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NEVADA RARE DISEASE ADVISORY COUNCIL DRAFT MEETING MINUTES

Date: October 6, 2023

9:30 am – 10:39 am

Meeting Locations:

Pursuant to NRS 241.020(3)(a) as amended by Assembly Bill 253 of the 81st Legislative Session, this meeting was convened using a remote technology system and there was no physical location for this meeting.

Chair Annette Logan-Parker opened the meeting at 9:35 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Annette Logan-Parker (CHAIR); Gina Glass (Vice-Chair); Amber Federizo, DNP, APRN, FNPBC; Ihsan Azzam, MD, PhD; Jennifer Millet, DNP, RN; Valerie Porter, DNP, BSN, MBA; Kimberly Palma-Ortega; Veneta Lepera; Paul Niedermeyer; Craig Vincze, M.D.; and Sumit Gupta, MD (Quorum=9)

COUNCIL MEMBERS ABSENT:

Naja Bagner (excused absence); Nik Abdul Rashid, MD (excused absence); Susana Sorrentino, MD; and Christina Thielst

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

Ashlyn Torrez, *Health Program Specialist I, Office of State of Epidemiology (OSE)*; Elizabeth Kessler, *Health Program Specialist II, OSE*; and Kagan Griffin, *OSE Operations Manager, OSE*

OTHERS PRESENT:

Amber Williams, *Cure 4 Kids Foundation*; Brigette Cole, *NV Childhood Cancer Foundation*; Catherine M. Nielson, *Nevada Governor's Council on Developmental Disabilities*; Paige Barnes; Shirley Kim; and Jaden Federizo

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 Logan-Parker opened the floor for public comment.

Hearing none, Chair moved on to the next agenda item.

- 10) INFORMATIONAL: Update on Dr. Sumit Gupta's recommendation for appointment. – Chair Annette Logan-Parker

Chair Logan-Parker welcomed Dr. Dumit Gupta to the Council and expressed her appreciation of his time, and stated that she was looking forward to working with Dr. Gupta.

Councilmember Sumit Gupta thanked Chair Logan-Parker.

- 3) POSSIBLE ACTION: Approval of minutes from August 4, 2023, Rare Disease Advisory Council Meeting. – *Council Members*

Chair Logan-Parker introduced the agenda item to approve the meeting minutes from last Council meeting with an edit to adjust the absences of Councilmember Paul Niedermeyer and Councilmember Shirley Folkins-Roberts to excused absences as both Councilmembers informed of their absence prior to the meeting, and asked the Council for a motion.

Dr. Azzam motioned to approve the meeting minutes from the August 4, 2023, RDAC meeting with the edit to Mr. Niedermeyer and Ms. Folkins-Roberts to add excuse absence. Ms. Jennifer Millet seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

- 4) INFORMATIONAL: Review and discussion of the Rare Disease Advisory Council's bylaws in regard to council member terms. – Ashlyn Torrez, *Health Program Specialist I, Office of State Epidemiology (OSE), DPBH*

Chair Logan-Parker introduced the agenda item to discuss the RDAC's bylaws in regard to the Council Members terms.

Ms. Torrez reviewed [NRS 439.5075](#), [NRS 439.5077](#), and [RDAC's bylaws](#) with the Council in regard to Council Member terms of three years as set forth in the bylaws. Ms. Torrez added that re-appointment will happen in the same manner as initial appointment. Ms. Torrez stated members will fill out an online application and send CV/Resume to Ms. Torrez that will be vetted through the Director's Office for final approval.

Ms. Valorie Porter asked for council members whose terms have expired to resubmit their paperwork that was filled out the first time council members were appointed.

Ms. Torrez confirmed that is what Council Members with expired terms are doing.

Chair Logan-Parker stated she will be review the RDAC bylaws and discuss term limits of the Council Members at a future Council meeting.

- 5) POSSIBLE ACTION: Confirmation of consideration to renew expired terms of RDAC members and the Chair. Recommendations will be submitted to the Administrator for consideration of submission to the Department of Health and Human Services (DHHS) Director for consideration of renewal of appointment. – *Council Members*

Chair Logan-Parker introduced this agenda item to renew the ten expired Council Members terms: Dr. Azzam, Amber Federizo, Georgina Glass, Kimberly Palma-Ortega, Chair Logan-Parker, Naja Bagner, Dr. Rashid, Valerie Porter, Veneta Lepera, and Jennifer Millet. Chair Logan-Parker asked the Council for a motion.

Ms. Millet stated that her CV was not in the meeting materials, and she will send her CV to Ms. Torrez again.

