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Governor

Richard Whitley, MS
Director

DEPARTMENT OF HEALTH AND HUMAN SERVICES
NEVADA DIVISION of PUBLIC and BEHAVIORAL HEALTH

Cody Phinney, MPH
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Chief Medical Officer

Nevada Rare Disease Advisory Council (RDAC)
Meeting Minutes

April 5, 2024

9:33 AM – 11:03 AM

Meeting Locations:
Pursuant to NRS 241.020(3)(a) as amended by Assembly Bill 253 of the 81st Legislative Session, this meeting will be convened using a remote technology system and there will be no physical location for this meeting. Chair Annette Logan-Parker opened the meeting at 09:33 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

(14) Annette Logan-Parker (Chair); Gina Glass (Vice Chair); Amber Federizo, DNP, APRN, FNP-BC; Ihsan Azzam, MD, PhD; Jennifer Millet, DNP, RN; Kimberly Palma-Ortega; Naja Bagner; Craig Vincze, PhD; Christina Thielst, LFACHE, MHA; Sumit Gupta, MD; Brigette Cole; and Kim Anderson-Mackey (Quorum=8)

COUNCIL MEMBERS ABSENT:

Paul Niedermeyer; Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; and Kimberly Palma-Ortega.

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

Ashlyn Torrez, *Health Program Specialist I, Office of State of Epidemiology (OSE), DPBH*; Kagan Griffin, *Health Program Manager II, OSE, DPBH*; and Wesley Herring, *Health and Human Services Professional Trainee, OSE, DPBH*

OTHERS PRESENT:

Ferrari Reeder, Public Affairs; Amber Williams; Melissa Bart-Pange, Belz-Case Government Affairs-Scribe.

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) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from February 5, 2024. – Council Members

Chair Logan-Parker introduced the agenda item to approve the meeting minutes from last Council Meeting held February 05, 2024, and asked for a motion.

Council member Gina Glass motioned to approve the meeting minutes from the prior Council meeting dated February 05, 2024. Council member Naja Bagner seconded the motion to approve. There were no objections or edits. A quorum voted to approve the prior meeting minutes.

4) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of Department of Health and Human Services (DHHS) to appoint Melissa Bart-Plange to fulfill "Parent or guardian who has experience caring for a child with a rare disease" pursuant to NRS 439.5075(1)(b)(7). – *Council Members*

Chair Logan-Parker introduced this agenda item to appoint Melissa Bart-Plange to RDAC to fulfill parent or guardian who has experience caring for a child with a rare disease. Chair Logan-Parker asked the Council for a motion.

Councilmember Craig Vincze motioned to approve Melissa Bert-Plange to recommend the appointment to the Director of DHHS. Councilmember Gina Glass seconded the motion to approve. There were no objections. A quorum voted to approve Melissa Bert-Plange to be recommended to the Director of DHHS for appointment to the Council.

5) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of Department of Health and Human Services to appoint Pamela White pursuant to NRS 439.5075(2). The Council may, by affirmative vote of a majority of its members, request the Director to appoint to the Council additional members who have expertise on issues studied by the Council. Such members serve for a period determined by the Council. – *Council Members*

Chair Logan-Parker introduced this agenda item to appoint Pamela White to the RDAC to fulfill the role of an additional member who has expertise on issues studied by the Council. Chair Logan- Parker asked the Council for a motion.

Councilmember Christina Thielst motioned to approve Pamela White to recommend her appointment to the Council. Councilmember Summit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve Pamela White to be recommended to the Director of DHHS for appointment to the Council.

6) FOR POSSIBLE ACTION: Discussion and possible action to approve the NV-RDAC drafting an official letter of support addressed to the Governor, DHHS and NV-Medicaid leadership regarding the support of and recommendation for the State of Nevada to sign up for the Cellular and Gene Therapy (CGT) Access Model recommended by Centers for Medicare and Medicaid Services (CMS), and to allow access to Medicaid beneficiaries to both of the recently Food and Drug Administration (FDA) approved drugs for sickle cell disease (SCD) gene therapy (CasgevyTM (exagamglogene autotemcel), and LyfgeniaTM (lovo-cel), Currently using HCPCS code J3590 for unclassified biologics). – *Chair Annette Logan-Parker*

   Chair Logan-Parker introduced this agenda item to approve the NV-RDAC drafting an official letter of support addressed to the Governor, DHHS and NV- Medicaid leadership regarding the support of and recommendation for the State of Nevada to sign up for the Cellular and Gene Therapy (CGT) Access Model recommended by CMS, and to allow access to Medicaid beneficiaries to both recent FDA approved drugs for SCD gene therapy. Chair Logan-Parker asked the Council for a motion.

