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**NEVADA RARE DISEASE ADVISORY COUNCIL
DRAFT MEETING MINUTES**

**Date: 9/06/2024
9:37 AM – 10:32 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 9:37 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Annette Logan-Parker (CHAIR); Amber Federizo, DNP, APRN, FNPBC; Jennifer Millet, DNP, RN; Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Naja Bagner; Paul Niedermeyer; Craig Vincze, PhD; Christina Thielst, LFACHE, MHA; Sumit Gupta, MD; Brigette Cole; Kim Anderson-Mackey; Melissa Bart-Plange; and Pamela White (Quorum=9)

COUNCIL MEMBERS ABSENT:

Gina Glass (Vice-Chair); Ihsan Azzam, MD, PhD (excused); Naja Bagner (excused); and Paul Niedermeyer (excused)

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

Ashlyn Torrez, *Office of State Epidemiology, (OSE), DPBH*; Amber Hise, *Chronic Disease Prevention & Health Promotion, DPBH*; Jeri Borges, *OSE, DPBH*; and Kagan Griffin, *OSE, DPBH*

OTHERS PRESENT:

Madison Bowe; Ferrari Public Affairs; Verena Samara, MD; and Devraj Chavda, 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.

Council member Kim Anderson-Mackey stated that she had trouble getting into the meeting and apologized for being late.

Meeting timestamp 9:39 AM Councilmember Brigitte Cole put into the chat: “Hello Ashlyn, this is Brigitte Cole, unfortunately I will need to step away at 10:30. Thank you!”

Meeting timestamp 9:39 AM Councilmember Valerie Porter put into the chat: “I am here had my mic muted sorry.”

Chair Logan-Parker thanked Councilmember Kim Anderson-Mackey and asked if there was anyone who wished to provide public testimony. Hearing none, Chair Logan-Parker moved on to the next agenda item.

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

Chair Logan-Parker introduced the agenda item to approve the April meeting minutes and noted that there was a typo on the agenda that the RDAC meeting was on April 5th not 4th. Chair Logan-Parker added that the meeting minutes were posted on the Division of Public and Behavioral Health (DPBH) RDAC website. Chair Logan-Parker asked the Council for a motion.

Councilmember Jennifer Millet motioned to approve the meeting minutes from prior council meeting dated April 5th, 2024. Councilmember Sumit Gupta seconded the motion to approve. There were no objections. A quorum voted to approve the meeting minutes from prior council meeting dated April 5th, 2024.

- 4) POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from June 7, 2024. –
Council Members

Chair Logan-Parker introduced the agenda item to approve the meeting minutes from last Council Meeting held June 7th, 2024. Chair Logan-Parker stated the meeting minutes were posted on the Nevada RDAC website and were emailed to the council members September 5th, and then Chair Logan-Parker asked for a motion.

Councilmember Brigitte Cole motioned to approve the meeting minutes from prior council meeting dated June 7th, 2024. Councilmember Valerie A. Porter seconded the motion to approve. There were no objections. A quorum voted to approve the meeting minutes from prior council meeting dated June 7th, 2024.

- 5) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of Department of Health and Human Services to appoint Madison Bowe to fulfill [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 stated Madison Bowe has expressed interest in becoming a member of the RDAC. Chair Logan-Parker added that Ms. Bowe was not able to get her application in on time, and Ms. Bowe expressed wanting to address the Council. Chair Logan-Parker stated that the Council will add the actual voting to recommend her to the next meeting agenda. Chair Logan-Parker opened the floor to Ms. Bowe.

Ms. Madison Bowe introduced herself as a 29-year-old with a condition called Stiff Person Syndrome and has been very invested in advocacy for about two years now. Ms. Bowe added that she was Emergency Medical Technician (EMT) before getting sick and has experience in emergency medical services. Ms. Bowe felt that her expertise in policy at the state and federal level and her work experience would be valuable to the Council to advocate for the rare disease community.

Chair Logan-Parker thanked Ms. Bowe. Chair Logan-Parker added that the Council looks forward to getting her letter of intent and that the council will do the official vote to recommend Ms. Bowe at the next meeting. Chair Logan-Parker commented that Ms. Bowe is welcome to participate in any of the meetings as a member of the public in the meantime.

Chair Logan-Parker asked if there were questions for Ms. Bowe.

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

- 6) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of Department of Health and Human Services (DHHS) to appoint Dr. Devraj Chavda to fulfill the role of a physician who practices in cardiology, emergency care, neurology, oncology, orthopedics, pediatrics, or primary care and provide care to patients with rare diseases pursuant to [NRS 439.5075\(1\)\(b\)\(1\)](#). – *Council Members*

Chair Logan-Parker introduced the agenda item to recommend Dr. Devraj Chavda's appointment to DHHS Director's Office. Chair Logan-Parker wanted to note that there was a typo on Dr. Chavda's last name on the agenda. Chair Logan-Parker asked Dr. Chavda to introduce himself to the Council.

Dr. Chavda introduced himself and stated his specialty is pediatric neurology. Dr. Chavda noted most of his patients have a rare disease and expressed his expertise will be very helpful to advocate for his patients. Dr. Chavda is also with the American Epilepsy Society..

Chair Logan-Parker thanked Dr. Chavda and asked the Council for a motion.

Councilmember Christina Thielst motioned to approve the recommendation of Dr. Chavda to the Director of DHHS for appointment to the Council. Councilmember Valerie A Porter seconded the motion to approve. There were no objections. A quorum voted to approve Dr. Devraj Chavda to be recommended to the Director of DHHS for appointment to the Council.

