

Steve Sisolak
Governor

Richard Whitley,
MS
Director



DEPARTMENT OF
HEALTH AND HUMAN SERVICES
DIVISION OF PUBLIC AND BEHAVIORAL
HEALTH

Helping people. It's who we are and what we do.



Lisa Sherych
Administrator

Ihsan Azzam,
Ph.D., M.D.
Chief Medical Officer

NEVADA RARE DISEASE ADVISORY COUNCIL
MEETING MINUTES
July 16, 2021
9:00am-11:00am

Meeting Locations:

This meeting will be held online and by phone. The online and phone meeting location is:

Video conferencing device: [105936574@teams.bjn.vc](https://teams.bjn.vc/join/105936574)

Video Conference ID: 119 782 212 2

Phone: +1 775-321-6111, 830760691# United States, Reno

Phone Conference ID: 830 760 691#

Melissa Yerxa opened the meeting at 9:02 a.m.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Ihsan Azzam, MD, PhD; Linetta Barnes, BSN, RN; Amber Federizo, DNP, APRN, FNP-BC (CHAIR); Gina Glass (Vice Chair); Valerie Porter, DNP, BSN, MBA; Nik Abdul Rashid, MD; Kimberly Palma-Ortega; Paul Niedermeyer; Max Coppes, MD, PhD, MBA; Veneta Lepera, BSN, RN; Annette Logan-Parker; (Quorum=8)

COUNCIL MEMBERS ABSENT:

Shirley Folkins-Roberts; Jennifer Millett, MSN, RN; Brynlin Thornley; Naja Bagner

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

Joseph Filippi, Executive Assistant; Jennie Belka, Administrative Assistant II; Melissa Yerxa, Student Intern

OTHERS PRESENT:

Pierron Tackes, Deputy Attorney General Nevada
Linda Anderson, Senior Deputy Attorney General Nevada
Allison Genco, Jeanette K. Belz, Jennifer Gaynor, Jody Legg, Linda Anderson, Tara Raines,

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) PUBLIC COMMENT

Chair Federizo opened the floor for public comment. No public comment was made.

3) FOR DISCUSSION: Review of Legislative session SB40, relating to the collection of health care data; SB175, enacting provisions relating to lupus; and SB420, relating to health insurance. – Council Members

Chair Federizo opened up the discussion by noting that SB40 passed. This will assist with the creation of an all payer claims database. This database will have commercial payers, who are willing to participate, voluntarily share their information. If they choose to not participate, it will be a great place, even at a Medicaid or Medicare level, to recognize the costs. Despite the database not being specific to rare disease, Chair Federizo stated that creates an opportunity for the council to work with the Patient Protection commission, who put forward the bill, to start a plan of action with them. This plan of action can include determining how the database is created and how it can be set to have more presence within the database that is more rare disease specific. The first year funding and appropriations that the legislature has given for this bill has been minimal, so therefore Chair Federizo does not anticipate much progress on this bill until next year in 2022. This will create an opportunity for the council to work with the Patient Protection commission to make sure that this database starts to provide the needs for the councils' diagnoses.

Chair Federizo stated that SB175, which the council submitted amendments to Senator Neal, did pass. However, Senator Neal did not approve the amendment to include rare disease. SB420 ended up being more of a study versus being a public option, does take a look at the creation of a public option insurance plan for the state. It will be a study and there will be no real implementations until 2026. At the same time, it provides the council an opportunity to be a part of those discussions in terms if payers are going to be participating in this public option, then what do they need to do in the rare disease phase. This can be beneficial for the council as there are more details that can go into in. Some of the bill elements were passed that will go into effect this month (July).

Chair Federizo followed up with stating that she believes that SB40 and SB420 will both be opportunities for the council to work with the Patient Protection Commission and DHHS on how to advance forward over the next few years. Chair Federizo opened up the discussion to the council if any members have any comments or thoughts about the bills.

No additional comments were made.

4) POSSIBLE ACTION: Discussion and possible action to approve report to include: 1) Recommendation to the Governor's Office granting authority to present at least one Bill Draft Request (BDR) per legislative session 2) Actions taken or under consideration impacting a rare disease disorder by DHHS must first be presented to the Rare Disease Council for input. – Council Members

Chair Federizo stated that the council is tasked with providing reports to the state by November of 2021. Chair Federizo wanted to review recommendations with the council. One of the recommendations that Chair Federizo prompted a vote for is to present a recommendation to the governor's office, or through

the governor's office, that the council is allowed to present at least one BDR each session. Chair Federizo opened up the discussion.

Council member Nik Abdul Rashid reiterated what Chair Federizo stated for clarification, recommending to present one BDR per legislative session. Chair Federizo confirmed stating that the recommendation is to present to the governor's office the ability to grant authority for the RDAC to present at least one bill draft request (BDR). This is based on previous issues with the RDAC not being able to present bills and needing to go through the Patient Protection Commission and senators, limiting the RDAC's ability to present something on behalf of rare disease. Council member Annette Logan-Parker requested clarification on how these items will be voted on, which Chair Federizo stated that it will be voted on separately.

Council member Paul Niedermeyer noted he had two comments about this agenda item. His first comment was addressing the wording of the report so we are unencumbered by legislators that the RDAC can curate its own bill unencumbered by outside parties. His second comment is to modify the sentence, instead of at the end "for input," say "for advice and consultation," which implies more of an interactive dialogue and working with DHHS versus providing a presentation. This would have the sentence read: "Actions taken or under consideration impacting rare disease disorders by DHHS was first presented to the RDAC for advice and consultation.

