

Joe Lombardo  
Governor

Richard Whitley,  
MS  
Director



Cody Phinney,  
MPH  
Administrator

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

## NEVADA RARE DISEASE ADVISORY COUNCIL

### DRAFT MEETING MINUTES

February 2, 2024

09:30 am – 10:29 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 09:34 am.

#### 1) INTRODUCTIONS AND ROLL CALL

##### **COUNCIL MEMBERS PRESENT:**

(14) Annette Logan-Parker (Chair); Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Kimberly Palma-Ortega; Paul Niedermeyer; Craig Vincze, PhD; Christina Thielst, LFACHE, MHA; Sumit Gupta, MD; and Brigette Cole; Gina Glass (Vice Chair); Amber Federizo, DNP, APRN, FNP-BC; Kimberly Anderson-Mackey; Naja Bagner (Quorum=8)

##### **COUNCIL MEMBERS ABSENT:**

Ihsan Azzam, MD, PhD; and Jennifer Millet, DNP, RN

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

Ashlyn Torrez, *Health Program Specialist I, Office of State of Epidemiology (OSE), DPBH*; Amy Kiehne, *Administrative Assistant III, OSE, DPBH*; Kagan Griffin, *Health Program Specialist II, OSE, DPBH*

##### **OTHERS PRESENT:**

Geordan Goebel, *Deputy Attorney General (DAG)*; Amber Williams, *Cure 4 Kids Foundation*; Lindsey Viscarra, *State Policy Manger, Western Region, NORD*; Blez & Case Gov; Ferrari Reeder; Sabrina Schnur

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 agenda next item.

- 3) INFORMATIONAL ITEM: Welcome the newest Rare Disease Advisory Council Member, Kim Anderson. She will be filling the role of the Chair of the State of Nevada Advisory Council on Palliative Care and Quality of Life created by Nevada Revised Statutes (NRS) 232.4855. – *Chair Annette Logan Parker*

Chair Logan-Parker welcomed Kim Anderson-Mackey to the Council. Chair Logan-Parker opened the floor to Ms. Anderson-Mackey to provide an introduction and share with the Council a little bit about the interest Ms. Anderson-Mackey has in regard to rare diseases and palliative and quality of life.

Council member Ms. Anderson-Mackey thanked Chair Logan-Parker. Ms. Anderson-Mackey began by stating her excitement to now hold a position with the RDAC Council. Ms. Anderson-Mackey mentioned she was born, raised, and spent most of her adult life here in Las Vegas since 2017. Ms. Anderson-Mackey has held the position as Vice Chair and as of September this year the Chair of the Palliative Care and Quality of Life Council. Ms. Anderson-Mackey is hoping to unite both Councils to strengthen and support the knowledge and experience each Council has, since both Councils are connected with rare disease areas of focus. Ms. Anderson-Mackey spent the majority of her career in the healthcare field. Ms. Anderson-Mackey's profession began with 15 years in Catheterization Laboratories and then ventured over nearly 20 years ago to End of Life Journey, with a company called Solari. Since then, while always staying patient focused, has focused on developing a strategic plan and implementing the materials throughout the city. Ms. Anderson-Mackey worked with Cash 4 Kids as well as with adults to see what would benefit care needs most for the legislative sessions two and a half years ago. Ms. Anderson-Mackey found the best way to help others would be to open her own agency. Therefore, Ms. Anderson-Mackey had partnered with a physician locally and opened her own agency which is clinically led to serve both adults and pediatrics. Ms. Anderson-Mackey is currently in Palliative Care and Hospice right now career-wise. Ms. Anderson-Mackey is married to a fireman and has a 23-year-old daughter and a 28-year-old son. Ms. Anderson-Mackey finds there is so much work she personally was involved in with friends, family, and the public to structure her experience. Ms. Anderson-Mackey stated the emotion one experiences when finding a child and a loved one who is experiencing a medical need, but unable to find the answers and solutions locally, is a difficult process. Ms. Anderson-Mackey feels excited about being involved in the process and to be of service. Ms. Anderson-Mackey thanked the Council for their time.

Chair Logan-Parker expressed her appreciation for her time and stated that she was looking forward to working with Ms. Anderson. Chair Logan-Parker stated RDAC looks forward to collaborating with Palliative and Quality of Life Council. Chair Logan-Parker opened the floor for the Council to comment on agenda item number 3. Hearing none, Chair Logan-Parker moved to agenda item number 4.

- 4) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from December 8, 2023. – *Council Members*

Chair Logan-Parker introduced the agenda item to approve the meeting minutes from last Council

Meeting held December 08, 2023, and asked the Council for a motion.