Ms. Gina Glass motioned to approve the renewal of the ten expired Council Member terms. Ms. Valorie Porter seconded the motion to approve. There were no objections. A quorum voted to approve the renewal of the Council Members expired terms.

- 6) POSSIBLE ACTION: Discussion and possible action regarding Shirley Folkins-Roberts's resignation from the Rare Disease Advisory Council as a "organization who provides services to patients with rare disease." Under Nevada Revised Statutes (NRS) 439.5075(1)(b)(1) and the appointment of Brigette Cole to fulfill the vacated position as a "organization who provides services to patients with rare disease." – *Council Members*

Chair Logan-Parker introduced the agenda of Shirley Folkins-Roberts who elected to not renew her term and made the recommendation to appoint Ms. Brigette Cole to fulfill the vacancy and asked the Council for a motion to approve.

Recording timestamp [33:56] Bridget Cole put in the chat:
"Thank you everyone. I look forward to working with you."

Dr. Craig Vincze motioned to approve the recommendation of appointment to the Director's Office of Ms. Cole to fulfill Ms. Folkins-Robert's vacancy. Ms. Valorie Porter seconded the motion to approve. There were no objections. A quorum voted to approve the recommendation of appointment to the Director's Office of Ms. Cole to fulfill Ms. Folkins-Robert's vacancy.

- 7) POSSIBLE ACTION: Discussion and possible action to recommend to the Director of Department of Health and Human Services (DHHS) to remove Dr. Susanna Sorrentino from the Council, pursuant to *Article 4, Membership: Section 5, Removal of a Member. Part 3 Unexcused absence from two consecutive meetings of the council. (4.5.3) of the bylaws.* – *Council Members*

Chair Logan-Parker introduced the agenda item to remove Dr. Susanna Sorrentino from the Council, and asked the Council for a motion.

Mr. Niedermeyer asked if someone tried to contact Dr. Sorrentino to see if there may be any extenuating circumstances for her absences.

Chair Logan-Parker stated that she has reached out, and Ms. Torrez has sent emails to her as well.

Ms. Porter asked what the number of physicians that are currently on the Council after Dr. Sorrentino's removal.

Chair Logan-Parker replied that one physician position will be left open with Dr. Sorrentino's removal from the Council. Chair Logan-Parker added that the Council is allowed to have three physicians on the Council, Dr. Gupta and Dr. Rashid fill two of the roles leaving one vacancy if the Council approves to remove Dr. Sorrentino.

Ms. Glass motioned to approve the removal of Dr. Sorrentino from the Council pursuant to Article 4, Section 5, Part 3 of the RDAC bylaws. Ms. Veneta Lepera seconded the motion to approve. There were no objections. A quorum voted to approve removal of Dr. Sorrentino from the Council pursuant to Article 4, Section 5, Part 3 of the RDAC bylaws.

- 9) INFORMATIONAL: Discussion regarding vacancies of the Rare Disease Advisory Council (RDAC) – *Chair Annette Logan Parker*

Chair Logan-Parker introduced this agenda item for informational purposes only and explained the Council will discuss how they would like to fill these vacancies at a future Council meeting. Chair Logan-Parker mentioned that Linetta Barnes term was also expired, she has moved out of state, and she has missed the last four consecutive meetings including the October 6th meeting. Chair Logan-Parker added that an email was sent out to Ms. Barnes thanking her for time and dedication and welcomed her to attend the RDAC meeting as a member of the public as a non-voting member moving forward. Chair Logan-Parker added that her position of parent or guardian who has experience caring for a child with a rare disease has created a vacancy. Chair Logan-Parker opened the floor for any Council Members who want to discuss Ms. Barnes or how to fill the current vacancies of the Council.

Hearing none, Chair moved on the next agenda item.

- 8) POSSIBLE ACTION: Discussion and possible action of the Annual Report that is due to Governor Lombardo and the Director of the Legislative Counsel Bureau in December 2023, pursuant to Nevada Revised Statutes (NRS) 439.5077(2)(b)(2). – *Council Members*

Chair Logan-Parker introduced the agenda item of Annual Report that is due to Governor Lombardo and the Director of the Legislative Counsel Bureau at the end of 2023. Chair Logan-Parker stated that she needs to add a list of the Council Members and Support Staff to the thank you page that will be after the title page. Chair Logan-Parker reviewed the meeting material titled NV Annual Report 2023. Chair Logan-Parker opened the floor to the Council Members for feedback.

Ms. Porter expressed her excitement on the Annual Report and stated that the Annual Report was well done.