Chair Federizo asked if any other council members have any input for the first recommendation. No additional comments were made.

Chair Federizo motioned to approve the recommendation to the Governor's Office granting authority to present at least one Bill Draft Request (BDR) per legislative session. Council Member Nik Rashid seconded the motion to approve. The Council voted unanimously to approve the first recommendation.

Chair Federizo introduced the second recommendation that taken or under consideration impacting a rare disease disorder by DHHS must first be presented to the Rare Disease Council for advisement and consultation. Chair Federizo provided additional information about this recommendation, stating that the RDAC was implemented within DHHS. Some of the Medicaid services manual plans and some recommended changes that impact nerve disease went forward without linking the impact on whether it would affect rare disease. Chair Federizo stated that there were a few things that were brought up previously that should have been brought to the RDAC prior to it being considered for implementation. This recommendation would include consultation and advisory with the Rare Disease Advisory Council when items that may impact that population are placed as an agenda topic. Chair Federizo opened up the discussion for comments. No additional comments were made.

Chair Federizo motioned to approve the recommendation that taken or under consideration impacting a rare disease disorder by DHHS must first be presented to the Rare Disease Council for advisement and consultation. Council Member Linetta Barnes seconded the motion to approve. The Council voted unanimously to approve the second recommendation.

- 5) FOR DISCUSSION: Presentation and discussion on barriers to rare disease care in the community, including discussion regarding available resources to assess financial impact of rare disease and models of care for Newborn Screening, Pediatric Cancer and inherited bleeding disorders. – Council Members

Chair Federizo reiterated that the RDAC will need to provide a report with recommendations by November. She stated that she would like to go by each council member and have them convey or have

a discussion about what are the biggest barriers that need to be met. Chair Federizo shared that she understands everyone faces different things and she aims towards comprehensively addressing everyone's needs in the recommendations and reports. This is inclusive of available resources to provide a beneficial impact to entities or models that may be impactful. Chair Federizo stated that she did include a note that some of the objectives are not able to be met due to finances for a statistician or the ability to qualitatively and quantitatively analyze certain things in regard to cost of care. Some of these things will come in time, but as of now, the RDAC does not have the mechanisms in place to either access that data, or the finances to pay a statistician. With that, Chair Federizo would like to gather recommendations individually per council member and then use these recommendations to determine an action plan.

Due to technical difficulties, Chair Federizo repeated what was previously stated on how she would like to gather recommendations from each council member to help determine summarized recommendations to provide for the RDAC report in November. Chair Federizo continued with what her recommendations are. One of the things that Chair Federizo believes will help, in the realm of disease that Chair Federizo is in, is if the state would consider an annuity of care. For individuals who go from fee for service to managed care and back, there is no provision that requires that there be the same providers in managed care as there is for fee for service. This results in patients having their primary care change several times, which can cause a gap in services or the case being lost. At the state level, there could be continuity of the provider directory between the fee for service and managed care. This recommendation would be to the state that Nevada State Medicaid would provide more continuity of care on a Medicaid level and if you were in managed care, you will have access to all the providers you've met regardless of if the Medicaid type changes.

Chair Federizo opened up the discussion again stating that the council can draft recommendations and vote on them at the next quarterly RDAC meeting.

Council Member Annette Logan Parker provided a recommendation, which is that the state of Nevada consider recognizing a unique and separate childhood cancer comprehensive state plan in addition to the State of Nevada's comprehensive cancer control plan. Currently, there is one that encompasses the State of Nevada and it is heavily influenced by the adult population. Council Member Annette Logan Parker recommends that the state consider recognizing a separate companion piece to that comprehensive control plan that would be specific to the unique needs of childhood cancer.

Chair Federizo will include this recommendation. She informed Council Member Annette Logan Parker to send a follow up email so the preferred language is used for the recommendation. She followed up with bringing up specifics can be beneficial when it comes to reimbursement increasing.

Council Member Annette Logan Parker followed up with the reimbursement, stating that part of the recommendation of the childhood cancer plan would also be to address the administrative burden for the providers as well as the state of Nevada. Looking at the adjudication algorithm that Medicaid was originally designed for poor healthy children. Some may have experienced when wanting a patient to have example a four or five level visit that exceeds the 12 month rolling allotment, we exhaust those level four and five codes very quickly in the year and then both the state of Nevada and the providers spend a lot of time and the administrative burden of appealing and reworking and joint operating

committee meetings. Council Member Annette Logan Parker stated that she feels the council can influence the state, not only from a fee perspective but from an administrative burden perspective because everybody can save money on both ends, without necessarily increasing the reimbursement by coming to agreement on the administrative burden associated with caring for children with rare diseases.

Council Member Ihsan Azzam stated that at this time, he does not have any recommendations.

Council Member Linetta Barnes also stated that she doesn't have any recommendations at this time. She asked for clarity that there is still a focus on the newborn screening pediatric care and inherited bleeding disorders. Chair Federizo confirmed that those will be a focused topic, but at the time the council will focus on global recommendations.

Chair Federizo informed the council that it is okay if anyone doesn't have recommendations to say at this time and told the council members to follow up with her so she can include it in future agenda topics to approve at the next RDAC meeting.