**Council member Gina Glass motioned to approve the meeting minutes from prior Council meeting dated December 08, 2023. Council member Valerie Porter seconded the motion to approve. There were no objections or edits. A quorum voted to approve the prior meeting minutes.**

- 5) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of the Nevada Department of Health and Human Services (DHHS) to re-appoint Gina Glass as a member of the Council, pursuant to NRS 439.5075(2), for a term of 3 years. – *Council Members*

Chair Logan-Parker introduced this agenda item to renew the expired Council Member term: Gina Glass. Chair Logan-Parker asked the Council for a motion.

**Councilmember Valerie Porter motioned to approve Gina Glass to be recommended to the Director of DHHS to be re-appointed for another three-year term. Councilmember Craig Vincze seconded the motion to approve. There were no objections. Council Member Gina Glass abstained from this vote. A quorum voted to approve Gina Glass to be recommended to the Director of DHHS to be re-appointed to the Council for another three-year term.**

- 6) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of the Nevada Department of Health and Human Services (DHHS) to re-appoint Jennifer Millet as a member of the Council, pursuant to NRS 439.5075(2), for a term of 3 years. – *Council Members*

Chair Logan-Parker introduced this agenda item to renew the expired Council Member term: Jennifer Millet. Chair Logan-Parker asked the Council for a motion.

**Councilmember Chrstina Thielst motioned to approve Jennifer Millet to be recommended to the Director of DHHS to be re-appointed for another three-year term. Councilmember Valerie Porter seconded the motion to approve. There were no objections. A quorum voted to approve Jennifer Millet to be recommended to the Director of DHHS to be re-appointed for another three-year term.**

- 7) INFORMATIONAL ITEM: Tribute and a public thank you to Dr. Nik Abdul Rashid for her service with the Rare Disease Advisory Council, and her work providing care to patients suffering from sickle cell disease, cancer, and hemophilia. – *Chair Annette Logan Parker*

Chair Logan-Parker introduced the agenda item to pay tribute to Dr. Nik Abdul Rashid. Chair Logan-Parker announced Dr. Abdul Rashid has passed away in January 2024 after an extended battle with cancer. Chair Logan-Parker illustrated and expressed her appreciation for Dr. Nik Abdul Rashid. Chair Logan-Parker mentioned Dr. Nik Abdul Rashid was with the RDAC Council as a Council Member since the beginning creation of RDAC. Chair Logan-Parker declared Dr. Nik Abdul Rashid had a long career in Las Vegas as a pediatric hematologist oncologist. Chair Logan-Parker went on to say Dr. Nik Abdul Rashid was extremely dedicated to the patients who were seen, and this is a huge loss to our community as well as to the Council. Chair Logan-Parker wanted to take a minute to honor Dr. Nik Abdul Rashid for the contributions to RDAC and commitment particularly to the sickle cell community. Chair Logan-Parker opened the floor for anyone who would like to say something on behalf of Dr. Nik Abdul Rashid.

Council member Kimberly Palma-Ortega thanked Chair Logan-Parker and stated her highest remorse for the passing of Dr. Nik Abdul Rashid. Ms. Palma-Ortega mentioned she is grateful for the relationship which began 16 years ago. Ms. Palma-Ortega stated Dr. Nik Abdul Rashid was the oncologist who provided care for her son Jonathan Palma-Ortega over the years. Ms. Palma-Ortega mentioned social media illustrated Dr. Nik Abdul Rashid's dedication to all patients, remained the same across the board, no matter who Dr. Nik Abdul Rashid worked with. Ms. Palma-Ortega stated Jonathan was only one out of 500 in the world who Dr. Nik Abdul Rashid impacted and cared for. Ms. Palma-Ortega increased her knowledge base as well as Jonathan's situation and condition was improved due to the relationship with Dr. Nik Abdul Rashid. Ms. Palma-Ortega illustrated and expressed her appreciation for Dr. Nik Abdul Rashid as a colleague, resource, and friend. Ms. Palma-Ortega thanked Chair Logan-Parker for taking the time to acknowledge Dr. Nik Abdul Rashid not only for her work in the community but also for this Council.

