via teleconference only. 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 participated by using one of the following:

Rex Gifford opened the meeting at 9:00 a.m.

1) **Introductions and Roll call**

COUNCIL MEMBERS PRESENT:

Ihsan Azzam, MD, PhD; Amber Federizo, DNP, APRN, FNP-BC (CHAIR); Shirley Folkins-Roberts; Gina Glass (Vice Chair); Jennifer Millet, MSN, RN; Valerie Porter, DNP, BSN, MBA; Nik F. Nik Abdul Rashid, MD; Brynlin Thornley; Veneta Lepera, BSN, RN; Annette Logan-Parker; Naja Bagner

COUNCIL MEMBERS ABSENT:

Max Coppes, MD, PhD, MBA; Linetta Barnes, BSN, RN; Paul Niedermeyer

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

Julia Peek, Deputy Administrator; Lindsey Kinsinger, Manager, Office of Public Health Investigations and Epidemiology (OPHIE); Rex Gifford, Administrative Assistant III; Joseph Filippi, Executive Assistant;

OTHERS PRESENT:

Linda Anderson, Senior Deputy Attorney General Nevada
Pierron Tackes, Deputy Attorney General Nevada
Sara Cholhagian, Executive Director, Patient Protection Commission

Roll call was taken and is reflected above. It was determined that a quorum of the Rare Disease Advisory Council (RDAC, the Council) was present.

2) INFORMATIONAL: Presentation of Senate Bill (SB) 40, providing for the collection of certain data relating to health care – Sara Cholhagian, Executive Director, Patient Protection Commission

Chair Federizo introduced the agenda item, Presentation of Senate Bill (SB) 40 by Sara Cholhagian. The Chair stated she would allow Ms. Cholhagian to introduce herself and SB 40 which they would discuss later in terms of how they would move forward as a council in support neutral of this bill.

Ms. Cholhagian: Good morning, thank you so much, Chair Federizo, for this opportunity to come in front of your council. For some background information, Amber reached out to me several weeks ago. We first intended to have a discussion at one of her subcommittee meetings and there was a need to reschedule. I am always open and welcome to any opportunity to collaborate or talk about the Patient Protection Commission, our initiatives and current pending legislation with any state body seeks to collaborate with our efforts. If you don't know who I am, I serve as the Executive Director for Nevada's Patient Protection Commission. One of the bill draft requests that the commission put forward for this legislative session which revolves around transparency measures, specifically Senate Bill (SB) 40. The intent behind SB 40 is to mandate certain reporting of data to collect data to allow for the monitoring of the healthcare industry. There are some specific components of the bill, I will touch upon quickly for you, so you have brief summary. I do encourage you to read the bill in its entirety and also the amended version that will be reprinted for the entire Senate to consider adopting. The bill as introduced, is five things. First, it requires an inventory of the required health data Nevada (NV), that can be used to analyze trends and cost prices, consolidations and patient access to care. Second, it requires a report each year, summarizing healthcare quality Nevada for presentation to the Governor, Legislature and the Patient Protection Commission. Three, it ensures that the commission and Department of Health and Human Services (DHHS) have the authority to request ad hoc reports regarding price consolidation and access to care. The fourth component is really the heart of most of the bill language. It requires establishments and all para claims data base, specifically, requiring DHHS to establish the data base relating to health insurance claims resulting from medical, dental or pharmacy benefits provided to the state. Then public and private insurance that provide health benefits and that are regulated under NV law must submit data to the data base. Certain insurance regulated by the federal law plans have been given specific authority to voluntarily submit data to the data base. The fifth and final component of the bill is that it mandates reporting of data to the State of NV, the Patient Protection Commission, DHHS and the Attorney General's office to allow for the monitoring of the healthcare industry. That concludes my brief presentation or overview of the bill and Chair Federizo, I am happy to answer any questions that you or your members may have about the bill.

Chair Federizo started with some questions about the amendments. For the amendment, I believe it was from Senator Ratti, in regard to reports that are not confidential. What would that encompass?

Ms. Cholhagian answered, Senator Ratti's conceptual amendment had several different components. She asked if the Chair knew what section she was referencing so she might be able to provide some clarity on that?

Chair Federizo stated section 1-2. The two reports per year containing or analyzing information not confidential by law.

Ms. Cholhagian responded that, section 1-2, in the bill that section relates to the commission to request to allow for the commission or DHHS to have the authority to request ad hoc reports and so relating to price consolidation, access to care. That captures all of the state's entities, including local governments. The commission, may for instance want to request information from the Attorney General's (AG) office, relating to certain mergers and acquisitions or consolidations efforts. Under that scenario, the AG put in an amendment seeking to make sure that any report that is asked of their office, that they are not required to submit any information that is deemed confidential by law. For example, if they did not want to be in a position they were mandated to require a report, that would also conflict with some of their ongoing investigative work. That was a way for them to ensure that they could comply, but also were not compelled to do something that would interfere with their ongoing investigations, particularly multi-state collaborative efforts.

