Joe Lombardo
Governor

Richard Whitley, MS
Director

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NEVADA DIVISION of PUBLIC and BEHAVIORAL HEALTH

Cody Phinney, MPH
Administrator

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Chief Medical Officer

NEVADA RARE DISEASE ADVISORY COUNCIL

DRAFT MEETING MINUTES

Date: 10/04/2024
9:34 AM – 10:46 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 9:34 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; Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Craig Vincze, PhD; Sumit Gupta, MD; Brigette Cole; Kim Anderson-Mackey; Melissa Bart-Plange; and Pamela White (Quorum=9)

COUNCIL MEMBERS ABSENT:
Jennifer Millet, DNP, RN; Naja Bagner (excused); Paul Niedermeyer (Approved leave of absence); Christina Thielst, LFACHE, MHA;

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:
Kagan Griffin, *Office of State Epidemiology (OSE), DPBH*

OTHERS PRESENT:
Elyse Monroy-Marsala, Luke Flanagan - Dept of Public Affairs (on phone), Amber Williams, Chelsea Bishop, Devraj Chavda, MD, Linda Anderson, Verena Samara, MD

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 Logan-Parker moved on to the next agenda item.

3) FOR POSSIBLE ACTION: Approval of minutes from September 6th, 2024, Rare Disease Advisory Council Meeting. – *Council Members*

Chair Logan-Parker introduced the agenda item to approve the meeting minutes from September 6, 2024. Chair Logan-Parker stated that the meeting minutes need to be adjusted to say that for Paul Niedermeyer he is on a leave of absence. Chair Logan-Parker asked the Council for any other edits to the meeting minutes.

Hearing no other edits from the Council, Chair Logan-Parker asked the Council for a motion.

Council member Gina Glass motioned to approve the meeting minutes from prior council meeting dated 9/6/2024. Council member Dr. Sumit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

4) INFORMATIONAL: Presentation on the new working group focused on childhood and Adolescent and Young Adult (AYA) cancer plan section for the Nevada Cancer Plan. – *Chelsea Bishop, Registered Nurse (RN), Nevada Cancer Coalition*

Chair Logan-Parker introduced guest presenter Chelsea Bishop, registered nurse, and Ms. Bishop, a board member of the Nevada Cancer Coalition. Chair Logan-Parker explained Ms. Bishop will talk about an important project that the Nevada Cancer Coalition is working on. Chair Logan-Parker opened the floor to Ms. Bishop.

Ms. Kagan Griffin shared the ‘Nevada Cancer Coalition’ Presentation with the Council.

Ms. Bishop introduced herself to the Council and thanked the Council. Ms. Bishop stated the main reason she is on the Nevada Cancer Coalition (NCC) is having a late daughter with Neuroblastoma. Ms. Bishop worked as a nurse before her daughter was diagnosed, and these days Ms. Bishop does advocacy with a non-profit organization, Act for Kids Nevada. Ms. Bishop said that when her daughter was diagnosed six and half years ago, Ms. Bishop was frustrated that the Centers for Disease Control and Prevention (CDC) map for childhood cancer had Nevada’s information greyed out, meaning there was no data for the state of Nevada. Ms. Bishop expressed her excitement to share the work of NCC, and NCC’s efforts to start a work group for childhood cancer and adolescent and young adult section for the next five years. Ms. Bishop added that currently in Nevada there are 60 open research trials for kids, including some at Renown. Ms. Bishop stated that childhood cancer is the leading cause of death among children, and the new cancer plan under development will show the needs of childhood cancer survivors and their families, as childhood cancer survivors require lifelong surveillance. Ms. Bishop expressed the importance of having a section just for childhood and adolescent young adult cancer, and this section should be a standard in Nevada. Ms. Bishop added that in the coming months, by February 2025, NCC will have a summary of the childhood adolescent young adult cancer section, and a finalized version will be presented at the 2025 Cancer Control Summit in late summer 2025. Ms. Bishop thanked the Council for their time and asked for questions.

Chair Logan-Parker thanked Ms. Bishop for her presentation and expressed her gratitude to Ms. Bishop for working on the section for childhood cancer. Chair Logan-Parker commented that childhood cancer and adult cancer are measured differently measurable. Chair Logan-Parker asked Ms. Bishop for her thoughts on how Nevada's Cancer Plan will differ from traditional comprehensive Cancer Control Plans that are seen in other states.