   Recording timestamp 33:05 Amber Williams put into the chat: “https://nvrdac.org/cgt/”

   Recording timestamp 34:05 Dr. Craig Vincze put into the chat: “thank you Amber!”

Councilmember Gina Glass motioned to approve the NV-RDAC drafting an official letter of support addressed to the Governor, DHHS and NV- Medicaid leadership regarding the support of and recommendation for the State of Nevada to sign up for the Cellular and Gene Therapy (CGT) Access Model recommended by CMS, and to allow access to Medicaid beneficiaries to both recent FDA approved drugs for SCD gene therapy. Councilmember Summit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the NV-RDAC's drafting an official letter of support addressed to the Governor, DHHS and NV- Medicaid leadership regarding the support of and recommendation for the State of Nevada to sign up for the Cellular and Gene Therapy (CGT) Access Model recommended by CMS, and to allow access to Medicaid beneficiaries to both recent FDA approved drugs for SCD gene therapy.

7) INFORMATIONAL ITEM: Discussion of Rare Disease Day, February 28th Media Coverage. – *Chair Annette Logan-Parker*

Chair Logan-Parker introduced the agenda item to discuss the Media Coverage of Rare Disease Day, February 28th. Chair Logan-Parker announced she had done an in-studio interview, as well as an on the air radio piece. Chair Logan-Parker expressed the focus of the media campaign was to provide information about the RDAC and the launch of the statewide needs assessment. Chair Logan-Parker went on to say the Cure 4 the Kids Foundation were able to get published on several online and print publications. Chair Logan-Parker asked if the Council had anything to share.

Council member Christina Thielst mentioned she had reached out to northern and rural parts of the state with slow results. Council member Christina Thielst asked if anyone has contacts in Northern Nevada media.

Chair Logan-Parker mentioned she has contacts with the Cure 4 the Kids public relations team, and media team. Chair Logan-Parker declared that there had been a wonderful success in the south.

Council member Gina Glass went on to say she and five other Nevada representatives were in Washington, D.C. for Rare Disease Day. Council member Gina Glass added the representatives were there advocating for rare diseases on Capitol Hill. Ms. Glass felt the turnout has been pretty good, especially since 2019, considering how far away Washington D.C. is. Ms. Glass mentioned the Rare Action Network ambassador is in Northern Nevada and would be a good contact when it comes to advertising.

Chair Logan-Parker declared RDAC had good exposure with Gina and Pam and the crew up in Washington, D.C. and then with Christina pushing things in the North and her in the South, she thinks the Nevada RDAC had a successful campaign from a public relations perspective. Chair Logan-Parker thanked everyone for participating. Chair Logan-Parker mentioned every opportunity to get the needs assessment additional exposure should be taken advantage of and emphasized how the work the RDAC is doing is important.

Council member Christina Thielst had a question about the urgency of the needs assessment and expressed the challenge of getting the information into the hospitals. Ms. Thielst stated she has had success going into the clinics, but not certain items are being displayed.

Chair Logan-Parker answered that the needs assessment is a multi-year campaign, and that it is going to take a long time to gather information. Chair Logan-Parker stated further down the agenda there will be an opportunity for conversations about the needs assessment. Chair Logan-Parker re-iterated this will be an ongoing multi-year campaign and individuals will need to see the posters a few times. Chair Logan-Parker stated Pennsylvania kept their needs assessment open for upwards of five years before sufficient data had been collected.

Council member Gina Glass mentioned there is no longer an ambassador for Nevada Rare Action Network. Ms. Glass stated if anyone on the council is interested in becoming that ambassador, there are a lot of PR opportunities with being the rare action ambassador for your state, so that might be an opportunity for some present in the north.