Council Member Linetta Barnes stated that she does have a recommendation on if there is a way for the verbiage for all of the MCO's across the board to allow for testing of the parents in regard to newborn screenings. She explained that a lot of the times, parents do not know their trait status and they continue to have children. Ms. Barnes shared that in California, they allow testing for immediate family. Council Member Nik Rashid followed up Ms. Barnes statement that California does more than allow this testing, but funds the testing. California pays for parental screening.

Chair Federizo promoted the council members to bring any recommendations regardless of how grandiose because they can try to find a way to address these concerns.

Council Member Max Coppes shared his concerns about funding. As many of the council members work in the area of rare disease and they come up with ideas, they are informed that it cannot be funded. Dr. Coppes expressed his frustration about the commitment and response and requested that legislation share the purpose and importance of the RDAC and how they would view success for the council. Chair Federizo shared similar frustrations with the inability to complete a quantitative analysis, not having a statistician, and not having appropriation for the council like other councils did. Dr. Coppes followed up that this gives off the impression that the RDAC is not important as they cannot do their job. If there is no appropriation, then the council should disband until there is funding. Chair Federizo agreed that the council needs appropriation funding, but there are many elements that can still be addressed without funding, like working with Nevada Medicaid to recommend changes to Medicaid. There are several elements that are not well designed for rare disease, even without funding, that the council can still pursue and address. The report to the state will include elements that the council cannot do because there is no additional funding. In the future, the RDAC can look at the progress made and determine if this council could instead be a subgroup of the Patient Protection Commission and then have access to their funds. The RDAC can still address areas without funding, but the frustration makes sense. There are elements that cannot happen without appropriation and that is something that should be included in recommendations moving forward. This can include councils that are coming into the state, with recommendations that until they have appropriations for the council, they shouldn't push it through legislation.

Council Member Annette Logan Parker stated that she agrees with both Council Member Max Coppes and Chair Amber Federizo. She believes that because this is the RDAC's first report, the council has an opportunity and an executive summary to outline the frustration that Dr. Coppes has described. Ms.

Logan Parker continued that the council, if possible, can solicit additional money through philanthropy or contributions to do some of the work that the council wants to be done. If legislature isn't able to fund it through appropriations, then the council might want to recommend that the requirements are lightened and that the council can seek other funding sources to have the work done.

Council Member Veneta Lepera followed up stating that she agrees with that Council Member Max Coppes stated. Being Chair of the Palliative Care Quality of Life Council, Ms. Lepera shared that they were developed by statute, given no funding, and been operating for five years with no funding. They also sit on the post board which has now moved under the DHHS, which has no funding but can access license plate funds. Ms. Lepera suggested if it would be beneficial for the RDAC, the Palliative Care Quality of Life Council and the post board to find a senator or Congress person that wants to take on heading the funding for it all because these groups are all connected. Although rare disease is childhood focused, a part of rare disease is, if they are not at a hospice level, there is only so much home health can do, there is a gap in between. When you have a chronic illness and a life limiting illness, that's palliative care. So, all of these things flow together and there is power and strength in numbers. Ms. Lepera shared that one of her recommendations, which she is also including in her Palliative Care Council report, is that there needs to be an umbrella where funding can come from. Additionally, Ms. Lepera suggested that the report includes that there should be specific funding for rare childhood cancers, families that are trying to cope with minimal support from Medicaid, whether it is a child or adult.

Due to technical difficulties, Council Member Veneta Lepera repeated her previous recommendations that in the RDAC report, it should be brought up the importance to recognize the need for palliative care in the Medicaid grounds and regulation for home. There is a window where people with chronic life limiting illnesses are not able to access resources to help with care, whether it is a child or adult. Ms. Lepera will be referring back in her report that she works with several councils that all address similar issues with not having any resources allocated to them, to increase education, or to go to the senators and Congress to have them lobby to write bills that would give these councils the supports they need.

Council Member Ihsan Azzam followed up for clarification of what the council is addressing. He asked if the concern at hand is that the council is formed under legislature for the care of individual with rare diseases, but lacks funding. The concern is how to provide supports with the lack of funding at this time.

Chair Federizo confirmed that his statement is correct. She noted that she believes there are still some recommendations that the council can make. Although, if the council makes recommendations and nothing happens because they don't have authority or money to prove the importance or the ability to look at evidence-based research to gain the funding to do research, it is hard to prove that it's needed. It will lead to a cycle of recommendations and nothing happening. Chair Federizo stated if there are areas the council can change in the next few years, that would be ideal. There may be areas where their recommendations may fit in the future and changes that can be made without funding. The council can look into alternative ways of funding, like Council Member Annette Logan Parker previously suggested, to approach the industry and obtain non-branded grants to gain funding. Chair Federizo followed up that it is important to have these conversations and include what they can in the report. If it is decided that the council should disband, the report will still include recommendations until funding is available.

Council Member Ihsan Azzam suggested one thing that is a very important public health problem/issues is where legislature decides to create some group or council and later on, funding will happen. Dr. Azzam provided the example of the Prostate Cancer Task Force, which they previously were referred to as the Governor's Task Force on Prostate Cancer, had no funding with a huge project. With that example, Dr. Azzam shared that the council has two options. One is to create a plan stating what can be done in order to improve the life of the patients with rare diseases and their families. This is with or

without funding; showing that with funding, things will be significantly higher or better. One important thing which is seen is the coordination of care for patients through a team approach, because such a complex disease entity cannot be managed by one specialty. So, recommending case management through the State of Nevada for cases and a team approach can be done through Medicaid. Dr. Azzam stated that the council will first need to describe what is happening now, where it is disorganized, uncoordinated care. This will eventually result in negative health outcomes and more payments. Secondly, what can be done with health funding. The third part is what can be done to improve the quality of life for the patients and their families if funding will be available and state how much funding the council is looking for. Based on previously experience with the Prostate Cancer Task Force, Dr. Azzam shared that everyone was frustrated that a group was formed without funding, but after a while they were able to allocate temporary funding, which was really effective to improve the quality of life for patients and families.