Chair Logan-Parker added a recommendation that the Council be allowed to do at least one Bill Draft Request (BDR) for every Legislative session. Chair Logan-Parker asked the former Chair, Amber Federizo to share her experiences on after the Annual Report was submitted what the feedback was.

Ms. Federizo stated that there was not a lot of emphasis on support for RDAC having their own BDR, but rather to be a part of another organization's BDR. Ms. Federizo expressed her frustration that being a part of someone else's BDR is focused on the global healthcare aspect as opposed to rare disease.

Recording timestamp [47:47] Valorie Porter put into the chat:
"Agree 100%"

Chair Logan-Parker agreed with and thanked Ms. Federizo. Chair Logan-Parker felt that it would be appropriate to include the language of requesting the Council have their own BDR. Chair Logan-Parker asked Ms. Federizo to provide additional recommendations that should be considered for the Annual Report.

Ms. Federizo recommended to submit a financial fiscal budget according to the duties assigned to Council from [NRS 439.5077](#), and start small then work up to the larger objectives that way there is a plan of funding to obtain the objectives of the Council.

Chair Logan-Parker agreed with Ms. Federizo and added that the report should also reflect the Childhood Cancer License Plates Program at the Department of Motor Vehicles (DMV), even if the balance is small. Chair Logan-Parker commented that of the duties assigned to the Council, in order to make them obtainable would be to get an investment in the people, talent, and infrastructure. Chair Logan-Parker added that in the financial fiscal budget will include the in-kind costs that was done for the RDAC. Chair Logan-Parker asked Ms. Torrez what the process is for the Council to be able to request the balance of the license plates program at the DMV.

Ms. Torrez responded that she would need to reach out the Administrative Services Officer (ASO) in charge of that budget account for what the process would look like to get the balance of the funds and report back to the Council.

Chair Logan-Parker thanked Ms. Torrez, and added that the addition of the financial report will be a good stark contrast between what is actually being funded for the RDAC, and the cost of what is actually required to get the duties done assigned to the Council in [NRS 439.5077](#).

Ms. Federizo recommended that Council members who do run clinics submit a report of the outlay of the finances. Ms. Federizo felt that the Council is not able to address the duties assigned in NRS 439.5077 because many of the clinics in Nevada are privately carrying what the state needs to help pick up.

Chair Logan-Parker wondered how the Council could gather all of that information, and expressed interest in digging further into that topic.

Mr. Niedermeyer added that the source of funding that supports the State of Nevada for Medicaid Services and positively influences medical insurance providers to provide more and up-to-date rare disease testing and treatment during patient care should be influenced by this Council who does rare disease analysis and collects data.

Chair Logan-Parker expressed interest in digging into that further when RDAC goes through the data analysis piece. Chair Logan-Parker stated that the Annual Report does include specific pieces about data collection efforts in Nevada that are under-resourced themselves, making it difficult to provide the data that is needed. Chair Logan-Parker asked the Council to review the Annual Report document before the next RDAC meeting in December.

11) INFORMATIONAL: Council member information sharing announcements. – *Council Members*

Chair Logan-Parker opened the floor to the Council members for any announcements or comments.

Dr. Craig Vincze commented that he started a Foundation in honor of his son, who passed away from a rare cancer two weekends ago, and had a fundraising poker tournament that had an amazing turnout and raised \$23,000. Dr. Vincze expressed his passion for those involved with rare disease at the grassroots level all the way up to the international level. Dr. Vincze added that most of the money that was raised at the fundraiser will go to the Dana-Farber Cancer Institute, who has Harvard professors and pathologists that are doing this groundbreaking work. Dr. Vincze added that earlier the Council discussed reporting the incidents of rare disease and if the data is not being collected well at the state level, then it is possible for the Council to apply for federal funds. Dr. Vincze added that the Center for Disease Control and Prevention (CDC) database reports that Nevada does not have any rare disease incidents in the state thus, the state does not qualify for the funding. Dr. Vincze suggested the Annual Report make a recommendation that if the Council gets the funds and spends the money towards the state for better reporting, financially speaking there will be a big return. Dr. Vincze commented that the state does not get federal funding that the state could be getting, then that financial burden falls to the state and creates a bottleneck.