Gina Glass stated her appreciation for Dr. Nik Abdul Rashid. Ms. Glass stated Dr. Nik Abdul Rashid provided care as her daughter's hematologist since Ms. Glass relocated to Las Vegas from California. Ms. Glass recollected 7 years when Dr. Nik Abdul Rashid was a real champion and supporter of the sickle cell community. Ms. Glass recalls the many changes, one being the sickle cell bill that is in effect at this time. Ms. Glass mentioned the sickle cell bill would not have been as good as it is or even in effect if it weren't for Dr. Nik Abdul Rashid's work on it. Ms. Glass finds that the sickle cell community, along with clinical, being a real advocate for this small, underserved community. Ms. Glass listed not just in Nevada, but throughout the United States, a person could find Dr. Nik Abdul Rashid at many different conferences and public events which have to do with sickle cell. Ms. Glass recalls a few vacations Dr. Nik Abdul Rashid personally took to center her time around sickle cell conferences. Ms. Glass felt Dr. Nik Abdul Rashid was a champion as a healthcare provider and a personal friend. Ms. Glass stated Dr. Nik Abdul Rashid would text to identify personal care needs and follow up with the best intentions. Ms. Glass stated she loves Cure 4 Kids, but left going to that practice, because her daughter, who was a patient of Dr. Nik Abdul Rashid, told Ms. Glass she had to be wherever Dr. Nik Abdul Rashid was. Ms. Glass appreciates and bears witness that an impact is left by the work conducted by Dr. Nik Abdul Rashid. Ms. Glass finds the passing of Dr. Nik Abdul Rashid to be of great loss to the sickle cell community, cancer community and hemophilia community.

Chair Logan-Parker mentions she knew Dr. Nik Abdul Rashid for 20 years. Chair Logan-Parker verifies Dr. Nik Abdul Rashid was a dear friend and colleague and will be greatly missed. Chair Logan-Parker thanked the Council for the opportunity to pause, honor and thank Dr. Nik Abdul Rashid for the contributions made publicly. Chair Logan-Parker opened the floor comment. Hearing none, Chair Logan moved the next agenda item.

- 8) INFORMATIONAL ITEM: Presentation on the work that the National Organization for Rare Disorders (NORD) is doing with other Rare Disease Advisory Council's across the country. – *Lindsey Viscarra, State Policy Manager, NORD*

Chair Logan-Parker introduced the agenda item to present guest speaker, Lindsey Viscarra who has held a career with NORD. Chair Logan-Parker expressed her gratification when corresponding previously with Ms. Viscarra to have attendance for today's Council meeting. Chair Logan-Parker looks forward to

connecting with Ms. Viscarra to bridge NORD and RDAC together. Chair Logan-Parker lets Ms. Viscarra hold the floor.

Lindsey Viscarra began thanking Chair Logan-Parker. Ms. Viscarra produced a PowerPoint presentation of the compiled information she wished to share. Ms. Viscarra first slide was an introduction slide. Ms. Viscarra declared her name and occupation credentials as the State of Nevada, Policy Manager for the Western Region for NORD. Ms. Viscarra has held this position for six months and voices interest in seeing several of the Council members again. Ms. Viscarra spoke about the work conducted with the RDACs across the country. Ms. Viscarra stated Chair Logan-Parker previously requested any and all information known regarding newborn screenings. Ms. Viscarra stated NORD has a Policy Analyst, Allison, who is an expert on the newborn screening processes. Ms. Viscarra worked with the Policy Analyst and gathered information to present for this Council meeting. Ms. Viscarra stated the information is broad with a high-level overview of newborn screening. Ms. Viscarra welcomes questions, but mentions when the questions arrive, Ms. Viscarra will direct questions to Allison the Policy Analyst as this individual at the agency knows more than Ms. Viscarra regarding the processes. Ms. Viscarra has a background in health policies at several different nonprofit organizations. Ms. Viscarra stated involvement in working with the Assembly Speakers Office in the California State Assembly. Ms. Viscarra has three children and two of which have rare diseases. On the next slide of the presentation, Ms. Viscarra read NORD's mission statement. Ms. Viscarra mentioned the last policy piece of the mission statement outlines her role with the Western Region for 26 States. Ms. Viscarra went on to detail the primary coverage of work on RDAC consists of policy for step therapy, newborn screening, medical nutrition, state related insurance, Medicaid and all kinds of other issues that are important to the rare disease community. Ms. Viscarra stated the next slide details the 40-year history of NORD. Ms. Viscarra stated NORD just celebrated its 40<sup>th</sup> year anniversary last year in 2023 since the company was formed in 1983 after the passage of the Orphan Drug Act. Ms. Viscarra continued, NORD is the only independent and nonpartisan United States Organization working with rare diseases in the intersection of care, research, policy, and community. Ms. Viscarra stated NORD works with the national and local decision makers. Ms. Viscarra mentioned NORD's priorities are new and better therapies, access, and affordability. Ms. Viscarra ascertained the comprehensive health insurance telehealth services, help to strengthen policies to support timely diagnosis, including newborn screening. On the next slide, Ms. Viscarra spoke to declare RDAC is an advisory body that gives a platform for the rare community to have a stronger voice in state government. Ms. Viscarra stated RDACs address the needs of rare disease patients and families by giving stakeholders an opportunity to make recommendations to state leaders. Ms. Viscarra mentioned the RDACs look different in every state and some of them are very small, some are very large. The largest Ms. Viscarra could recall was an RDAC that held 29 Council members, each member having different duties. Ms. Viscarra concluded this PowerPoint side, that each RDAC has a different makeup, but their goal is all the same. Ms. Viscarra stated the goal all RDACs have are to get established, provide resources and support to the community. Therefore, Ms. Viscarra stated her position is to assist with State of Nevada's RDAC to help wherever necessary. On the next slide of the presentation, Ms. Viscarra read NORD's Project RDAC goal is to optimize the RDACs that are already in place, and to create more RDACs across the county. Ms. Viscarra stated there are 27 RDACs across the county at this time. Ms. Viscarra expressed her excitement about currently having 5 bills this year in the western half of the county. Ms. Viscarra has a toolkit that can assist with resources for the RDACs which are already in place. Ms. Viscarra stated her delight at seeing Council members again, Ms. Glass and Ms. Bagner, whom she already met October 2023. Ms. Viscarra stated NORD is working on some