Recording timestamp 47:11 Gina Glass put into the chat: “Actually it looks like we no longer have a NV Rare Action Network Ambassador, so here is an opportunity for someone maybe in the North to join and represent the Rare community here 🙂 https://rareaction.org/resources-for-advocates/state-profiles/nevada/”

Chair Logan-Parker opened the floor for additional comment. Hearing none, Chair Logan-Parker moved on to the next agenda item.

8) INFORMATIONAL ITEM: Overview and discussion of Childhood Cancer Action Days in D.C. – *Council Member Brigette Cole*

Chair Logan-Parker introduced the agenda item of the Overview and discussion of Childhood Cancer Action Days in D.C. Chair Logan-Parker lets Council Member Bridgette Cole hold the floor.

Council Member Brigette Cole declared she is the director of programs and services at Northern Nevada Children’s Cancer Fund. Ms. Cole stated her visit to Washington, D.C. was a wonderful opportunity, and wanted to share what had been asked of congress, noting the overlap with rare disease. Ms. Cole noted the mission of Northern Nevada Children's Cancer Foundation is to enhance the quality of life for children with cancer and their families, both financially and emotionally. Ms. Cole stated Northern Nevada Children's Cancer Foundation, advocates for increased research funds and raising public awareness for childhood cancer. Ms. Cole stated on February 14th she was joined with over 200 advocates representing 35 states in Washington, DC and there were over 160 congressional meetings. Ms. Cole mentioned Cure 4 the Kids was unable to make it, but the Tyler Robinson Foundation and Northern Nevada Children's Cancer Foundation came together to represent the entire state of Nevada. Ms. Cole discussed the impactful "leave-behind" initiative, which involved presenting beads of courage symbolizing various aspects of the childhood cancer journey to congressional members. Ms. Cole detailed the specific requests made to Congress, such as funding for the Childhood Cancer Star Act and the Childhood Cancer Data Initiative. Ms. Cole emphasized the need for increased research funding, particularly for rare childhood cancers, and highlighted the potential benefits of such funding for developing innovative treatments.

Council Member Craig Vincze offered additional insights, emphasizing the importance of addressing funding disparities in rare cancer research. Dr. Vincze underscored the significance of collaborative efforts and shared statistics illustrating the disproportionate impact of rare cancers on mortality rates.

Recording timestamp 01:04:12 Gina Glass put into the chat: “thanks for your advocacy efforts for childhood cancer Bridgette.”

Chair Logan-Parker expressed gratitude for Bridgette Cole’s comprehensive presentation and Craig Vincze’s valuable contributions. Chair Logan-Parker noted the importance of collaboration and the ongoing efforts to improve data collection and research funding in the field of childhood cancer. Chair Logan-Parker asked the council for comment.

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

9) INFORMATIONAL ITEM: Overview and discussion of the next Drug Utilization Review Board (DUR) Meeting scheduled for April 18, 2024. – *Chair Annette Logan-Parker*

Chair Logan-Parker introduced the agenda item to discuss the next Drug Utilization Review Board (DUR) Meeting scheduled for April 18, 2024. Chair Logan-Parker reiterated the importance of keeping close contact with the drug use review board. Chair Logan-Parker relayed the upcoming session of the Drug Use Review Board will be focusing on the adoption of prior authorization criteria for two recently FDA-approved gene therapy drugs designed to treat sickle cell disease. Chair Logan-Parker provided pertinent information regarding the timing and agenda of the upcoming Board meeting, emphasizing the importance of public participation and comments.

Council member Gina Glass confirmed her intention to attend the Drug Use Review Board meeting in person and outlined the organization's efforts to inform and engage the community in supporting the prior authorization of the new therapies. Ms. Glass highlighted the significance of Nevada's advocacy for sickle cell-related policies, noting the precedent set by the sickle cell bill passed in 2019. Ms. Glass added emphasis on the importance of gene therapy not only for sickle cell community, but the rare disease community in its entirety.

Council member Amber Federizo raised concerns regarding the potential long-term efficacy and risks associated with gene therapy. Ms. Federizo outlined possible pitfalls, drawing parallels with experiences in hemophilia treatment. Ms. Federizo stressed the importance of comprehensive consideration of these factors in the development of prior authorization criteria to ensure optimal patient outcomes.

Recording timestamp 01:14:51 Gina Glass put into the chat: “Thank you Dr. Federizo for that information and reminder.”