Ms. Bishop replied that there has been some overlap with adult and childhood cancer like the data collection and sharing. Ms. Bishop added that the comprehensive care plans and financial assistance also have overlaps. Ms. Bishop stated that adult cancer is about the prevention of getting cancer, like using sunscreen to avoid skin cancer, and so on. Ms. Bishop stated that a lot of things that affect children with cancers are not necessarily needing prevention measures but measuring what the children with cancer are getting access to for long term care, or any type of care that the children may need. Ms. Bishop believed that mental health support for children and adults would be different, as the treatment methods for children with mental health needs are play therapy, art therapy, and groups of children getting together. Ms. Bishop added that for adults, mental health therapies are more pharmaceutical based.

Chair Logan-Parker thanked Ms. Bishop, and stated how important data collection and sharing initiatives are to the Council. Chair Logan-Parker expressed her excitement with the progress being made with data collection efforts in Nevada. Chair Logan-Parker asked Ms. Bishop to let the Council know if Ms. Bishop if they need any support.

Ms. Bishop thanked Chair Logan-Parker and agreed that there has been a lot of strides with data collection efforts in Nevada and the quality of data. Ms. Bishop was hopeful that Nevada Central Cancer Registry will continue the momentum.

Chair Logan-Parker agreed with Ms. Bishop that there has been huge progress with data collection efforts. Chair Logan-Parker expressed her frustration a few years back seeing Nevada colored differently on the map for childhood cancer. Chair Logan-Parker continued that the Cure 4 The Kids Foundation, the Rare Disease Advisory Council, and the Nevada Central Cancer Registry has made tremendous progress by Nevada Central Cancer Registry going back to 2019 have cleaned up the data and submitted 2022 data to the (CDC). Chair Logan-Parker showed her gratitude towards Nevada Central Cancer Registry and the Department of Health and Human Services (DHHS) for hearing the Councils' concerns and Foundations that treat childhood cancer patients. Chair Logan-Parker added that Nevada Cancer Registry and Cure 4 The Kids Foundation are interfacing with the with the electronic health records to help Nevada Cancer Registry with data collection and submission of quality data to the CDC. Chair Logan-Parker added that the Cure 4 The Kids Foundation hired a cancer registrar to work with Nevada Central Cancer Registry and Cure 4 The Kids Foundation colleagues at Renown for childhood cancer. Chair Logan-Parker was hopeful that the trickle effect will happen with the data dating back to 2019 at the federal level soon but will take some time. Chair Logan-Parker added that she will share any language with Ms. Bishop and NCC to share with the community.

Ms. Bishop thanked Chair Logan-Parker.

Chair Logan-Parker asked the Council for any questions or comments.

Council Member Christina Thielst put into the chat at 9:53 AM: "I think breaking out children/adolescents in the plan, as appropriate, is important, especially for data. Specific data will contribute to assessing needs/gaps and aid in planning. It is common in healthcare management that this populations needs are assessed."

Council Member Brigette Cole put into the chat at 9:55 AM: "We are excited to participate in the Cancer Control Plan and advocate for pediatric cancer patients and their families in Nevada."

Council Member Gina Glass put into the chat at 10:03 AM: "Pam is trying to reconnect she got disconnected."

Chair Logan-Parker thanked Ms. Bishop and opened the floor for public comment. Hearing none, Chair Logan-Parker moved on the next agenda item.

5) FOR POSSIBLE ACTION: Discussion and possible action for the Council to submit a letter of support of Bill Draft Request (BDR) 124 for the 83rd Legislative Session (2025) sponsored by Senator Pazina which will establish a Pediatric Stem Cell and Bone Marrow Transplant Program in Nevada and allow the letter of support be submitted to the Nevada State Assembly – Health and Human Services and the Nevada Senate Health and Human Services. – *Council Members*

   Chair Logan-Parker introduced agenda item number six and stated that the BDR number was incorrect, and the agenda will need to be corrected. Chair Logan-Parker clarified that BDR 124 is for stem cell and BDR 123 is for newborn screening. Chair Logan-Parker added that the Pediatric Stem Cell and Bone Marrow Transplant Program in Nevada is a collaborative effort with the Cure 4 The Kids and Summerlin Hospital, focused on developing a robust pediatric hematology oncology team by achieving the Foundation for the Accreditation of Cellular Therapy (FACT) accreditation. Chair Logan-Parker added that FACT accreditation requires five successful transplants to contract with insurance companies and expand transplant services in-state which is currently being done out-of-state. Chair Logan-Parker added that the initiative sought funding from the Governor's Finance budget for additional staff and resources to complete the program for the state of Nevada. Chair Logan-Parker asked the Council for a motion.