Chair Federizo followed up saying that it would be a great opportunity, with each council member sending Chair Federizo their comprehensive recommendations of what they would like to see would provide great insight. Like Dr. Azzam said, to provide things such as administrative changes that can be done without funding and then once funding is allocated, what changes could result in that.

Council Member Ihsan Azzam shared that the council will need to state the problem clearly and say what is being done now, what could be done without funding, and how funding will change the equation.

Chair Federizo stated that she will include what Dr. Azzam shared since it aligns with the vision of what the public option would look like. To fund positions for a social worker and case workers, legislature is aware that there is a continuity of care issue and may be unsure of how it can be coordinated. If the council is able to describe what a plan incorporating case workers and social workers and what their impact would be, it will help navigate supports for patients and their families.

Council Member Ihsan Azzam stated that the council can include examples that patient navigators really change the outcome for many patients in Nevada and nationwide. The council can give the example that even the National Breast and Cervical Cancer Early Detection Program was able to do it, to create the position of patient navigators and vision navigators, acting as case managers, as team convenience, and as communicators between patients and their providers and the patient and family. It would not cost the council anything to suggest best practices on improving the quality of life for patients and their families. If the council presents an impressive and clear definition of the problem and the goal of what we want to accomplish, there will be a chance of having funding in the future. Dr. Azzam shared that, from experience, funding will follow when it is seen that they are committed and they are able to define clear goals and outcomes, who will do what, when and how if we get funding.

Chair Federizo agreed with Council Member Ihsan Azzam that coming up with elements and recommendations that state what it will look like and what are the possibilities. Once they see an actionable plan from the council with different elements in pediatric cancer stating that there needs to be changes in the administrative level, it can free up time and productivity to be able to use these assets elsewhere. It is frustrating that the council will recommend things when they do not have authority, but

by providing recommendations and a plan, the council would have done everything they can to reach that of addressing them, even without funding.

Council Member Ihsan Azzam followed up that it should be approached like writing a proposal for a funding source because this way the council will be able to provide that to any agency who may provide funding, state or nationwide. Dr. Azzam suggested clearly defining the problem that rare disease are not very rare and the burden of how much it is costing, such as the financial burden and the societal burden on the patients and their families and the community. He noted that the solution is not going to remedy everything but will improve the quality of life for everyone. Dr. Azzam recommended that the report be formatted to define the burden, the problem, and what the needs are in order to make it the problem go away or easier and reduce the societal and financial burden.

Chair Federizo agreed with Dr. Azzam and thanked him for his input and feedback. She followed up with suggesting if there were anything he would like to comprehensively put together from that action plan for the patient navigator to send it to her and she will do some additional work on it. If the council were to submit for an RFP, they would make sure that every council members needs are addressed in the report.

Council Member Nik Rashid shared that for sickle cell, which is what sickle cell bleeding disorder is, access to care has always been the major issue that she has seen. In terms of fee for service Medicaid for patients, Dr. Rashid shared that every person with a rare disorder, especially if they were born with the rare disorder with it being a genetic or inherited condition, should qualify for fee for services Medicaid so that there is continuity of care. If you know, based on the diagnosis, not just based on parental income and if they have private insurance coverage, they should be eligible for supplemental Medicaid. For example, when a parent starts working and they have private insurance and because of copayments they are unable to afford the basic medication that the child needs to continue taking care of them. Similarly, for sickle cell there are scans every year to survey their medical condition and sometimes there will be a switch from one radiology institution to another, so there is no continuity of care. Or in the instance of being transferred to several different hospitals. These are frustrations for healthcare providers and very frustrating for parents and patients.

Dr. Rashid continued by noting that Nevada is lacking in a lot of services. One of the areas include testing for patients, for example genetic testing, where testing will need to go out state. This is not covered by Medicaid. There are a lot of patients that need to do genetic testing in terms of technology, diagnosis of a rare condition and there are unable to get it because it is out of state services. Trying to get services out of state is hard and it is difficult if they just have state funding or Medicaid.

Chair Federizo added to Dr. Rashid's comments that utilizing models of care similar to what is being done in other states. If a provider for rare disease is asking for a particular test that is needed for a diagnosis, it is important to have those covered. Many of them do not have continuity between different payers to different institutions, which causes issues. For example, if imaging is seeing a child for the first time, they don't have the comparisons because they don't have the images that were previously done. Chair Federizo followed up for Dr. Rashid's recommendation to be tailored towards creating a program of need. She requested that Dr. Rashid follow up with her on in depth services of what she is looking for to address for the program and to make sure it's a comprehensive recommendation.

Council Member Nik Rashid followed up that, in relation to what Dr. Azzam recommended, to have a patient navigator and case management to review all of these cases would make sense for the disorder. Chair Federizo explained that there will need to be a detailed plan because if this is brought to the state and asking for a vision navigator, community assistance individuals, that person will do the best that they can think of. She recommended creating a plan for the case manager to help the patient link with their needed resources based on diagnosis. Instead of the patient navigator waiting for the patient to call them, they can comprehensively look at the records and find the appropriate resources based on need. Dr. Rashid followed up that a lot of these asks were tied into the sickle cell bill AB254, it is just taking a while for things to go into effect.