Chair Federizo answered, thank you, that clarification is what she was looking for. Additionally, from the Council's perspective, they have been talking about the ability to try to establish a better means to account for prevalence incidents of rare diseases in the state. She is assuming, it will be housed in DHHS, allow for even for ICD10 level accumulation, if they submitted a request to DHHS to have this from this paired data base? Would they be able to obtain that just from a numbered level of ICD10 not connected to patient identifiers?

Ms. Cholhagian stated the Chair was asking some very specific questions about the functionality of all paired data base, in particular the data release of the data base. What she could tell the council, through the implementation process, the legislation passed, DHHS will be establishing rules around the data. She thinks it is in section 12 and section 13, where, she thinks, they would have the ability to make a request. They would have to outline specific reasons to what request they want, but she would say under that scenario, that they would likely, maybe put in a request to the state for a report. They would be able to look at the request accordingly, to see, one, if they have the data, and two, if it would be something the state produces or if it is something that comes out of the database.

Ms. Cholhagian offered that the Chair is a little bit ahead, in her opinion, but if it is valuable to her, as this moves along and should this legislation move forward, she would encourage the Chair and this body to maybe have a discussion with the health information technology person in the state, who would be in charge of implementing the data base. She believes the health information technology person would be able to help, maybe answer some questions or give the council greater perspective.

Chair Federizo responded that was perfect. She had a final question. In the determination of the fiscal note was there additional funding that the state identified might be a possibility for funding it?

Ms. Cholhagian answered that it was a really good question. She thinks what they'll see is this bill will be heading to the Senate Finance and Assembly Ways and Means, the money committees, to work out the details of fiscal note. She is going to leave that answer up to the people in that arena to talk about the fiscal note. It is not the commission's fiscal note, it's the state's fiscal note, so that would be better answered by the state than herself. Ms. Cholhagian would be afraid she might give either false information or misdirection and did not want to answer that in any specificity at this time.

Chair Federizo thanked Ms. Cholhagian and said she appreciated everything and that the council would probably be reaching out to her as this moves forward, now that they've hit the deadline for the bill to pass. The Chair stated the council was fortunate that SB40 has made it, that milestone marker.

Ms. Cholhagian responded she really appreciated the opportunity to come in front of your board. She always welcomes an opportunity for collaboration. And offered, if the chair or any members on this call would like to have a subsequent follow up or if she can provide any clarity on this measure or anything the commission is doing, please email her and let her know what they can do to get together.

Chair Federizo responded she did have a request, if Ms. Cholhagian could email her when any of the meetings, hearings or work sessions are scheduled to occur, it would enable her to notify the entire council as the meetings are occurring so that they can be a part of those as well.

Ms. Cholhagian thinks she would be able to add Chair Federizo to her list. She would be hesitant for the Chair to rely upon her for that notification. She thought they might be better helped with all of the legislation by following the legislative tracking on NELIS and by signing up for the bills. The legislature has a pretty sophisticated system and she thinks the council might be able to get an account that grants them more than five measures to track. They can select Senate Bill (SB) 5, and they will get notified as soon as the legislature sends out a notification. She thinks that there is a misunderstanding that she may be the first one to know about a bill and that is not always the case. The legislature is not subject to open meeting law, and often times they will schedule things when it's convenient and she may be notified at the same time. It is better to go straight to the source, than to rely on her. She would hate to have the council rely on her and then be too swamped to inform them in adequate time.

Chari Federizo replied that would be perfect because she didn't realize she could request for an increase. Now that she knows there is an override, she will request that, thank you.

Ms. Cholhagian added, yes, she thinks you can. She thinks there is an override for government entities and you might be able to get that. She thought that Joseph might be able to help with that.

Joseph Filippi went on the record, answering, she was spot on. Unfortunately, he doesn't think we can request that the chair have an addition, as far as her personal legislative tracker. He believes they have to have a state email address in order to have an unlimited amount they can track on the personnel legislative tracker site. However, he knows that he is tracking over 150 bills for our division. He might not be able to always send you timely updates, just because there are so many bills that we're responsible to track. However, he knows Lindsey Kinsinger is on the line and knows she's familiar with tracking some of the legislation through her program. Perhaps she or one of her staff can track SB 5 for the council and send out an email or notice whenever a hearing is scheduled for that.

Lindsey Kinsinger added, yes, this is Lindsey Kinsinger for the record. She will track that and send the Chair updates.

Chari Federizo answered, perfect, thank you so much.

Council Member Millett offered she is also on the Nevada Nurses Association (NNA) Legislative Committee and they're actually looking at a lot of bills that are going through right now, SB 44, SB 70, so there are a lot of things they can be looking at and tracking.

Chair Federizo answered, perfect and thanked everyone.

3) PUBLIC COMMENT

Chair Federizo opened the floor for public comment. No members of the public appeared on the WebEx or by phone. This was verified by Rex Gifford and this item was closed.

4) FOR POSSIBLE ACTION: Consideration and Approval of previous Rare Disease Advisory Council Minutes from January 8, 2021 – Chair

Chair Federizo introduced agenda item number 4, approval if the previous council meeting minutes from January 8, 2021.