resources and a plan for creating a method for all of the RDACs across the country to have an opportunity to communicate with one another. Ms. Viscarra moves the presentation forward to the next slide, which lists a map for the current states who currently have a governing agency, department, university, or department health which maintains an RDAC. Ms. Viscarra outlines her the current bills being worked on by herself for Washington, Iowa, and Oklahoma. Ms. Viscarra mentioned she is still waiting for bills to come in for California and Arizona. Ms. Viscarra stated the Eastern half of the country is being worked on by her colleague, Carolyn. Ms. Viscarra recalls Carolyn is working on bills for Vermont and Michigan. Ms. Viscarra hopes to add more states to the map this year. Ms. Viscarra detailed an event that was held by NORD in October 2023, called the Breakthrough Summit, where 17 of the 27 RDACs came together. Ms. Viscarra continued by stating her excitement for the event along with how well the RDACs got along and enjoyed learning from each other. Ms. Viscarra recalls moments when the crowd needed to be reminded to stay on task, keep to the schedule for the event and avoid side conversations. Ms. Viscarra mentioned a plan is in place for the next time RDACs are due to meet at an event NORD puts on, where there will be extended time to allow for the networking, side conversations or spontaneous changes in schedule to occur. Ms. Viscarra found one of the unpredictable moments which occurred at the conference was Pennsylvania had a presentation about their survey and funding avenues. Ms. Viscarra recalled Open Meeting Law being a topic of discussion which challenged the group along with long conversations regarding surveys, stakeholder engagement, and panels. Ms. Viscarra remembers Ms. Glass was on one of the panels where good feedback was received for next year's preparations. Ms. Viscarra referred back to the newborn screening in relation to the state report card, which came out Wednesday January 31, 2024. Ms. Viscarra mentioned the state report card is brand new for this year as one is released each year. Ms. Viscarra stated there is the latest edition state report card listed on the [NORD website](#). Ms. Viscarra listed the 9 categories listed on the state report card; Medicaid financial eligibility, medical nutrition, newborn screening, state Medicaid program, state regulated insurance, RDACs, step therapy, telehealth, and prescription drug costs. Ms. Viscarra went on to detail the policy staff will take all of the 9 categories, policy areas and then evaluate every state based on the laws in those states. Ms. Viscarra moves to the next slide of the presentation. Ms. Viscarra discusses the State of Nevada's report card, stating Nevada is doing pretty well and meeting all of the categories. Ms. Viscarra shows the Council how to read about the grading methodologies for each of the categories and specific policies that is happening in Nevada. Ms. Viscarra directs the Council to see the overview for the main state report card. Ms. Viscarra describes the overview currently links each of the descriptions for specific categories with reference to the grading methodologies. Ms. Viscarra continued to the next slide. Ms. Viscarra stated that as far as newborn screenings go, NORD supports robust, well-funded newborn screening programs in every state. Ms. Viscarra stated that newborn screening traces its origins to the 1960s, when Dr. Guthrie developed a blood test to screen for the disease phenylketonuria (PKU). Ms. Viscarra mentioned, since the 1960s, programs have been established in every state and territory throughout the United States. Ms. Viscarra stated that currently, about four million babies are screened annually for at least 31 serious disorders that can be detected at birth. Ms. Viscarra detailed of those four million newborns screened over 12,000 are found to have a disorder that, if left undiagnosed and untreated, would cause severe developmental disability or death. Ms. Viscarra continued to the next slide. Ms. Viscarra stated Nevada's newborn screening program and Nevada scores AB grade on the newborn screening state is graded. Ms. Viscarra mentioned NORD used to score a grade based off of five categories, but now the score is calculated based on 4 categories relating to newborn screenings. Ms. Viscarra went on to state that the grades are then averaged for an overall grade and Nevada screens for 58 conditions, which is great. Ms. Viscarra stated Nevada also tests 32 of the 37 conditions on the