Council Member Ihsan Azzam stated that the council can have their wish list or recommendations as extensive as possible and it may not be approved at all, but it should be granular and detailed of what the council wants. Similar to what Dr. Rashid mentioned, some of the genetic testing are not covered because they are out of state. One of the recommendations should be that the testing should be covered regardless of if the test is in state or out of state. Nobody has the financial ability to cover it, and it has to be covered since it's a needed test. Dr. Azzam suggested that everyone state what the problems they are seeing are and what the burdens they are seeing at this time and then include what recommendations they have to fix it. Dr. Azzam noted that they want money and it's not going to approved unless there are comprehensive recommendations.

Chair Federizo agreed with Dr. Azzam that it is important to include specifics, like asking for and providing a plan so they can take action.

Council Member Kimberly Palma-Ortega brought up how Chair Amber Federizo attended the Medical Care Advisory Committee meeting. Ms. Palma-Ortega shared that she feels the more the council is able to present and bring in different perspectives, it may show legislation that the council is making attempts on different levels with different aspects. She suggested to look into other committees and councils that the RDAC members sit on and provide opportunities for presentations. Ms. Palma-Ortega stated that, as a parent perspective, when going through the process of receiving services, parents trust anyone and everyone that is working on the case. This emphasizes the importance of needed help and advocacy to support the quality of care and transitions through pediatric and adult health care. Additionally, bridging the support for those aged in between child health care and adult health care. She noted that parent involvement and education is an important factor. Ms. Palma-Ortega emphasized the importance of developing a roadmap. Since there are a variety of disorders being looked at, such as pediatric cancer and blood disorders, there will be different roadmaps that each individual requires. The council can work with legislation to gain more awareness out there and work with organizations to develop a roadmap each specific criteria. This can include parents working alongside providers so there is a clear understanding of what is to be expected. There are different types of support available, such as SSI or Katie Beckett Medicaid. It's also important to teach parents how to look up resources, whether it's local or national, to see what the next steps may entail. This can include what to do in case there is a change in insurance coverage, employment status, what procedures are needed and if these procedures are medically necessary. Ultimately, being able to bridge the gap between physicians so they can work together to provide services for the patient. By providing a community health worker (CHW) it could assist as a parent mentor role. This can take the burden off of providers and help teach parents how to do

certain things by themselves. Ms. Palma-Ortega summarized her recommendations as navigating how to educate parents to assist with the quality of care, which can increase the amount of support when addressing legislation.

Chair Federizo thanked Council Member Kimberly Palma-Ortega and stated that it ties into the previously discussed patient navigation. Chair Federizo told Ms. Palma-Ortega to follow up with her if she has any specific transitioning roadmap or plans based on her personal experience as an ideal process to send as a recommendation.

Council Member Valerie Porter emphasized the importance of what has already been stated. Since the primary focus has been on newborn and pediatric health care, Ms. Porter's recommendation was to include the geriatric and adult population in future agendas. This can also include the veteran population in the state since now everyone is 100% service connected. Also, Ms. Porter brought up the geographic barriers that adult and children people struggle with. This encompasses telehealth, transportation, and increasing patients to see providers that may be in rural areas.

Chair Federizo requested that Council Member Valerie Porter send her a rundown of how transportation services could be addressed because it is a significant issue for several populations, including the Native American tribes who only have one care within the tribe.

Council Member Paul Niedermeyer shared that he would recommend building a rich taxonomy or directory in current positions, nurses and other medical professionals. In the state of Nevada, that helps delineate their skills and diagnostic gifts. Perhaps working with NSHE, mainly UNR and UNLV's medical programs and researchers that would be willing to make this a reality. With limitations with the National Organization for Rare Disorders (NORD), that serves to advocate for rare diseases with three plus affiliate organizations that help identify and treat various types of rare diseases, there is still no taxonomy and no directory that exists of medical personnel. There is no directory of organizations and medical personnel or diagnosticians generalists or specialists that offer their services within their field of expertise. Finding physicians or nurse practitioners can be a treasure hunt, which requires a lot of time, patience, money and a bit of luck. Medical schools teach the students Occam's razor, or the law of parsimony, and students are taught to look for the disease that is most likely based on signs and symptoms. Physicians and advanced practitioners or nurses who have an unusual ability to pattern match, and problem solve complex puzzles or riddles, identifying and diagnosing rare disease. The rare disease community has a search engine for medical professionals called FindZebra.

Mr. Niedermeyer continued sharing that last year he was under the false impression that the American Board of Medical Specialties or ABMS had a distinction for diagnostician, like many people Mr. Niedermeyer shared that he was captivated when he was younger, leaving medical journals like Dr. Gregory House, where a team of diagnosticians work to solve really tough patient cases was real. In reality, few exists in real life, at least not publicly by that monitor. In my instance doctors, known as diagnosticians, are given that nickname by their peers, because of their abilities. It is not tied to any official designation. Physicians are taught to be generalists first and specialists second. The ones that take on a rare disease come from primary care physician referrals to other doctors who end up in common act, looking at problems intuitively to pattern match and figure out what's going on. They usually have a deep passion for science, statistics and math, work in children's hospitals, clinics or medical centers.