Council Member Lepera made a motion to approve the minutes of the January 8, 2021 meeting of the RDAC. This motion was seconded by Council Member Millett. A verbal vote was taken, and the motion passed unanimously.

5) INFORMATIONAL: Discussion and updates relating to the Bill Draft Requests (BDR) relating to rare disease policy assigned to subcommittee members for surveillance during the 81st Legislative Session which includes the following BDRs:

BDR 40-5, BDR 38-6 (SB123), BDR 40-8, BDR 38-13, BDR 53-32, BDR 54-43, BDR 50, BDR 57-54 (SB139), BDR 55, BDR 38-56, BDR 54-61 (AB177), BDR 40-62, BDR 57-71 (AB135), BDR 43-88 (SB134), BDR S89

(SB96), BDR 40-192, BDR 49-229 (AB175), BDR 40-239 (AB164), BDR 251, BDR 252, BDR 40-478, BDR 38-522, BDR 38-541, BDR 54-632, BDR 654, BDR 40-655 (AB176), BDR 40-747, BDR 40-522 (AB181

Chair Federizo introduced agenda item 5, Discussion and updates relating to the Bill Draft Requests. She offered a special thanks to the Legislative Subcommittee who had to dig through all of the BDRs before they were actually assigned numbers to find out what may be applicable to the council and what might not be applicable to the council. Many of these bills did not make it out of committee, the subcommittee ended up narrowing it down to, essentially, Senate Bill (SB) 40 and (SB) 175. There were other highlights that were out there, such as SB 189 which would have allowed eligibility of children on Medicaid to sustain continuously for 12 months on Medicaid instead of coming on and off which would have assisted the council's rare disease population, but that bill did not look like it would come out of committee. At this time, they've narrowed all of the bills down to what has passed through, which is SB 40 and SB 175. The Chair asked if any of the council members have additional questions on any of these other Bill Draft Requests or any of the other bills that may have not gone thru committee. The Chair added she knows that there are a lot to review, but she wanted to take a moment here in the informational section to answer questions about the other bills. Hearing no other additional comments on the bill draft on the request that they were reviewing, the surveillance with the legislative subcommittee, they will move on to section 6.

6) POSSIBLE ACTION: Discussion and possible action to approve subcommittee presentation of letter testimony in support, neutral, or against proposed BDRs with discussion of possible proposed amendments to AB40 and SB175.

Chair Federizo introduced agenda item 6, which is the Discussion and possible action to approve subcommittee presentation of letter testimony in support, neutral, or against proposed BDRs. This will be specific to SB40 and SB175. She opened the floor to any of the council members who would like to make any comments on the presentations from this morning with Sara or any additional comments from their reading of SB 40. She asked if anyone have any strong opinions or want to go in only neutral of SB40 or against it? This will be up to all of the council to decide whether it's in support, neutral or against. Or whether they just stay on the periphery. She moved forward with suggesting that they vote for a letter of testimony be drafted in support of SB 40 through their Legislative Subcommittee. The council would have to grant this access at this time. One of the things that she was not aware of at their prior meetings is that they have to, when they have the council as a whole, provide that authority to the Legislative Subcommittee. They were kind of hindered in their ability to do anything prior to that. This vote would allow the Legislative Subcommittee to draft a letter of support for SB 40. All of the final drafts will be sent individually to each council member. Due to open meeting law, they will have to send them individually, prior to them being finally approved, but if the council could begin with a vote for a letter of support for SB 40.

Chair Federizo motioned that they do a letter in support. Council Member Folkins-Roberts seconded the motion and agreed in favor. A vote was taken by the council and the motion approved unanimously.

Chair Federizo continued, that will pass. They will begin drafting the letter of support and informing everyone along the way before the final draft is submitted to the Nevada (NV) State Legislature. In addition to that they needed to take a look as SB 175 which made it all the way out of committee. A lot of the other bills did not, unfortunately. SB 175 is an addition for Lupus to be added to a similar manner as sickle cell reporting in its variants that would occur. What the premise would be is that instead of adding individual conditions such as Lupus, if the Rare Disease Advisory Council (RDAC) would like to draft a letter of amendment to Senator Neal, to possibly allow this still to be inclusive of rare disease. In that way, rare disease would fall under that sickle cell monitoring bill in addition to what the primary diagnosis addition was for Lupus for Senator Neal. This would be approval to approach Senator Neal with an amendment to attempt to possibly add in our rare disorders. One of the reasons that SB 40 may not encompass everything they need as a council, is that is only applies to all claims. In order to have all claims, you have to have some form of insurance. Unfortunately, SB 40 will not account for uninsured populations, so we could still miss out on data that is collected. That's from the payor portion, of course, this would be from a healthcare institution aspect and if they were already reporting that data and prior report that data in terms of Sickle cell it may not be too much of an ask to require additional ICD10s in addition to Sickle cell. She opened that up to discussion from the rest of the council to see what their opinions are on it.