Chair Logan-Parker congratulated Dr. Vincze on his foundation and the turnout of the fundraiser, and agreed with Dr. Vincze comments on the Annual Report. Chair Logan-Parker commented that she also has some announcements that she was invited back to Washington D.C. for a second time to participate in the Cancer Moon Shot Childhood Cancer Forum. Chair Logan-Parker added that she was selected to be part of the financial toxicity conversation and was able to discuss the financial impact on families when facing catastrophic diagnosis and share the good work being done by the Nevada RDAC. Chair Logan-Parker added that she discussed the needs assessment that is being launched in 2024, and was able to discuss data collection challenges that Nevada is having. Chair Logan-Parker commented that there was an agreement amongst those who attended the Forum that there is a need for the federal government to come in and mandate a separate and specific childhood cancer and adolescent young adult comprehensive cancer plan that has different deliverables. Chair Logan-parker continued to say that she is planning to meet with Governor's Office of Economic Development about the data collection in the state of Nevada and her recommendations to improve data collection to utilize resources such as outsourcing to a university or different entity to start collecting data that will be accepted by the CDC. Chair Logan-Parker stated Nevada has been on the map for lacking in childhood cancer statistics for

many years, and the country is going backwards because Indiana now also does not have recognized data at the federal level. Chair Logan-Parker expressed that it is critically important for this Council to consistently push in every conversation with any lawmaker or can contribute to helping the state of Nevada collect the data that is required.

Mr. Neidermeyer commented that he would like to add to Dr. Vincze's comment made earlier that ties in with prior discussion the Council has made about Electronic Health Records (EHR), and what is happening with Epic incorporating Artificial Intelligence (AI) into their system. Mr. Neidermeyer added this is in trial phase and will start to roll out to specific sites to take diagnostic criteria and give differential diagnoses and potential testing among other things to providers for definitive care. Mr. Neidermeyer commented that if AI is going to be giving suggestions for testing that meets rare disease criteria or uphold a threshold for testing because the patient has symptomology that may support a rare disease diagnosis, then the provider needs to have an opportunity to order and document within the EHR such as Epic or other EHR systems. Mr. Neidermeyer added that the takeaway is the funding to get that test done because most hospitals and most insurance companies do not want to pay for a test that is going to be expensive, and if the insurance provider may cover it because the patient is uninsured. Mr. Neidermeyer continued that the way to get the funding for the testing is going to be a lever for recording and getting good analysis to then get data available from the EHR to make it easier for data collection and analysis on a periodic basis.

Ms. Federizo commented that she would like to add another recommendation to the Annual Report to address the lack of presence from Nevada Medicaid at the RDAC meetings, other Nevada representatives, and the Medicaid Insurance Council that should be here at these meetings.

Dr. Ishan Azzam commented that he wondered if any state in the nation is able to collect the real disease data, because there are successful modules on how to collect data. Dr. Azzam felt that the problem is with Nevada's Cancer Registry is that the data is incomplete. Dr. Azzam added that Nevada or the Council could survey other states who were successful in collecting their disease data, then Nevada does not have to re-invent the wheel and utilize the other states systems. Dr. Azzam continued that as Dr. Vincze mentioned about getting federally funded, if Nevada is able to start somewhere then the federal funds can become more accessible to enhance the system.

Chair Logan-Parker agreed with all the council members who spoke, and stated that she had some other updates. First, the Cure 4 Kids Foundation has elected to purchase an interface with the Nevada Central Cancer Registry because the Cure 4 Kids Foundation has worked with the Cancer Registry Program for so long to try and submit the Cure 4 Kids Foundation's data on childhood cancer but due to staffing, Cure 4 Kids Foundation was not able to submit their data. Thus, an interface from the Cure 4 Kids Foundation EHR is currently under development to be available in 2024, and eventually there is hopes to incorporate sickle cell in addition to childhood cancer. Chair Logan-Parker added that the interface will automatically extract every month and go into the Nevada Central Cancer Registry already in the format that the Cancer Registry program requires for submission. Chair Logan-Parker continued with her other update to the Council, that a grant submission was done on the federal level for sickle cell data collection infrastructure by Ms. Ashlyn Torrez. Chair Logan-Parker asked Ms. Torrez to elaborate on the sickle cell data collection grant.

Ms. Torrez commented that the state of Nevada was accepted to receive federal funding, but during the application process the state of Nevada did not score high enough compared to other states that applied to receive any funding due to the lack of funds, and the state of Nevada will be resubmitted if more funding becomes available.

Chair Logan-Parker asked for Ms. Torrez to clarify what it means to be accepted to receive funding, but not get any funding.

Ms. Elizabeth Kessler clarified that the Centers for Disease Control and Prevention can only fund so many jurisdictions and thus everyone who applies get a grade. Ms. Kessler added that if the organization or state scored high enough, the project will get approved but only the highest scoring applications get the funding. Ms. Kessler continued that as more funding becomes available within the next year rather than having that state or organization re-apply, the applications are kept and may be re-awarded at a later date, however, that is contingent on CDC getting more funding to roll out.