Mr. Niedermeyer shared how his personal experience has given him insight when it comes to discovering a definitive diagnosis. He continued to share that for those that don't work for caregivers and patients seek out physicians who are unconventional. There is a perception among physicians of working outside of the practitioner's expertise would mean that may not be knowledgeable in how to address the health concern at hand. Some medical professionals may be fearful of compliance licensing or Medical Board issues. For example, if a treatment regime falls outside the normal practice and the patient requires a medical dose that is multiple times the normal therapeutic dose off, a pharmacist filling that scripts, maybe uncomfortable filling it. They may decline to fill it for the patient, not realizing or understanding that dose is necessary and appropriate for that patient. Some pharmacists might feel compelled to report that physician to the medical board, not realizing that this is appropriate again for the rare chronic disease that patient has. Mr. Niedermeyer recommends that building a distinction or delineation for diagnosticians who treat rare disease may help pharmacists understand the context under which the prescription is given and remove this is an issue. He shared that it would be wonderful to see the Nevada encourage the American Board of Medical Specialties (ABMS) to weigh in on meaningful discussions and continually work around what it might take to create a new distinction for general diagnosticians, that involve genetics, AI, repurposing FDA approved drugs for new indications and other relevant areas of expertise would be welcomed and appreciated. This also applies to nursing specialties as well.

Council Member Niedermeyer recapped his recommendations are 1) funding to build a rich taxonomy, a directory of physicians and nurses and other medical professionals in the state of Nevada that are licensed here to help the money, their skills and diagnostic gifts, as it applies to rare chronic disease; 2) the state of Nevada fund a study on creating a new specialty or specialties for advanced nursing programs, physician DO or MD residency programs for rare disease. While in concert requesting the ABMS provide a position statement on this issue. Mr. Niedermeyer shared that it's important to move forward and not wait for permission or favorable feedback from the ABMS, let's just get started because the problem is obvious to everyone involved. The results of a rich taxonomy or directory and study of new nursing and physicians for rare disease could help build momentum for funding higher education, nursing and medical school programs linked to rare disease and put Nevada at the forefront of research. This can assist with having the whole constellation of genetic testing here in the state and compel the ABMS to seriously entertain it as a specialty, which opens up a myriad of options for all types of health care coverage under the blanket umbrella of rare and chronic disease. Mr. Niedermeyer informed Chair Federizo that an email is already drafted to send to her.

Chair Federizo shared her appreciation of Council Member Paul Niedermeyer's in depth recommendations. She stated that it will be critical to have those conversations outside of the state with making recommendations for the ABMS. They have already experienced difficulties making and affording residency with general practice, but these recommendations can add an element of specialties. This can open up opportunities to develop a brief residency or training within organizations and expose the experience of pharmacists and prescribing medications.

- 6) POSSIBLE ACTION: Discussion regarding the education subcommittee and website design and possible action to delegate authority to the Education Subcommittee to approve and modify website content and educational outreach, as well as apply for and receive educational grants on behalf of RDAC. – Council Members

Chair Federizo expressed appreciation for everyone involved in the educational subcommittee to meet the needs and support for moving forward. She informed the council that the educational subcommittee has started with the website design. On Monday, they will be moving forward with one of the elements

Council Member Niedermeyer shared, to have access for patients to obtain information in regard to their diagnosis and determining a provider depending on the needed specialty. Chair Federizo shared that the subcommittee is looking at elements that the main council can vote on, which is the patient's ability to go to the website and look up their diagnosis by diagnosis name and hoping to code and link that diagnostic name to provider in the state of Nevada who currently treat those conditions regardless of how they may be labeled through an insurance directory. Especially since insurance directories are not always accurate. From there, the subcommittee aims to encoding links that are inclusive of that disorder and connect with consumer based organizations specific to the disorder to provide additional resources in the state. The goal is to have additional resources through with a diagnosis name, rather than having it fragmented, it will be a one-stop website that a patient can go to get a medical provider and recommendations based on diagnosis with community based organizations specific to their diagnosis. The website will also include general connections to resources, such as Nevada 211 or if a patient with rare disease require additional supports such as rental assistance or other services that the state can provide. The taxonomy behind rare disease is not well thought out, so this is one way to actually go by the name of the diagnosis, rather than the specialty with which it is placed.

Chair Federizo stated that one thing that she will need from the council is if the subcommittee is able to proceed with updates, revisions and recommendations based on the voting of the council prior. This refers to all of the things that were brought up at the last meeting that needed to be approved for the education committee to proceed forward with. Chair Federizo is asking for global approval for the educational subcommittee to approve and modify the website content. This agenda item will be broken into two votes. The first vote would be for the council to delegate authority to the educational subcommittee to approve and modify website content and educational outreach. The reason this vote is needed is because the council is under Open Meeting Law and because the council is structured in such a formal premise. The subcommittee would need to have permission from the main council to do anything, even if there was an update or an idea. Chair Federizo stated that she will also open it up for any questions in regard to the topic prior to motioning for a vote.

Council Member Paul Niedermeyer responded, sharing that he would be interested in being able to review and provide comments for the website build.

Chair Federizo asked if Mr. Niedermeyer would be interested in joining the educational subcommittee because a caveat with the open meeting law for correspondence to be available. Mr. Niedermeyer said he is okay with joining.

Council Member Ihsan Azzam asked about including professional education component where probably healthcare providers can access presentations to educate them on the existence of rare diseases so they will not be surprised when they hear about a disease. Dr. Azzam stated that he thinks the website should be addressing the public education and professional education, where people can get continuous medical credits if they attend a certain event. Another thing would be to include information to connect with telehealth. Dr. Azzam additionally suggested connecting with the Medical Care Advisory Committee and revisiting explaining the problem, the burden, and what the RDAC is planning to do and recommendations through a presentation.