Council Member Rashid asked for clarification on SB 175, is that surveillance data collection specifically for sickle cell? Or is it something else?

Chair Federizo clarified this is separate from the sickle cell bill, what it does is amend the sickle cell bill to be inclusive of lupus. SB 175 is unique to this legislative session seeking to add lupus to the already approved legislative requirement that requires sickle cell reporting from healthcare institutions. This would add lupus to that.

Council Member Rashid replied what they want is to draft a letter to see if they can add other rare diseases as well. She asked if they would include the ICD10 diagnosis codes?

Chair Federizo responded that she thinks to make it as clean as possible they would probably utilize the National Organization for Rare Disorders (NORD) terminology in terms of rare disease. But that it is open to the council's recommendation. She does worry and agree there may be an interpretation of what is rare disease and whether or not they want the council to submit certain ICD10 codes. They may need to do that in terms of the implementation phase or whether or not the council can approach it from a rare disease aspect from the onset.

Council Member Folkins-Roberts offered she thinks that this sounds like a good opportunity to expand gathering of the rare disease. This seems like the perfect opportunity to ask for an amendment.

Council Member Logan-Parker agreed, she thinks if the council could help expand that list, even if they just take what they're currently collecting on their data on and using those ICD9/10s. She agrees and thinks it's a great opportunity to expand some of the rare conditions that fall outside of sickle cell and lupus.

Chair Federizo asked if there was any other discussion?

Council Member Barnes went on the record. She asked if for this first ask, is this only asking for the lupus to be added on for data collection? Or is it asking for all rare diseases to be added on for data collection?

Chair Federizo answered the current bill as it's written is to add lupus, and this is an amendment to that bill, but the bill goes through draft revisions many of the language can be modified including the specific disorders in which it would encompass. This would be an ask on top of what the SB 175 is trying to do in regard to just a primary focus of lupus and change that into all rare disorders of which would be inclusive of lupus.

Council Member Barnes thanked the Chair. The only reason she asked is, she remembers when they had their first public hearing. The council was trying to narrow down what the council wanted their priorities to be just for the RDAC. They had said there are just so many, that they needed to focus in on a few and then support all. Right? She was wondering, they have this ask, and she agrees it's a great opportunity. How does it not become overwhelming to say, a provider, at some point, if it's all rare diseases, that's going to asked to provide these numbers. Will they just kind of do it in stages? What are they thinking?

Chair Federizo stated, she was right, and that would be applying more. And as they heard this morning, she was kind of getting ahead of themselves in terms of what SB 40's potential could be in terms of what they could ask, reporting and how that implementation should look like and some of that is done more after things are passed and seeing what kind of specifics they can get. If they can start with even with these institutions as results of this legislation, they're starting with even just the focus that they had because they won't have as many resources as a council as these institutions would have in this reporting. If they are already modifying their institutional electronic health records to be reporting this data, she doesn't know. In terms of the information technology required to add ICD10 codes to reporting, but if they are already doing those fundamental pieces in terms of sickle cell and then with this bill doing it for lupus, the Chair can imagine that it wouldn't be too difficult to make it inclusive of more ICD10.

Council Member Barnes replied, Okay, she was trying to look up SB 175 online and what she saw was they were 18-2015, but she thinks that might be the wrong one.

Mr. Filippi, offered he is happy to send out the language via email to all of the members for SB 175.

Council Member Folkins-Roberts replied that would be great, she would appreciate that.

Deputy Administrator Peek introduced herself: This is Julia Peek, I am the Deputy Administrator for the Division of Public and Behavioral Health (DPBH), do you mind if I just add a couple thoughts on this piece for consideration?

Chari Federizo answered, Yes, please.

Deputy Administrator Peek added: We have worked with many of you on the sickle cell reporting system, and I'll just be honest, one of the most difficult things is the implementation of this and the concern has been that we didn't have dedicated funding to support this. I certainly appreciate it's hard for the providers, but it's hard on the public health side to collect and audit that data and prepare the information.. On that lupus bill we did put a fiscal note. If you expand that to rare disease, I actually think that's a smart idea because then you're creating, like a cancer registry. You're creating a rare disease registry and by doing that, again, we will put a fiscal note on that, but it's to your benefit because we need the staff to support you and get the information you need to look at, diversity and diagnosis and access to services, etc. Everything that was outlined in both the Sickle cell registry and the RDAC. Again, our greatest challenge, and you all have witnessed it, is not having dedicated staff to work on either of these efforts. I encourage you to all think about that and when you see a fiscal note on a bill, know it's not to hurt the bill in any way. It's truly to get you all what you need. Understand it's really hard to get state general funds for some of these things, but to support you all in rare disease data and intervention, we really do need some fiscal support for this. Thank you so much.

Chari Federizo thanked Deputy Administrator Peek.

Council Member Folkins-Roberts thanked Deputy Administrator Peek for the great information. They appreciate it.

Deputy Administrator Peek thanked Council Member Folkins-Roberts.