recommended uniform screening panel, or Rust, the newborn screening program in Nevada, is supported entirely with fees generated by birth registration and states with a grade screen. Ms. Viscarra added the way you earn an A grade is to screen for all the rest of the conditions or more conditions which have not been added previously. Ms. Viscarra stated to add the rest of the conditions, after approval is granted, with an effective and efficient development, the process must include funding streams. Ms. Viscarra stated funding streams are controlled, for the newborn screening program, to have an effective newborn screening advisory committee. Ms. Viscarra concluded by saying the last slide of the presentation holds M. Viscarra contact information. Ms. Viscarra would be happy to dive into any questions or policy area where the Council may find interest in or if an area requires further clarification.

Chair Logan-Parker inquired on the date for the next in person Breakthrough Summit meeting.

Ms. Viscarra stated the next Breakthrough Summit meeting will be held in October 2024. Ms. Viscarra mentioned she was hired after the NORD team planned the October 2023 Breakthrough Summit meeting. However, Ms. Viscarra did mention the NORD team notified Ms. Viscarra the invitations were sent out listing the information for the Breakthrough Summit meeting months ahead of time. Ms. Viscarra predicts the same for 2024.

Chair Logan-Parker showed appreciation and thanked Ms. Viscarra for her presentation. Chair Logan-Parker volunteered for the State of Nevada RDAC Council to be of assistance to participate or provide information to any of the western states who Ms. Viscarra may find in the developmental stages of getting their RDACs started.

Ms. Viscarra thanked Chair Logan-Parker for her assistance, feedback, participation, and time to present at this Council meeting.

Chair Logan-Parker opened the floor for any further discussion, questions, or comments. Hearing none, Chair Logan-Parker moved to the next agenda item.

- 9) INFORMATIONAL ITEM: Report on Rare Disease Advisory Council (RDAC) Subcommittee on the Strategic Plan from the January 5, 2024, RDAC Subcommittee Meeting. – *Chair Annette Logan Parker*

Chair Logan-Parker introduced the agenda item to discuss and report on the Subcommittee activities conducted by the RDAC Subcommittee Council. Chair Logan-Parker added a short overview, the first RDAC Subcommittee Council meeting was held on January 05, 2024. Chair Logan-Parker stated the meeting minutes will be posted on the Department of Health and Human Services (DHHS) RDAC website after they get approved during the March RDAC Subcommittee Council meeting. Chair Logan-Parker detailed during the RDAC Subcommittee Council meeting, the objectives reviewed were the Strategic Plan, While You Wait Campaign, While You Wait Campaign and supply materials. Chair Logan-Parker also mentioned at the RDAC Subcommittee Council meeting Cure 4 Kids is picking up the cost for all the printing related to this project at this time and Cure 4 Kids is happy to do that as a contribution for the RDAC. Chair Logan-Parker stated during this RDAC Main Council meeting that the materials have since been printed and are getting ready to distribute the materials in the community. Chair Logan-Parker will be preparing materials to be sent to the Council members who volunteered to distribute accordingly. Chair Logan-Parker expressed compassion and appreciation to the volunteers as

Chair Logan-Parker understands the time to distribute While You Wait Campaign materials such as the needs assessment, posters, and brochures into the communities will take time and hard work. Chair Logan-Parker wants to reach back out to the 27 RDACs who were previously surveyed, to find out their progress since the last survey period. In doing this, Chair Logan-Parker hopes to determine what is working, what is not working, and see what the State of Nevada RDAC Council can learn from the national network of RDACs. Chair Logan-Parker mentioned this process has not yet begun. Chair Logan-Parker hopes to have this process completed by the RDAC Main Council meeting set to take place in April 2024. Chair Logan-Parker stated the big initiative for the RDAC Subcommittee Council is for the While You Wait Campaign materials to be distributed and available to the public.