Chair Federizo stated that she will add those to the subcommittee meeting agenda to discuss. Chair Federizo told the council to send her any ideas that they would like to see on the website so that they can be added to the agenda for the educational subcommittee to include. She stated that the goal of the vote is to ensure that the council members will send over recommendations that the educational

subcommittee could generate it for the website without needed to bring it to the main council for a vote. Chair Federizo asked the council if there were any additional comments. No comments were made.

Chair Federizo motioned to approve for the subcommittee may approve and modify the website content and educational outreach. Council Member Nik Rashid seconded the motion to approve. The Council voted unanimously to approve the first recommendation.

Chair Federizo moved to the second part of the vote to allow the educational subcommittee to apply for grants on behalf of the RDAC. These would be specific to only educational content, so if there was an opportunity to apply for or receive an educational contract from any entity that will provide education, the subcommittee would be given authority to pursue the application of said grants. Chair Federizo opened it up to discussion. No comments were made.

Chair Federizo motioned to approve the educational committee to have the authority to apply for grants in regard to educational content. Council Member Nik Rashid seconded the motion to approve. The Council voted unanimously to approve the first recommendation.

- 7) POSSIBLE ACTION: Discussion and possible action to establish pharmaceutical industry advisory panel. – Council Members

Chair Federizo shared that this agenda item came from the request of a pharmaceutical company requesting from the state to be included on the council. Chair Federizo stated that she recommended that an advisory committee could be formed versus having someone from pharma being on the council. She expressed concern that it would be opening a door for one manufacturer in particular to have a seat on council could be very gray and could assert some bias and not look good. Although, it could be beneficial to have someone on a subcommittee or advisory committee with a particular rare disease drug could present and explain their concerns or recommendations or for the council to be able to share concern and recommendations to them but not all of them to be able to vote. Chair Federizo opened up the discussion for comments.

Council Member Paul Niedermeyer shared that he would be open to having a pharmaceutical industry provide updates for meetings specific to them on whatever schedule the council would approve and provide information and possible discounts that the council can provide to patients with chronic and rare diseases. If they are able to provide a discount card or something that basically again addresses the issue with pharmacists dealing with doctors who prescribe medications for patients as almost a way of removing or alleviating the conflict or concern of dosing, or off label use. Mr. Niedermeyer shared that he believes it would be more appropriate to limit any involvement with any one particular firm or company to avoid opening the door and limit conflict.

Council Member Ihsan Azzam shared that he agrees that they shouldn't be voting members. However, they can be beneficial. If the council can let the pharmaceutical companies know that the RDAC exists, they can also provide presentations and updates on what they are doing in regard of advancements in treating and developing new pharmaceutical products for rare diseases. This is an educational opportunity for the RDAC to know what's new.

Chair Federizo followed up that what can be done with these comments is develop a pharmaceutical industry advisory panel for their presentations and they can present every six months to present updates. They can also be invited in the future if it is identified that their feedback based on specific rare disease

or specific company. Chair Federizo shared that they provide an element of opportunity to connect and educate or offer grant funding for potential research initiatives. Aside from presenting, they can come together and decide if there is something that the council could move forward in conjunction with them. So having them on an advisory panel will be beneficial and having them present updates every six months, or twice a year.

Council Member Annette Logan Parker shared that she could leverage the different pharmaceutical organizations to help advance the work of this council. Ms. Logan Parker brought up the concern of the term advisory council or advisory board because it leads to the interpretation that they would be advising the council, which could potentially get in the way in the future for different things. She suggested changing the wording from advisory to something else to make sure it is not misinterpreted.

Chair Federizo stated that it could be changed to pharmaceutical and formulary subcommittee. Then later, with new gene therapies, this could also be a format the council to come together to decide in those capacities under what approval might look like for those as they move forward. That way, there is no need to create a secondary subcommittee for these discussions specific to these drugs in conjunction with these committees. Within an approved vote to the main Council, in terms of how the council might utilize these drugs as they come into the market. Chair Federizo suggested changing the name to pharmaceutical and formulary subcommittee. Then discussions surround medication can be addressed within that subcommittee.

Council Member Annette Logan Parker shared that it's a complicated topics and noted that importance of protecting the integrity of the council.

Chair Federizo followed up with stating that they can form this subcommittee. There will need to be council member to join that subcommittee to meet quorum. The subcommittee can discuss what gets approved to be presented at the main council meeting. Once developed, Chair Federizo can invite manufacturers to join and ask if they have anything that they would like to present and what that would entail. The subcommittee would be more geared towards reviewing those requests, seeing what that would look like, and then could also put things around the limitations of what happens within there. If it leads to them being invited as a directory of a contact resources or whether it has to do anything within that subcommittee.

Council Member Ihsan Azzam asked the importance of needing a subcommittee as they should be considered external partners who will submit a presentation twice a year. If the educational subcommittee approves it, it will happen. He expressed how if any external partners would like to present for an educational matter, that it should be welcomed. If any experts would like to present to the council, such as if the CDC or National Institute of Health, it should be welcome, especially if it is updating the council on what good things they are doing.