Council member Christina Thielst motioned to submit a letter of support to the Nevada State Assembly Health and Human Services and the Senate Health and Human Services in support of BDR 124 from the 83rd Legislative Session (2025). Council member Dr. Sumit Gupta seconded the motion to approve. There were no objections. A quorum voted to submit a letter of support of BDR 124 from the 83rd Legislative Session (2025) to Nevada State Assembly Health and Human Services and the Senate of Health and Human Services.

6) FOR POSSIBLE ACTION: Discussion and possible action for the Council to submit a letter of support of BDR 123 for the 83rd Legislative Session (2025) sponsored by Senator Pazina which will revise the

provisions relating to newborn screening and allow the letter of support be submitted to the Nevada State Assembly – Health and Human Services and the Nevada Senate Health and Human Services. – *Council Members*

Chair Logan-Parker introduced the agenda item and stated that the BDR number should be 123 for the 83rd Legislative Session. Chair Logan-Parker added that a letter of support is being sent to the Nevada State Assembly Health and Human Services and the U.S. Senate Health and Human Services regarding a bill to expand the state's newborn screening program. Chair Logan-Parker continued that the bill will be sponsored by Senator Pazina, the bill seeks to address inflation and cost increases, as the current $81 fee for newborn screening has not changed in 10 years despite rising expenses. Chair Logan-Parker stated that the Newborn Screening program, which relies on temporary funding from the American Rescue Plan Act (ARPA) and CDC grants, faces potential funding challenges as these resources are set to expire, prompting the need for legislative action. Chair Logan-Parker asked the Council for a motion.

Council member Dr. Sumit Gupta commented that there are 35,000 babies born every year in Nevada. Dr. Gupta added that all newborns get screened twice, once before discharged from the hospital and once more by the Primary Care Pediatrician. Dr. Gupta felt that diagnosing rare disease conditions early was beneficial for quality of life, right treatments and can change the course of the condition. Dr. Gupta added that due to financial challenges, doctors are not able to implement all the recommended screenings on newborns here in Nevada. Dr. Gupta commented that Nevada's state ranking for newborn screening around 48 or 49 out of the 50 states and BDR 123 will help expand the Newborn Screening Program.

Chair Logan-Parker thanked Dr. Gupta and commented that part of BDR 123 would be to have a 2.6% annual increase in the newborn screening fee and BDR 123 will bring current Nevada statutes up to date. Chair Logan-Parker felt that the Council supporting BDR 123 from the 83rd Legislative Session aligns with the Council's strategic plan and duties. Chair Logan-Parker asked the Council for questions.

Council member Dr. Sumit Gupta motioned to submit a letter of support to the Nevada State Assembly Health and Human Services and the Senate Health and Human Services in support of BDR 123 from the 83rd Legislative Session (2025). Council member Dr. Ihsan Azzam seconded the motion to approve. There were no objections. A quorum voted to submit a letter of support to the Nevada State Assembly Health and Human Services and the Senate Health and Human Services in support of BDR 123 from the 83rd Legislative Session (2025).

7) FOR POSSIBLE ACTION: Discussion and possible action to approve the annual report that is due to Governor Lombardo and the Director of the Legislative Counsel Bureau (LCB) in December 2024, pursuant to NRS 439.5077(2)(b)(2). – *Council Members*

Chair Logan-Parker introduced agenda item number seven to approve the annual report due at the end of the year to Governor Lombardo and the Director of LCB. Chair Logan-Parker added that the annual report was sent out to the Council members in September, and Council member Christina Thielst had some feedback such as adding a QR code linking to the needs assessment and incorporating a quote from the World Health Organization. Chair Logan-Parker stated that the annual report outlines the year's activities, successes, and the needs assessment. Chair Logan-parker added that there will be the opportunity for further edits or changes before final approval. Chair Logan-Parker asked the Council for a motion.

Council member Kim Anderson-Mackey commented that as this her first year on the Council, she expressed her admiration for the annual report and the level of detail given. Ms. Anderson-Mackey added that the Council planning ahead for 2025 provides a level of credibility for the folks at the state level.

Chair Logan-Parker thanked Ms. Anderson-Mackey and asked the Council for any other comments or edits.

Council member Amber Federizo commented that in last year's annual report, the Council asked for the Division of Health Care Financing and Policy (DHCFP), or Nevada Medicaid to attend RDAC meetings, and asked if there was any response from the Governor's Office or DHCFP. Ms. Federizo felt that the Governor's Office should respond to the annual report when the Council submits.