Chair Logan-Parker opened the floor for RDAC Subcommittee Council members to speak. Hearing none, Chair Logan-Parker opened the floor for any questions that the Council might have for members of the Subcommittee. Hearing none, Chair Logan-Parker moved to the next agenda item.

10) INFORMATIONAL ITEM: Discussion on media opportunities for Rare Disease Day on February 29, 2024. – *Chair Annette Logan Parker*

Chair Logan-Parker introduced the agenda item to discuss the wide impact RDAC will experience when coordinating media opportunities. Chair Logan-Parker stated RDAC will have media opportunities for Rare Disease Day and throughout the month of February 2024. Chair Logan-Parker created a guest column for the Las Vegas press, about the RDAC While You Wait Campaign, needs assessment and how RDAC plans to roll out the supporting materials for the community to access. Chair Logan-Parker hopes to have the detailed column submitted and posted for public viewing. Once posted, Chair Logan-Parker prefers for Council members to network and distribute the listing across social media and publicize to workplaces regarding RDACs initiatives and intentions. Chair Logan-Parker stated RDAC has some broadcasting opportunities for Rare Disease Day which are not completely confirmed at this time. Chair Logan-Parker hopes to gain broadcasting coverage.

Chair Logan-Parker opened the floor for comment, announcements, or support requests regarding Rare Disease Day.

Christina Thielst spoke requesting a copy of the article that Chair Logan-Parker wrote. Ms. Thielst desires to place the column into a newsletter for the American College of Healthcare Executives.

Chair Logan-Parker agreed and stated that will be sent to Ms. Thielst via email. Chair Logan-Parker asked the Council for comment.

Hearing none, Chair Logan-Parker moved to the next agenda item.

11) INFORMATIONAL ITEM: Update and discussion of the 2023 Annual Report that was 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). – *Chair Annette Logan Parker*

Chair Logan-Parker introduced the agenda item to update the Council and discuss the implication of presenting the Annual Report to Governor Lombardo along with the Director of the Legislative Counsel



Bureau in December 2023. Chair Logan-Parker stated the Annual Report is listed on the RDAC website available for the public. Chair Logan-Parker personally emailed the Annual Report out to over 100 stakeholders. Chair Logan-Parker received a nice message from Dr. Nicola Longo, a geneticist who cares for patients with rare diseases in Southern Nevada. Chair Logan-Parker stated Dr. Longo complimented the Council on the Annual Report; stating the document is very well written and thorough and Dr. Longo was pleased to learn of the Council's progress. Chair Logan-Parker discovered several of the Nevada lawmakers responded to receiving the Annual Report. Chair Logan-Parker detailed gratitude was expressed to State of Nevada RDAC for the robust report, goals outlined and progress. Chair Logan-Parker found these responses encouraging.

Chair Logan-Parker asked the Council for comment.

Hearing none, Chair Logan-Parker moved to the next agenda item.

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

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

Bridget Cole with Northern Nevada Children's Cancer Foundation is traveling to Washington DC on February 13<sup>th</sup> and 14<sup>th</sup> for Childhood Cancer Action days. Ms. Cole expressed her excitement about the scheduled trip. Ms. Cole will be representing Nevada with Tyler Robinson Foundation while in attendance at this event. Ms. Cole intends to ask Nevada Congress members and legislators on appropriations for National Institutes of Health and National Cancer Institute, as well as the [Star Act](#). Ms. Cole stated her hopes of accelerating [kids access to Care Act](#), which is for Medicaid Services and needs to allow to crossover state lines. Ms. Cole has hopes of also supporting [Pediatric Cancer Drug Supply Act](#) that includes some of the rare disease pediatric drug shortage issues that have come across Nevada. Ms. Cole asked if anyone from the Council would be in attendance this year.

Chair Logan-Parker thanked Ms. Cole for her attendance in Washington DC. Chair Logan-Parker stated Cure 4 Kids will not be in attendance this year. However, Chair Logan-Parker is finalizing the Cure 4 Kids data to get over to Ms. Cole and plans on completing this process by close of business Friday, February 02, 2024, or by Monday, February 05, 2024. Chair Logan-Parker states her disappointment for not attending the Northern Nevada Children's Cancer Foundation event. Chair Logan-Parker showed appreciation towards Ms. Cole for representing Nevada at the federal level. Chair Logan-Parker requests Ms. Cole to follow up and let the Council know of any interesting details Ms. Cole finds while in attendance at the Northern Nevada Children's Cancer Foundation event. Chair Logan-Parker mentions the Council would benefit from information Ms. Cole might present at the next Council meeting regarding the trip.

Chair Logan-Parker asked the Council for comment.