Chair Federizo asked was there anyone else who had additional discussion? Hearing none, she motioned to draft a letter to Senator Neal recommending amendment of SB 175 to be inclusive to be an act relating to provisions to Lupus and rare diseases. They would also add that to their tracking for that. The first motion will be the RDAC is recommending amendment to SB 175 in support of any of the Legislative Subcommittee motions with this. Again, as these bills are drafted, she will send them out to the individual council members in addition to the Legislative Subcommittee.

Chari Federizo motioned to approve this amendment recommendation letter to Senator Neal. Council Member Rashid seconded the motion. A vote was take and the motion approved.

7) INFORMATIONAL: Discussion of data collected by each council member accounting for the diagnosis of focus and related data breakdown for each age group.

Chair Federizo introduced agenda item 7: Discussion of data collected by each council member accounting for the diagnosis of focus and related data breakdown for each age group. She began stating she had heard from many of the council members that, even just asking their own institutions, that there was some difficulty in obtaining some of this data. This is kind of a starting point for the council to determine somewhat what they have in the state, with the knowledge it likely has some significant gaps. Envisioning what kind of data they were looking at in terms of trying to get a handle on what they have at this date, they really don't know what they have in terms of NV, what are the needs of NV. These are basic steps to determine this data. Chair Federizo presented her data. She asked Mr. Gifford, asre you able to share the data I sent for myself, Dr. Rashid and Annette Logan-Parker? Did you receive those? Are you able to share screens for those? If not, I can just have everyone speak individually on them. I sent the demographic cohort data from bleeding and inherent blood disorders and then the data I received from Annette for her organization and, as well, from Nik for the newborn screening and sickle cell.

Mr. Gifford, answered, he would check his folder for that and if she wants to go ahead and speak to it while he was looking.

Chair Federizo apologized, she had received them, but did not forward them last night on to everyone. She tried to send them as a shared screen, but knew that might be a problem too. From the hemostasis and thrombosis centers aspect, when they looked at the age cohorts, currently right now they do not have any infants under less than one year. From that cohort up to age 70 + they have 548 individual and unique patients last year that they have seen for inherited blood disorders. What they may discuss in the next few agenda items is how they can utilize the data, at least, from the council's perspective, even utilizing it on a website informing people, being able to use it as an awareness of how many are in there. They didn't really have any issues on obtaining their data, but that is mostly because it is also a federal mandate that they take a look at these age cohorts, that they have to update that every single year. Their biggest cohort that they have is age 10-14, which kind of surprised her. In terms of the general demographic, which were seen, but that's kind of the over view from inherited blood disorders. She asked Council Member Rashid if she wanted to overview the newborn screening data?

Council Member Rashid apologized, she didn't actually tabulate the data for our sickle cell patients and clinic. She could do that in 5 minutes. However, the data she received from the newborn screening from the NV Public Health Lab Newborn Screening Program. The NV Public Health Lab started doing newborn screening in state from July 2014 until current. They have data from that date, July. Prior to that they sent them to Oregon, so it's a little bit harder to get that information. It's divided into the different diagnosis that is tested in the newborn screening. Mainly metabolic disorder, hemoglobinopathy, cystic fibrosis and endocrinology, specifically with thyroid, hypothyroidism. The problem is, it was easy to collect the number of patients diagnosed from 2014, however, it is a little bit time consuming. At this time, now the NV Public Health Lab is pretty swamped with COVID testing and things like that. So they were not were not able to break it down into different age groups. She wouldn't read through it, but she thinks they'll send this to all council members to review. The total patient diagnosis since 2014 with these rare disorders that are detected in the newborn screen, she believes is around 350, but they'll work on trying to divide them into the different age group when they have some time.

Chair Federizo, noted, she just realized that might be a little bit easier for them because they might be mostly in the infants and just a little below that. That would be good. She apologized, they didn't need the data on the sickle cell, they just associate your name, apologies for that sickle cell as well. They just need the newborn screening data.

Council Member Rashid added, it does include the sickle cell patients, but from 2014. If the council wants her to include the sickle cell patients in their clinic, obviously, she has older patients. Beyond 2014, now they would be about 6 years old. She does have older patients, so they can definitely include those in.

Chair Federizo continued, right, it might be something they end up adding to the website. But she believes they had discussed as a council in terms of --- having primary focus through so many avenues that they would focus on these particular ones to get them out there. With that, she asked to have Council Member Logan-Parker to overview her organization data. Thank you for sending those and aggregating it. Council Member Logan-Parker has some beautiful pie charts too. The Chair was going to have to ask Council Member Logan-Parker to get her very basic data to look that beautiful.