Chair Logan-Parker agreed with Ms. Federizo and stated that there has not been a response from the Governor's Office. Chair Logan-Parker discussed adding additional language to the recommendation area of the annual report to accommodate Ms. Federizo's recommendation. Chair Logan-Parker stated that she has not reached out DHCFP to attend RDAC meetings and mentioned adding to the annual report a goal to include DHCFP to future RDAC meetings. Chair Logan-Parker thanked Ms. Federizo for her feedback.

Ms. Federizo commented that she wanted to hold DHCFP accountable and get DHCFP engaged in the RDAC meetings.

Chair Logan-Parker agreed with Ms. Federizo and stated that the annual report will expand on Ms. Federizo's feedback. Chair Logan-Parker asked Ms. Federizo if she had any sample language to put into the annual report to send over to Chair Logan-Parker via email. Chair Logan-Parker asked the Council for any other questions or potential edits.

Hearing none, Chair Logan-Parker stated that the Council will be approving the annual report at the December meeting.

8) INFORMATIONAL: Update on the 'While You Wait' Needs Assessment Campaign that will evaluate the diagnosis and patient management aspects crucial for the continuation of care of individuals with rare diseases in the state of Nevada. – *Chair Annette Logan-Parker*

Chair Logan-Parker stated that the needs assessment process is progressing slowly, with efforts to ramp up in February during Rare Disease Month. Chair Logan-Parker added that close to 100 assessments have been completed, and data is being collected, though trends are not yet evident. Chair Logan-Parker continued that the initiative is supported by social media and news posts, and Chair Logan-Parker has been in contact with Pennsylvania's Rare Disease Advisory Council to learn from their experience with a similar needs assessment. Chair Logan-Parker opened the floor for any public comments or Council member questions.

Ms. Chelsea Bishop felt that a lot of families don’t think of themselves as having a rare disease and typically no doctor would say someone with childhood cancer has a rare disease. Ms. Bishop asked what kind of language the Council has found that has been helpful to add childhood cancers in hopes those individuals and families would complete the needs assessment without listing out every condition.

Chair Logan-Parker commented that Cure 4 The Kids Foundation is working to educate to reframe that childhood cancer is a rare disease. Chair Logan-Parker added that Dr. Alan Ikeda has been assisting with this shift, particularly in how childhood cancer was included in the rare disease needs assessment. Chair Logan-Parker mentioned in past conversations to adjust the marketing approach and offer a separate survey link for childhood cancer families to better align with the rare disease framework. Chair Logan-Parker expressed appreciation towards Ms. Bishop for her feedback.

Council member Kim Anderson-Mackey suggested to reach out to Private Duty Nurse (PDN) companies or any company providing concurrent care to have PDNs share the needs assessment to patients and families receiving care.

Chair Logan-Parker thought Ms. Anderson-Mackey's suggestion was a great idea and stated that any Council members who know of any listservs to let Chair Logan-Parker know to receive posters and flyers.

Ms. Anderson-Mackey stated that the Palliative Care and Quality of Life Council is having their annual conference in November and would like to share a couple of slides during a presentation to get the word out.

Chair Logan-Parker was pleased to connect offline and set up an announcement for the Palliative Care and Quality of Life conference.

Ms. Anderson-Mackey felt that this would be a wonderful opportunity to get involved and have other individuals hear the announcement for the needs assessment survey.

Chair Logan-Parker expressed her appreciation and thanked Ms. Anderson-Mackey.

Council member Christina Thielst commented that she came across an association that provides PDNs during her outreach for the needs assessment and expressed interest in providing more information on this association.

Chair Logan-Parker thanked Ms. Thielst for her outreach efforts.

Council member Dr. Ihsan Azzam commented on Ms. Bishop’s earlier comments and expressed that ‘rare disease’ is a horrible, outdated word. Dr. Azzam believed it was necessary to update the terminology, as the term was relevant 30-40 years ago when medical professionals did not fully understand the true impact of the illness. He emphasized that each disease affects individuals differently, and if the prevalence of a disease is greater than zero, it should not be considered rare.

Chair Logan-Parker agreed with Dr. Azzam and suggested to refresh the needs assessment to not have the term ‘rare’ in the marketing campaign. Chair Logan-Parker shared her idea to update the needs assessment marketing materials for Rare Disease Day coming in February.
Dr. Azzam stated that he felt there was a negative connotation with the term ‘rare’ disease because the individual could feel alone.