Christina Thielst stated she has the presentation that she wanted to share from the last Council meeting December 08, 2024. Ms. Thielst began the Patient Involvement in Drug Utilization Boards PowerPoint presentation by stating Ms. Thielst's position is a Rare Disease Legislative Advocate. Last October, Ms. Thielst attended an event for Everylife Foundation known as the Rare Disease Legislative Advocates,

Quarterly State Advocacy Webinar. At this event, a presentation was displayed. Ms. Thielst began to wonder if some of the issues were cause of concern for Nevada. Therefore, Ms. Thielst brought the PowerPoint presentation to RDAC. Ms. Thielst intends to go through a few slides of the presentation which are important topics. Ms. Thielst stated slide one is regarding drug utilization. Ms. Thielst continued, each of the states who have an approved board of pharmacists and physicians, decide which drugs are going on to the formulary for the state. Ms. Thielst moved to the next slide and found the graph depicting direct medical cost of rare diseases. Ms. Thielst pointed out the highlighted portion of the slide which is highlighted. Ms. Thielst confirmed, the highlighted portion states prescription medication and next to it is shown the cost. Ms. Thielst stated her personal situation medial care costs are extremely expensive, so witnessing the presentation illustrating doctor boards have the ability to restrict coverage to block patient access to certain drugs are a cause for concern. Ms. Thielst continued, rare patients already face significant barriers, and the cost is another one. Ms. Thielst finds being an advocate and witnessing what is going on with Drug Utilization Review (DUR) boards. Ms. Thielst stands before the boards to help the DUR Boards across the country, understand the unique challenges patients faced by rare disease patients. Ms. Thielst attests that developing drug formularies that account for the needs for rare disease communities is essential. Ms. Thielst has personal experience, in the healthcare field, in hospitals. Ms. Thielst finds low utilization is the key term for most drug types that wind up on the formulary lists since they are rarely used. Ms. Thielst understands rare disease medications are being counted, but some may be missed. Ms. Thielst would like to ask the Council if they would consider which rare disease medications are not on the formulary list but should be. Ms. Thielst asks the Council if the state of Nevada does not have the medications on the formulary list, should we address the DUR Board and let them know which ones to place on the list. Ms. Thielst points out the State of Nevada has a DUR Board wish list. Ms. Thielst illustrates that the wish list presentation slide defines the policy guidelines for requesting changes or updates. Ms. Thielst mentions prior notice is given to notify the public of an upcoming meeting via public notice, 30 days in advance. Ms. Thielst stated an agenda is drafted to outline an area for public comment where the public may speak up and make recommendations. Ms. Thielst continues, a person who would like to speak during public comment, has an opportunity to sign up prior, by giving 14 days' notice. Ms. Thielst finds it's a good policy to manage the meeting timeframe since there are many physicians or community members who may wish to address the Council. Ms. Thielst excitedly adds a remote option is available for non-local individuals who wish to attend the DUR Board meeting. Ms. Thielst mentions it is good to stay connected virtually since communication is important along with collaboration with other boards and state program. Ms. Thielst promotes working to find the rare disease medication drugs which RDAC can take to a DUR Board meeting to assist in the process. Ms. Thielst moves to the next slide. Ms. Thielst found a could more concerns, one being the access working group transparency timelines. Ms. Thielst points out the slide is informational; the slide is a good example of areas for needed improvement to keep the public considering ways to improve the process. Ms. Thielst is curious about whether the Council finds the DUR Board to be a good resource. Ms. Thielst requests a discussion on whether RDAC should invite the DUR Board to share in the future at an RDAC meeting.

Chair Logan-Parker thanked Ms. Thielst for presenting. Chair Logan-Parker provided an update, stating Nevada does have a drug use review board which has 4 scheduled meetings in a year. Chair Logan-Parker stated one meeting has occurred already in 2024, on January 18, 2024. Chair Logan-Parker mentioned the next meetings are scheduled for April 18<sup>th</sup>, then July 18<sup>th</sup> and October 17<sup>th</sup>. Chair Logan-Parker pointed out this information was found on the [DUR Board website](#), which is under the Nevada