Chair Logan-Parker acknowledged the validity of these concerns and highlighted ongoing efforts to address them through agreements between states and manufacturers, particularly in terms of negotiating coverage and addressing long-term implications. Chair Logan-Parker underscored the delicate balance between facilitating access to groundbreaking gene therapies and ensuring responsible consideration of potential risks and long-term effectiveness. Chair Logan-Parker opened the floor for additional comment.

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

10) INFORMATIONAL ITEM: 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 introduced the agenda item to provide an 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 Logan-Parker updated the attendees on the ongoing distribution of posters and flyers for the needs assessment initiative. She noted that the initiative has made significant progress with materials being displayed in numerous healthcare facilities and organizations. Chair Logan-Parker stated posters and flyers have been placed in Summerlin Hospital and will be posted at Sunrise Hospital after a compliance check. Chair Logan-Parker listed other current locations as the Make a Wish waiting room, the Southern Nevada University Medical Center (UMC), the Northern Nevada Children’s Cancer Foundation (NNCCF), physician offices, urgent cares, and other relevant locations. Chair Logan-Parker highlighted the importance of patience in the process of collecting data for the initiative. She mentioned while some progress has been made, there is still ongoing effort required to ensure comprehensive data collection. Chair Logan-Parker acknowledged the need for continued dedication to promoting participation and collecting meaningful data.

Council member Gina Glass expressed interest in obtaining flyers for an upcoming event.

Chair Logan-Parker assured Gina Glass she will coordinate the distribution of materials for the event offline. Chair Logan-Parker suggested either arranging for the materials to be dropped off or for Gina Glass to pick the flyers up from the Cure 4 the Kids office. Chair Logan-Parker concluded the discussion by encouraging anyone interested in promoting the needs assessment initiative to reach out for posters and flyers. Chair Logan-Parker reiterated the organization's willingness to support others in their efforts to raise awareness and gather data for the initiative. Chair Logan-Parker opened the floor for comments or feedback.

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

Recording timestamp 01:17:59 Brigette Cole put into the chat: “I have also reached out to Renown Hospital and other local pediatric offices here in Reno.”

Recording timestamp 01:18:58 Christina Thielst put into the chat: “I'm going to reach out to the Medical Staff Office for Renown, as well.”

Recording timestamp 01:19:59 Brigette Cole put into the chat: “Perfect! I have contact with Dr. Kris Deeter who is Chair of Pediatrics at Children's Hospital at Renown. She is reviewing and will let us know once approved.”

Recording timestamp 01:21:03 Brigette Cole put into the chat: “Christina let's connect on this and we can combine our efforts. My email is brigette@nnccf.org.”

11) INFORMATIONAL ITEM: Overview and discussion of the Department of Motor Vehicles (DMV) Childhood Cancer License Plate Program Funding Report. – *Chair Annette Logan-Parker*

Chair Logan-Parker introduced the agenda item to discuss the Department of Motor Vehicles (DMV) Childhood Cancer License Plate Program Funding Report. Chair Logan-Parker asked for the current amount in the fund created through the Childhood Cancer License plate program.

Ms. Ashlyn Torrez replied with information from the Administrative Services Officer, $38,000 is the current balance in the region. Ms. Torrez commented that requests for funds should be directed to her.

Chair Logan-Parker thanked Ashlyn Torrez for the update and moved on to the next agenda item.

12) INFORMATIONAL ITEM: Sickle Cell Disease Data Registry Progress Update. – *Chair Annette Logan-Parker; & Ashlyn Torrez, Lupus and Other Rare Diseases Program Coordinator, Office of State Epidemiology, DPBH*

Chair Logan-Parker introduced the agenda item Sickle Cell Disease Data Registry Progress Update. Chair Logan-Parker provided background information on the Nevada Sickle Cell Disease Registry, which was established during the 2019 Legislative Session. Chair Logan-Parker continued that the registry aims to collect data on newly diagnosed cases (incidence) and existing cases (prevalence) of sickle cell disease and its variants in Nevada. Chair Logan-Parker noted that the Division of Public and Behavioral Health has been working on regulatory development for several years to establish reporting standards for the registry.