Chair Federizo agreed with Dr. Azzam that it could be combined with the educational subcommittee instead of adding a new subcommittee. The educational subcommittee can have the authority over it and it can be an ongoing/reoccurring agenda item about what can be shared with the main council or what doesn't need to be brought to the main council. Then if they are interested in doing more presentations, they can provide it to the educational subcommittee versus waiting for the 6-month meetings. As this agenda item will be moved to the educational subcommittee, Chair Federizo stated that she will invite the manufacturer to provide her with contact information and directory information, then invite them to present or send over information and place it on the agenda for the educational subcommittee to review and decide if it should be moved forward with the educational subcommittee. From there, the

educational subcommittee can bring the presentations that provide value to the main council at the two meetings.

Council Member Nik Rashid followed up with Chair Federizo saying that she approves this idea to have the pharmaceutical companies as resources rather than create a whole subcommittee for them. Council Member Annette Logan Parker agreed with Dr. Rashid.

Chair Federizo stated that this agenda item does not call for a vote, but she asked the council if there is any additional comments or opposition as this topic will move to the educational subcommittee. No comments were made.

- 8) POSSIBLE ACTION: Discussion and possible action to establish and conduct a statewide needs survey for consumers and providers and possible delegation of authority to the RDAC Educational Subcommittee. – Council Members

Chair Federizo shared that she has been involved in a lot of NORD webinars and presentations and one of the things that they have found value in is conducting a statewide needs survey for consumers and providers. This would take a look at utilizing or repurposing some of the surveys that the other RDACs have already created in terms of reaching out to the community to see what their needs are and submitting them out. One of the difficulties is getting out to consumers, but once the Educational Subcommittee agrees on the creation of the survey, the subcommittee could go through community based organizations and provider institutions. The Educational Subcommittee will be working with the State Board of Medical Examiners, State Board of Pharmacy and State Board of Nursing to provide a directory of what they are treating their current contact information and also advising them of opportunities for rare disease education. Getting a survey of their needs, not just from the specialty side but also the primary care, and what their concerns are in terms of even referring patients would provide an opportunity for the council to determine the needs. Chair Federizo opened up the discussion to the council if they agree with proceeding with potential survey of consumers and providers for what they think their priorities are for rare disease.

Council Member Nik Rashid stated that she is not opposed to creating a survey, but she is wondering how it will be done.

Chair Federizo shared that it is the downside in terms of response and that's why the educational subcommittee will be reaching out to licensing boards. Although, there could be great responses from providers and communities. Chair Federizo suggested going through community based organizations, such as sending the survey to the National Hemophilia Foundation (NHF) to distribute through their directory to patients to see if there will be any responses. This may be a future agenda item if the council does not feel like it's in their best interest at this time. Chair Federizo shared that she brought it up as an agenda item because other RDAC's have done it but there is more community engagement in their states.

Council Member Linetta Barnes suggested that providing community and patient platform to submit ideas would be beneficial as a link on the website. Then if it is sent out, they are also referred back to the website so they can be linked to the information on the website.

Due to time, Chair Federizo suggested holding off on this agenda item until the website is online and can offer that as a link. She will place this item on the agenda for the next meeting and include examples

of what the surveys will look like so the council can delegate authority to the educational subcommittee at a later meeting unless anyone is in opposition.

Council Member Kimberly Palma-Ortega agreed with Amber's suggestion to bring it back to the educational subcommittee so that they can talk with other commissions, councils, and boards if they are interested in any collaboration. They can also help distribute the surveys. This will also allow the subcommittee to gain input from specialty doctors.

Chair Federizo will proceed to move this agenda item and once the educational subcommittee is ready, they will present it to the main council.

9) Discuss and determine future agenda items – Council Members

Chair Federizo opened up the discussion for agenda items for the next council meeting in October. These agenda items will need to be approved before the next meeting. At this time, Chair Federizo noted the options for in person meetings are limited since there is no availability at the Las Vegas location currently and only the Carson City locations is available for in person meetings. With that, Chair Federizo informed the council that the RDAC meetings will remain virtual.

Council Member Linetta Barnes mentioned how Council Member Annette Logan Parker has brought up an understanding of what the RDAC can do in regard to funding. Ms. Barnes requested if there is a representative available to provide an explanation for funding. Chair Federizo informed the council that she already has a request for the state to see if someone can provide the council with a formal overview of what is allowed in terms of what can and cannot be done in regard to funding.

Council Member Annette Logan Parker asked if meeting locations need to be in a government facility or if it's allowed to be in an auditorium or education facility. Chair Federizo stated that the requirement she is aware of is that it has to be open to the public, but she will follow up. Council Member Annette Logan Parker informed the council that she has access to an auditorium with audio and visual availability that she can offer for the Las Vegas location so the meetings can be in person. Chair Federizo will follow up if that is allowed and thanked Ms. Logan Parker for offering up that option.

Council Member Nik Rashid brought up reviewing the report that will be submitted in more detail. Chair Federizo stated that at that time, there will be a draft report based on everything that has been submitted to her that the council will review at the October meeting before sending out the final draft in November.

10) POSSIBLE ACTION: Discuss and schedule future meeting dates and times – Council Members

Chair Federizo asked if the council is okay with a Doodle Poll being sent out to determine the best meeting dates for October.

Council Member Valerie Porter stated that she is okay with that.

11) PUBLIC COMMENT

Chair Federizo opened the floor for public comment. Chair Federizo 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 made a comment.

12) Adjournment – Chair

Chair Federizo moved to adjourn and expressed appreciation for everyone on the council and everyone’s commitment to getting everything going.

Chair Federizo moved to adjourn the meeting at 11:01 AM.