Council Member Logan-Parker responded, Thank you. This is their first pass at our data. She feels like it needs to be scrubbed a little just to ensure that they didn't accidently have any duplication and/or unintentional omissions of something. They were able to break them down into the different age groups. 2020 they had a grand total of 1,219 unique patients that fell into one of the ICD9/10 diagnosis codes that this particular council is following. They were able to break them down and their largest age group is also 10-14. That encompasses all of our conditions, including childhood cancer. When the council gets the spreadsheet, they've been able to break it down by diagnosis. Council Member Logan-Parker tried to make it as simple as possible to understand. It is obvious, there is a lot of data, but it's definitely a good start of what they have. She had her team pull the data from January 2017, as well, they have that data available to them. They have that in the form of unique patients. Her team is working on, making sure they don't have any duplications. She thinks that there will be some effort to overlay. When they look at this data, because Dr. Rashid has newborn screenings, some of those patients will be counted in those numbers and the same patients that would be counted here. She only has the ability to track them by unique patient numbers. She thinks it's a good start. Their overall summary when it dates back to 2017, they had just under 3000 unique patients that have been seen in NV with one of the diagnosis codes that they're following. They can also go further if they need to. They have data that dates back to 2009. It would be just a little tricky because some of it is in ICD9 prior to the ICD10 implementation nationally. She thinks it's a good start, though. That's what she has. Anybody have any questions?

Mr. Gifford informed Council Member Logan-Parker he believes he found the spreadsheet she wase talking about. It says 2020 rare diseases summary? He asked if she like him to share it on the screen?

Council Member Logan-Parker responded, Yes, if he would, he can share it if people want to see it. They tried to simplify it as much as possible to makes sense. She feels like this is preliminary data because she just got it from her team. They've not had the opportunity to go through it and make sure that there weren't any diagnoses that are in here that shouldn't have been. They did a preliminary scrub and got the obvious things addressed, but they need to go a little deeper before she feels like it would be something they would want to say is 100% accurate. This is the summary sheet. They found ways to group it and those things need to be verified and validated, but this is how they are presenting it. If you click on the different age tabs, they break it up by age, they break it up by diagnosis. And the final is the de-identified actual data that we pull from. That's where the team needs to go through and make sure line by line that there isn't anything in here that shouldn't be. She can tell the council these are all unique individuals. They did their first scrub by unique patients, so there aren't duplications. A patient won't be counted twice in this number. Her concern is, did a diagnosis slip in there that shouldn't have and/or was there a diagnosis that should have been on the list that wasn't. They just need a little bit of extra time to validate those assumptions. Chair Federizo, to go back to one of your questions, once you set up your electronic health records system to pull this data, it can happen pretty seamlessly. Council Member Logan-Parker's team are planning on updating the council on this data on a quarterly basis moving forward. They're happy to share the data that they have that dates back to 2017. She is pretty confident that, at least under Cure 4 the Kids jurisdiction, there are just under 3000 patients that fit into these diagnoses that they're working on. She asked if anyone had any questions or suggestions on how they can improve their efforts or their presentation of the data?

Council Member Folkins-Roberts asked 3000 since 2017?

Council Member Logan-Parker answered, Yes.

Council Member Folkins-Roberts replied, Okay, great. Thank you.

Council Member Millett commented, she thinks this is fantastic. She thinks they have done a great job pulling the data and presenting it. She doesn't think that they're going to have too many issues going through it trying to make sure things are not duplicated, but thinks they're on the right path.

Council Member Logan-Parker responded, Thank you. It's just the time required to dedicate because she wants to make sure they go line by line. Then any things that they find, they need to go back and reset up their original query criteria so that it's right moving forward. Once they get it right, it's going to be seamless for them to continue to collect the data.

Council Member Porter added, that sounded great. She really liked the spreadsheet. It's really good.

Council Member Logan-Parker stated when she feels it's ready to be stamped as accurate as they can get it. She'll let everyone know and have the Chair send it out to the group.

Chair Federizo stated it looks like this excel has a coding behind it in terms of cell by cell entry that allows the other things. She asked Council Member Logan-Parker if she would be okay if they shared that as a model itself, so the rest of the council who're still collecting their data, have it look similar, if that would be okay? Because once they start posting it to the website, all of the data entry would look this beautiful.

Council Member Logan-Parker answered, absolutely, it's one of the reasons they kept the programming of the sheet. There is no reason for all of them to have to replicate something like this. If people are interested in using this, absolutely. They kept the formulas there, so anyone can use the formula.

Chair Federizo responded, perfect. Was anyone else on the council able to even finish, even if it's a preliminary data? A lot of this would be their first passes and it's just really getting that off the ground attempt to see what they have in terms of data. Does any other council member have any data to review?

8) POSSIBLE ACTION: Discussion and possible action to approve final language and revisions of the National Organization for Rare Disorders (NORD) information to create a Nevada informational brochure to bring awareness to the Nevada Rare Disease Advisory Council (RDAC) or to allow such revisions to be conducted and approved through meetings of the educational subcommittee.