Chair Logan-Parker thanked both Ms. Torrez and Ms. Kessler for their update and clarification. Chair Logan-Parker stated that is progress for not being discounted completely. Chair Logan-Parker agreed with Dr. Azzam that the state of Nevada needs to figure out how to get those resources that can be used to collect our data. Chair Logan-Parker expression her appreciation to Dr. Azzam for his suggestion to look at what other states are doing. Chair Logan-Parker recalled that one of the objective of the RDAC strategic plan is to reach out to the other RDAC's in the nation, and learn from them to get an idea of how their states are collecting data, what instruments are being used, and what worked for them and what dd not work for those states.

Ms. Federizo commented that in the first year of RDAC being created, this Council met with the other RDACs under the National Organization for Rare Diseases (NORD) and had multiple meetings with them. Ms. Federizo added that the primary difference between the Nevada RDAC and other states' RDACs is that they have a robust program. For example, in Massachusetts and Pennsylvania their RDACs were created by House bills and had funding available from their establishment. Ms. Federizo stated that Nevada's RDAC was not funded when this Council was created. Ms. Federizo summarized other state's RDAC are funded and can pull data from the state insurance program from the ICD 10 codes, which is not available in the state of Nevada.

Chair Logan-Parker agreed with Ms. Federizo, and commented that SB 315 from the 80th Legislative Session gave lofty goals for a very specific type of talent, infrastructure, and technology that the state of Nevada does not have. Chair Logan-Parker added that this Council has brought up many times in the past that the Council feels they have been set up to fail. Chair Logan-Parker continued that in either the first or second Annual Report, the Council suggest dissolving the RDAC because it will not go anywhere but this Council will continue reappointing different people and members of the RDAC to keep this Council going. Chair Logan-Parker commented that the reality is that if it were not for the in-kind contributions from the Cure 4 Kids Foundation, none of the things that the Council did this year would have been done. Chair Logan-Parker asked Ms. Federizo to share the response from the Annual Report that was submitted from the recommendation to dissolve the Nevada RDAC.

Ms. Federizo stated it was the second Annual Report that was submitted, and Nevada Medicaid did come to respond but in her opinion, was quite dismissive and had multiple excuses, and still there is no invite to attend any of the meetings they host or to attend the RDAC meetings. Ms. Federizo expressed the difficulty it is to work in an environment where the RDAC cannot get the internal departments within the state of Nevada to take this RDAC seriously. Ms. Federizo stated that the creation of this RDAC was a public relations move, but this RDAC existed before the formality of the Council being created, as most of the council members have been working for years and years for the rare disease patients. Ms. Federizo expressed the challenges of this Council is that a lot of the Council members existence outside of the Council makes more of an impact because the Council members are not beholden to some of the rules set for this Council. Ms. Federizo expressed that this Council will be hopeful that things will change.

Chair Logan-Parker thanked Ms. Federizo for her insight, and stated that she had one more announcement to share with the Council. Chair Logan-Parker shared that she was nominated for an Emmy, a finalist at the National Rare Voice Award in the category State Advocacy for Patient Organizations. Chair Logan-Parker added that her recognitions are for the work as the Chair for Nevada RDAC and some of the efforts that is being made at Cure 4 Kids Foundation through the Every Life Foundation for rare diseases. Chair Logan-Parker commented that she will also be traveling to Washington, D.C. in December to have the opportunity to share the work that this Council is doing and the work being done at the Cure 4 Kids Foundation. Chair Logan-Parker shared her thoughts that a lot of what the Council has collectively done for many years to improve things in Nevada is being recognized at the national level. Chair Logan-Parker expressed her excitement to represent the Nevada RDAC and to get the opportunity to share the Nevada specific effort with many national rare disease organizations and supporters. Chair Logan-Parker stated that she will report back her experience.

Recording Timestamp [1:20:48] Valerie Porter put in the chat:

“Awesome good job! Maybe you could give a presentation after your trip i.e. what happened etc.”

Chair Logan-Parker acknowledged Ms. Porter’s comment in the chat that she would love to do a presentation after her trip to DC. Chair Logan-Parker asked if there was anyone else on the Council who would like to share their announcements or thoughts.

None heard, Chair Logan-Parker moved on to next agenda item.

12) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comment.

Hearing none, Chair moved on to the adjourn the meeting.

13) ADJOURNMENT – *Chair Annette Logan-Parker*

Chair Logan-Parker moved to adjourn and expressed appreciation for everyone on the Council.

Chair Logan-Parker moved to adjourn the meeting at 10:39 am.

DRAFT