Ashlyn Torrez provided an update on reporting standards for the sickle cell registry. Ms. Torrez mentioned while the regulations were passed in August 2023, there have been delays in their codification. Ms. Torrez reported that reporting forms have been developed and will soon be distributed to healthcare providers and facilities that treat sickle cell disease. Ms. Torrez explained the reporting forms will be accompanied by Technical Bulletins and will be made available on the Office of State Epidemiology website. Ms. Torrez added the division has also developed a brand-new data dictionary to standardize data collection. Ms. Torrez highlighted the use of the data system EpiTrax for reporting illnesses, including sickle cell disease, and the development of a reporting form for this purpose.

Council member Dr. Ihsan Azzam clarified that the codification process is not within the purview of the Health Department but is handled by the Legislative Counsel Bureau. Dr. Azzam emphasized that delays in codification affect all areas, not just sickle cell disease reporting.

Council member Gina Glass asked about the current data registry for sickle cell.

Ms. Torrez explained while the data is currently internal, it can be requested and provided in a report form. Ms. Torrez also mentioned plans to make an epidemiological profile available to the public through the Office of State Epidemiology website.

Council member Gina Glass further inquired about the registry platform and how community-based organizations could support its implementation.

Ms. Torrez reiterated the registry is utilizing the EpiTrax system and mentioned plans for electronic reporting in the future. Ms. Torrez welcomed collaboration with community organizations to facilitate the dissemination of reporting forms and support the registry's implementation.

Chair Logan-Parker raised questions about the process for distributing reporting forms to healthcare providers and facilities.

Recording timestamp 01:28:37 Gina Glass put into the chat: “Thats what I was wondering Annette, just couldnt think of the wording lol”

Ms. Torrez clarified forms will be distributed via secure email and eFax initially, with plans for electronic reporting in the future. Ms. Torrez noted the frustration of not having the registry up and running but insists that the Office of State Epidemiology remains committed to making the registry operational and ensuring efficient data collection.

Chair Logan-Parker thanked Ashlyn Torrez for the encouraging update.

Hearing no more comment, Chair Logan-Parker moved on to the next agenda item.

13) INFORMATIONAL ITEM: Overview and discussion of the 2023 Rare Disease Data that is currently available in the state of Nevada. – *Chair Annette Logan-Parker*

Chair Logan-Parker introduced the agenda item to discuss the 2023 Rare Disease Data currently available in the state of Nevada. Chair Logan-Parker provided an update on the challenges faced in collecting data on rare diseases within the state. Chair Logan-Parker noted the lack of an organized system for data collection, with only limited information available from a single source, the Cure 4 the Kids Foundation. Chair Logan-Parker added that the data primarily focuses on patients between infancy and 24 years old with various rare diseases. Chair Logan-Parker emphasized the need for data from multiple sources to provide a comprehensive understanding of rare diseases in Nevada. Chair Logan-Parker explained that efforts are underway to make the available data accessible to the public through the RDAC website, with transparency about the data's limitations. Chair Logan-Parker moved on to the next agenda item.

14) INFORMATIONAL ITEM: Status Report and discussion of the Mercer Medicaid study regarding rare disease service delivery models, specifically focusing on the unique issues in Nevada, which was funded by the Interim Finance Committee in December 2022. – *Chair Annette Logan-Parker*

Chair Logan-Parker introduced the agenda item to discuss the Mercer Medicaid study regarding rare disease service delivery models, specifically focusing on the unique issues in Nevada, which was funded by the Interim Finance Committee in December 2022. Chair Logan-Parker noted that while the study ended prematurely, it provided enough information to recalculate rates for certain provider types outlined in SB 221. Chair Logan-Parker highlighted the department's commitment to ensuring parity in pay for other providers of rare disease treatments, with Mercer's ongoing involvement in discussions. Chair Logan-Parker expressed gratitude for this initiative and offered assistance from the RDAC if needed. Chair Logan-Parker acknowledged it is too early to assess the impact of SB 221 on childhood cancer and rare disease outpatient settings, pledging to keep the Council informed as implementation progresses. Chair Logan-Parker opened the floor for questions or comments.

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

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

Chair Logan-Parker opened the floor for Council Members to share information or announcements.

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

16) PUBLIC COMMENT AND DISCUSSION:

Chair Logan-Parker opened the floor for public comment.

Hearing none, Chair Logan-Parker moved to adjourn the meeting.

17) 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 10:33 am.