Chair Federizo introduced agenda item #8. She stated, The RDAC can modify all of NORD's documentation. They do have permission. They can also decide to utilize some of what NORD already has available. They actually have some pretty good graphic information in terms of what they utilize for awareness and education. In order to revise these documents to even approve them to what the council will ultimately have, to center it to the website, they have to a vote in the larger council to allow the Educational Subcommittee the authority to review them, revise them or otherwise add to them. She knows it sounds like, why would the council do that, but they actually have to garner permission to change those. First, the agenda item 8 is not so much taking the time out of the larger council meeting to review the leave behind from NORD, but it is a vote to allow the council to grant the Educational Subcommittee the authority to approve, revise or otherwise publish educational material and content related to the RDAC. She thinks the leave behind has been attached to a couple different agendas, but it's all of the same stuff from NORD. The rare diseases organization, they would be looking at the Educational Subcommittee as revising this information, but they cannot do that without authority from the main council.

Chair Federizo motioned to allow the Educational Subcommittee to have the authority to determine the modification of the NORD educational information or further publishing of any content to any website related to the RDAC. Council Member Folkins-Roberts seconded the motion. A vote was taken and the motion was approved.

9) POSSIBLE ACTION: Discussion and possible action to allow Cure 4 the Kids to provide website design and support for an individual Nevada RDAC website. Initial design to include registry of providers in rare disease for the state, NORD information, and subsequent additions approved by AG following submission to the educational subcommittee.

Chair Federizo introduced agenda item #9; Discussion and possible action to allow Cure 4 the Kids to provide website design and support for an individual Nevada RDAC website. The Chair noted, they have to request specific permission from the council to create this in this fashion and the initial design to include registry of providers of rare disease in the state and NORD information subsequent editions. Of course, everything they send out has to go through the Attorney General's office before it's published, but in the ability for them to build a more robust, more prominent area for rare disease in NV. They've been very thankful for the Department of Health and Human Service's (DHHS) website, but sometimes it's harder to get drilled down into rare diseases to find some of the information. Cure 4 the Kids has generously and graciously offered to build the website for RDAC and take a look at what this would look at. In addition to that, the council can discuss what they want this website to look like. From her perspective, she would like if the website could house information on providers by diagnosis. Often times patients will look at their health insurance benefits and they will look at specialists, but they may not always understand what specialist it is that they need for their rare disease. This is not something that will happen overnight, obviously, but if the RDAC website could link their diagnosis codes to providers, or even their recommendations for multi-disciplinary providers that do treat and are able to treat those patients in Nevada. As well as continuously updating their data pools from the individual council organizations through the website on an ongoing basis, so that they make a reference to legislative members or other public entities that they have somewhere from which we're drawing this information. This obviously aggregates better numbers that our own institutions can provide. Of course, the rare disease information, just the awareness and educational information, that will aggregate to the website on an ongoing basis. She asked to hear preliminary ideas from all the council members on how they would all like this to look. As soon as the council is done with the discussion, on how they would like it to look, she would like to move into the vote to allow Cure 4 the Kids to provide for the infrastructure and financial support for the website. She opened it up for discussion.

Council Member Logan-Parker responded, she agreed with what the Chair had recommended. She thinks there is a lot of opportunity to showcase all of the good work this council is doing together in bringing all of their different pieces of the information puzzle together. One site is definitely, going to be helpful for people who are looking into, what the council is doing. She thinks having a really good robust website is a great place to start.

Council Member Porter stated, she agreed. She really loves the idea of the links to the different specialties for the patients to find it. But she had one question. Would the website be just their website for RDAC, or is it going to be a Cure 4 the Kids site?

Council Member Logan-Parker continued, the way she envisions it is it would be the council's website. She just has teams who can build it. Once it is built, the council can determine how and where it should be maintained. The server platform could be on the county? Chairwoman Federizo can work out those details. They're just offering to put the labor behind building it and then giving it over.

Council Member Porter responded, thank you.

Chair Federizo agreed. The main website would look independent. The way she envisions it is, of course there would be notification of where the support is coming from, the support of this website, ongoing updates and infrastructure. But just like Council Member Logan-Parker said, it'll be the RDAC, but with the generous acknowledgment that the funding and the infrastructure needed to support it would be coming from Care 4 the Kids.

Council Member Logan-Parker asked if they wanted to discuss how this website should look like today, at this meeting?

Chair Federizo, answered, yes, just some preliminary ideas. They did have some time today, if the council wanted to put forth some additional ideas. It does help the Educational Subcommittee as they move forward in to make sure they align with what the larger council wants in terms of what it is they want to put on there.

Council Member Rashid, stated, she likes what the Chair recommended initially, where they include diagnosis and list of providers in the state that will see these diagnoses. Because sometimes that is not quite clear. She suggested a page that can link to different educational information on these particular diagnoses, that would be helpful. Information on newborn screening, a link to the newborn screening website. Also include community-based organizations that can support these different diagnoses, that definitely needs to be on the website. Just information on all the Legislative information that pops up, that needs to be on there. She doesn't know a lot of this and is learning in this council meeting, all the different legislation discussed. That should be on there too. It looks like a lot of work on there.

Council Member Logan-Parker stated, they've built a few websites so her team is competent in that. She spoke with them and they have some extra bandwidth and they are happy to volunteer. Yes, when you have the people who build websites, it's not as overwhelming for them as the thought of it is for us. She has no idea how to build a website, she just knows it needs to get done.