Department of Health and Human Services. Chair Logan-Parker previously attended a DUR Board meeting in the past, as Chair Logan-Parker desired to discuss a particular drug regarding gene therapy. Chair Logan-Parker states Cure 4 Kids finds issues with the drug utilization review that is found within the Department of Health and Human Services. Chair Logan-Parker acknowledges the transparency of the DUR Board, as the meeting schedule is posted well in advance. Chair Logan-Parker has determined that once a drug is listed on the drug formulary, the issue is found when the State of Nevada Medicaid, fee for service. Chair Logan-Parker stated rare disease patients most always fall under the category of fee for service because of their disability rating, rather than the managed care option (MCO). Chair Logan-Parker mentions the Department of Health and Human Services recently had launched a new physician administered drug fee schedule. Chair Logan-Parker states the fee schedule is very problematic for access because, with Chair Logan-Parker's experience, she can attest to the 55 drugs listed on the formulary are reimbursed under this physician administered drug fee schedule, meaning physician administered. Chair Logan-Parker commented on the State of Nevada for doing a good job of gathering items to add to the formulary. Chair Logan-Parker finds there is a huge access problem for the providers affording to buy the product to give to the patient. Chair Logan-Parker states the way the industry normally provides or administers the drugs, because of acquisition costs, prohibits the process. Chair Logan-Parker concludes, this all illustrates an access problem. Chair Logan-Parker states she will send the website to the Council regarding the drug utilization review process. Chair Logan-Parker finds through the presentation, Nevada is doing good as far as transparency. Chair Logan-Parker feels we can do better as an RDAC, when using social media as well as our own network. Chair Logan-Parker believes RDAC can publicize the public announcements which are put on the Department of Health and Human Services website. Chair Logan-Parker believes based on her personal experience, when working with providers, not everybody understands where to go to look for the meeting agendas, and how the schedule process is organized. Chair Logan-Parker mentions the meetings are typically held when physicians, particularly those who are not readily available, participate because they're in clinic seeing patients. Chair Logan-Parker asks the Council for suggestions on how to remedy the organization for public viewing, since that is something worth examining.

Ms. Thielst requests from Chair Logan-Parker any documentation stating the concerns Chair Logan-Parker just described. Ms. Thielst details her personal situation as her husband's retirement is a topic of interest. Ms. Thielst is working to renew insurance and trying to select a good plan. Ms. Thielst is mulling over the Medicaid or Medicare options. Ms. Thielst believes the process and limits are unclear. Ms. Thielst is excited to get additional information. Ms. Thielst feels excited and offers to help RDAC with any needs that may arise.

Chair Logan-Parker stated she will send out to the Council information regarding this as well. Chair Logan-Parker finds RDAC definitely can start including this in RDAC meetings. Chair Logan-Parker mentions she is happy to post the meeting schedule on RDAC website to bring some attention and emphasis to the concerns. Chair Logan-Parker found Ms. Thielst presentation and comments to be informative. Chair Logan-Parker thanked Ms. Thielst for her time and bringing questions to the Council. Chair Logan-Parker reiterates that RDAC will be including and reporting on these matters in the future.

Ashlyn Torrez requests Ms. Thielst to share the presentation with her so that the presentation can be posted to the Department of Public and Behavioral Health (DPBH) RDAC website for the February 02, 2024, meeting link.

Ms. Thielst agreed to send the presentation provided in the meeting to Ms. Torrez.

Chair Logan-Parker opened the floor for further comment.

Craig Vincze for the record, if you wanted to put it on the agenda meeting for the next Council meeting. Mr. Vincze would be happy to share a high-level summary of what was learned in Boston at the Target Cancer Foundation Think Tank event. Mr. Vincze feels the presentation would benefit Cure 4 the Kids. Mr. Vincze intends to help track and enable people with rare cancers to participate in clinical trials, closer to home, rather than having to go to these different national centers. Mr. Vincze would be happy to share with Ms. Cole any information on what the positions are doing to help from Max Vincze Foundation. Mr. Vincze will not be able to attend the Northern Nevada Children's Cancer Foundation event which Ms. Cole will be in attendance for. Mr. Vincze would like to provide any and all information necessary for Ms. Cole to take with her to Washington, DC.

Ms. Cole mentions email would be the best method of contact for this as Ms. Cole is planning to put together information to leave behind at the Northern Nevada Children's Cancer Foundation event. Ms. Cole notified the Council if anyone would like to add information to compile, Ms. Cole will accept it and compile it as a State.

Mr. Vincze mentions he will connect via email with Ms. Thielst. Mr. Vincze thanks Ms. Cole for her time.

Chair Logan-Parker expressed her excitement for the process and thanked Mr. Vincze and Ms. Cole for sharing. Chair Logan-Parker requested to have Mr. Vincze be placed on the agenda for April 2024, RDAC Main meeting. Chair Logan-Parker opened the floor for further comment. Hearing none, Chair Logan-Parker moved to the next agenda item.

### 13) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comment.

Hearing none, Chair moved on to adjourn the meeting.

### 14) 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 10:29 am.**