Ms. Thielst commented on her personal experience being a former hospital administrator and she felt that she understood the ins and outs of healthcare. Ms. Thielst added that during her long delay in getting diagnosed she realized doctors were not considering Chronic inflammatory demyelinating polyneuropathy (CIDP) as a possible diagnosis. Ms. Thielst continued that CIDP became an option for her to explore with her doctors by meeting other individuals with the same symptoms and experiences as Ms. Thielst, and she shared an idea that CIDP and other rare conditions are not really rare because so many individuals have similar experiences and are not diagnosed yet.

Chair Logan-Parker expressed appreciation for everyone who provided feedback on the needs assessment and will work to updating terminology in the marketing campaigns for the needs assessment for the new year.

Ms. Anderson-Mackey asked if from the 100 or so respondents to the needs assessment to find out whether the respondents condition meets the definition of rare disease.

Chair Logan-Parker replied that she could have Cure 4 The Kids Foundation Information Technologies (IT) staff investigate that and added that her team has only been looking at volume and not analysis of the responses.

Dr. Azzam commented that the term rare needs to be delineated who the rare is referring to, for example, the condition patient potentially has is not rare to the patient but rare to the provider who does not have enough frequency to be proficient in making a timely diagnosis. Dr. Azzam added that this was a big difference, and when added the statistical definition of what is rare and what not rare a threshold needs to be established for the who the condition is rare for, provider or patient.

Council member Valorie Porter put into the chat at 10:35 AM: “Since there are so many rare diseases that people may or may not be aware of, I am wondering if there is a link on the website or document that people could just reference to view the different rare diseases, may help with patients being able to identify. Just my thought. Thank you.”

Vice Chair Gina Glass put into the chat at 10:36 AM: “Valerie, NORD has a comprehensive list of all the rare diseases maybe we link it to our site for easier access?”

Chelsea Bishop put into the chat at 10:37 AM: “That’s a great idea!”

Council member Valorie Porter put into the chat at 10:37 AM: “Thank you at least patients would be ablet to maybe identify 🙂”

Council member Valorie Porter commented that some of Council members are having a side discussion in the chat and wanted to make Chair Logan-Parker aware. Ms. Porter stated that there are many diseases seven to 10,000 different conditions that people may or may not be aware are rare disease. Ms. Porter inquired whether adding a link to the National Organization for Rare Disorders (NORD) comprehensive list of rare diseases on the RDAC website, annual report, or needs assessment marketing materials could assist patients in determining if their condition might be classified as rare.

Chair Logan-Parker liked the idea to link the NORD comprehensive list on the needs assessment survey and added that the RDAC website already has a link to the NORD comprehensive list that Vice-Chair Gina Glass was referencing earlier. Chair Logan-Parker added that to her knowledge the NORD comprehensive list is the most robust and easy to navigate.

Ms. Porter commented that she has viewed the NORD comprehensive list before and thought the needs assessment survey should have the NORD comprehensive list as a reference.

Chair Logan-Parker expressed gratitude for everyone's feedback and stated that the needs assessment would continue to collect data for two years. Chair Logan-Parker added that the Nurse Practitioners at the Cure 4 The Kids Foundation would handout flyers and assist with outreach for the needs assessment. She felt positive about the progress made after the first year of the needs assessment rollout and noted that the strategy is being refreshed for year two. Chair Logan-Parker asked if there was any more comment.

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

9) INFORMATIONAL: Council member information sharing announcements – Council Members

Chair Logan-Parker opened the floor to Council members to share any announcements.

Council member Kim Anderson-Mackey announced that as the Chair for Palliative Care and Quality of Life, which is hosting its third annual education day, sponsored by Cure for the Kids in Las Vegas and available virtually. Ms. Anderson-Mackey added that the event will feature five one-hour Continuing Education Unit (CEU) sessions, along with vendors, and a speaker flyer will be emailed out soon. Ms. Anderson-Mackey stated that two designated speakers will discuss topics related to children and concurrent care models in Nevada, with some overlap in palliative care and quality of life.

Chair Logan-Parker asked Kim to forward that information to be promoted on the RDAC social media websites. Chair Logan-Parker added that Chelsea Bishop, our guest presenter, earlier discussed the Children's Hospital initiative, which aims to develop a stand-alone children's hospital in Southern Nevada. Chair Logan-Parker encouraged Council members to review the economic impact study conducted by Tripp Umbach and funded by the Lincy Institute, offering to send out a QR code for easy access to the report to help familiarize the Council with the details and scope of the initiative in Southern Nevada.

10) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment.

Hearing none, Chair Logan-Parker moved to adjourn.

11) ADJOURNMENT – Chair Logan-Parker

Chair Logan-Parker expressed appreciation for everyone on the council.

Chair Logan-Parker moved to adjourn the meeting at 10:46am.