Council Member Rashid said, she guessed that's what Council Member Logan-Parker's team does and appreciate her offering this, this is amazing. Thank you so much.

Council Member Logan-Parker replied, they're happy to do it.

Council Member Porter asked, With the community resources, she also wondered if there are specific links to different groups for different rare diseases? Or telephone numbers that have hotlines or helplines for people? She stated her populations are older adults. I think that might be something that might be helpful for them that have grown with their disease.

Chair Federizo added, she thinks that is a great idea.

Council Member Folkins-Roberts thanked Council Member Logan-Parker for doing this. She thinks most everyone in this committee represents southern Nevada, and she wanted to make sure northern Nevada has a part of this. She knows northern Nevada is much smaller and asked them to let her know what she can do if there are any resources they need from them. That part might not be easily accessible for them.

Council Member Logan-Parker replied, thank you.

Chair Federizo moved to vote to have Cure 4 the Kids provide website design and support for the individual NV RDAC website initial design inclusive of what they decide at the Educational Subcommittee to place on the website. This will be an ongoing item because as the Educational Subcommittee meets things will be added intermittently, not just at their quarterly council meetings.

Chair Federizo motioned to approve Cure 4 the Kids to provide website design and support for an individual NV RDAC website. Council Member Rashid seconded the motion to approve. A vote was taken and the motion was approved.

10) POSSIBLE ACTION: Discussion and possible action to vote to add Dr. Susanna Sorrentino as a non-voting member of the council, pursuant to NRS 439.5075(2), for a term of 3 years. – Council Members

Chair Federizo introduced agenda item #10. Discussion and possible action to vote to add Dr. Susanna Sorrentino as a non-voting member of the council. Dr. Sorrentino would be ex-officio, she would like to serve in an advisory capacity to the RDAC and would be a non-voting member. She believed everyone had received the resume for review. This would be a vote and motion to allow Dr. Susanna Sorrentino to be added as a non-voting member of the council.

Chair Federizo motioned to approve. Council Member Logan-Parker seconded the motion to approve. A vote was taken and the motion was approved.

Chair Federizo thanked the council and asked Mr. Filippi and Mr. Gifford, what formal avenues they needed for a non-voting member? She knew it was a little different from when they added Paul Niedermeyer, but was there anything specific for a non-voting advisory member?

Mr. Filippi responded he is not positive if they need to get an official letter from the director's office appointing the non-voting member or if the council just making the vote publicly is good enough. He asked the Attorney General's office for guidance for that.

Deputy Attorney General (DAG) Pierron Tackes responded their vote was sufficient to bring her on, they are within statutory authority to add members. This was sufficient.

Mr. Filippi replied that was perfect and thanked DAG Tackes.

11) Discussion of future agenda items – Council Members

Chair Federizo introduced agenda item 11, which was discussion of future agenda items. She asked if anyone had additional agenda items or any items she may have missed aggregating through the different meetings onward to this meeting. She opened for discussion if anyone had additional topics that they would like discussed at the next meeting. Hearing no additional discussion, they would pass on some of these agenda items as updates to the next council meeting just to provide a foundational agenda which may be revised in the weeks leading up to the meeting. Primarily status updates will occur in the interim leading up to the next meeting for SB 175 or SB 40, as well as, updates for the website. Without any other discussion of future agenda items, they moved on to agenda item 12.

12) Discussion and future meeting dates and times – Council Members

Chair Federizo introduced agenda item 12, which was the discussion of future meeting dates and times. She started with the main council meeting, which they decided would be every 3 months. The council determined they will schedule the next full council meeting for July 16th to run from the same time 9-11 a.m. In addition to the main council meeting she also wanted to touch base with anyone who is participating on the Educational Subcommittee as to when their next meeting may be feasible. She asked if the members of the Educational Subcommittee are able to meet on May 14th? From the same time 9 to no later than 11am? Are there any conflicts on that committee? None were heard. For the Legislative Subcommittee, the following that week on May 21st, is there anyone on that subcommittee who might not be able to attend? She knows there is some overlap on those committee members. She asked if they would like for her to push that a little bit later, she can. She didn't want to push it to late because the legislative session is very short.

Council Member Logan-Parker stated she will not be able to attend on that date, but could do Wednesday, May 19.
Council Member Folkins-Roberts stated she can do the 19th.
Chair Federizo responded perfect, let's adjust that to may 19th at 9-11am for the Legislative Subcommittee.

13) PUBLIC COMMENT

Chair Federizo presented the next agenda item, Public Comment. She asked if there was anyone from the public on the line and that they would have three minutes to make any discussions of topics discussed. No members of the public appeared on the WebEx or by phone. This was verified by Rex Gifford and this item was closed.

14) Adjournment – Chair

Chair Federizo moved to adjourn the meeting at 10:15am and reminded the Council of the next meeting scheduled for July 19, 2021 from 9am-11am. She thanked everyone for their time and commitment. She stated she would reach out to the subcommittees and thanked them again.