- 7) FOR POSSIBLE ACTION: Discussion and possible action to recommend to the Director of Department of Health and Human Services (DHHS) to appoint Dr. Verena Samara to fulfill the role of a physician

who practices in cardiology, emergency care, neurology, oncology, orthopedics, pediatrics, or primary care and provide care to patients with rare diseases pursuant to [NRS 439.5075\(1\)\(b\)\(1\)](#). – *Council Members*

Chair Logan-Parker introduced the agenda item to recommend Dr. Verena Samara to the Council to DHHS Director's Office. Chair Logan-Parker asked Dr. Samara to introduce herself to the Council.

Dr. Samara introduced herself as a foreign medical graduate from Germany. Dr. Samara came to the United States in 2010 on a research sabbatical working on spinal cord injury, but then decided to stay. Dr. Samara did her neurology residency in Utah at Salt Lake City and then her neuromuscular fellowship at Stanford. Dr. Samara is an adult neuromuscular specialist because of immigration requirements. Dr. Samara sees patients in the Carson, Tahoe areas of Northern Nevada. Dr. Samara added that she sees a lot of patients with rare, hereditary autoimmune neuropathies and muscular problems. Dr. Samara has also been part of the Newborn Screening Committee and taking care of spinal muscular atrophy (SMA) babies. Dr. Samara felt that being part of this Council would be a wonderful way to advocate for her patients on a higher level. Chair Logan-Parker thanked Dr. Samara and asked the Council for a motion.

Councilmember Kim Anderson-Mackey motioned to approve the recommendation of Dr. Samara to the Director of DHHS for appointment to the Council. Councilmember Christina Thielst seconded the motion to approve. There were no objections. A quorum voted to approve Dr. Samara to be recommended to the Director of DHHS for appointment to the Council.

- 8) FOR POSSIBLE ACTION: Discussion of, nomination of, and voting for a new Chair and Vice Chair of the Nevada Rare Disease Advisory Council for the next term of two years pursuant to *Article 6, Section 1 and Article 6, Section 2* of the Rare Disease Advisory Council Bylaws. – *Council Members*

Chair Logan-Parker introduced agenda item to nominate a new Chair and Vice Chair to serve a two-year term. Chair Logan-Parker noted that there was a survey sent out to the Council members to see if there was any interest in either position. Chair Logan-Parker stated that only herself and Vice-Chair Gina Glass were interested in these positions. Chair Logan-Parker expressed that both Chair Logan-Parker and Vice-Chair Gina Glass are happy to serve another term in these positions. Chair Logan-Parker noted that her position as Chair would be her second term, and Vice-Chair Gina Glass's third term. Chair Logan-Parker asked the Council for a motion for the Chair's position.

Councilmember Valerie A Porter motioned to approve Chair Logan-Parker as the Chair of the Rare Disease Advisory Council for a two-year term. Councilmember Dr. Craig Vincze seconded the motion to approve. There were no objections. A quorum voted to approve Chair Logan-Parker as the Chair of the Rare Disease Advisory Council for a two-year term.

Chair Logan-Parker asked the Council for a motion to approve Vice-Chair Gina Glass for a third term as Vice-Chair.

Councilmember Kim Anderson-Mackey motioned to approve Vice-Chair Gina Glass as the Vice-Chair of the Rare Disease Advisory Council for a two-year term. Councilmember Jennifer Millet seconded the motion to approve. of the Rare Disease Advisory Council for a two-year term. There were no objections.

A quorum voted to approve Gina Glass to have a third term as Vice-Chair of the Rare Disease Advisory Council for a two-year term.

- 9) **INFORMATIONAL:** Overview of the Track Cancer Foundation Think Tank Event from November 2023. – *Councilmember Dr. Craig Vincze, PhD*

Chair Logan-Parker introduced Councilmember Dr. Craig Vincze to present some slides on the Track Cancer Foundation Think Tank Event.

Dr. Craig Vincze presented on the Track Cancer Foundation Think Tank Event.

Dr. Vincze thanked the council for their time and asked the Council for questions.

Chair Logan-Parker thanked Dr. Vincze and opened the floor for any comments or questions for Dr. Vincze.

Council member Valerie Porter commented that the presentation was informative, and thanked Dr. Vincze.

Dr. Vincze commented that Target Rare Cancer Knowledge (TRACK) is a great tool in the toolbox that was fully remote clinical trial for patients with rare cancers or cancers of unknown primary. Dr. Vincze expressed excitement sharing this tool with the Council.

Chair Logan-Parker stated that she would have the website for Target Cancer Foundation on the resource's webpage of the Nevada RDAC website.

Dr. Vincze thanked Chair Logan-Parker.

Meeting timestamp 10:05 AM Councilmember Valerie Porter put into the chat: “can you please send the presentation and the link to the web site?”

Meeting timestamp 10:06 AM Councilmember Valerie Porter put into the chat: “Would have been a super opportunity for my younger sister 😊”

Meeting timestamp 10:09 AM Councilmember Christina Thielst put into the chat: “Amazing resource! When it comes to rare, virtual can make a huge difference.”

- 10) **INFORMATIONAL:** Overview of the Healthcare Advocate Summit Event on September 3, 2024, and Vice-Chair Gina Glass' scheduled presentation on Navigating Health Equity: Tackling Rare Disease and Disparities Through Advocacy and Action. – *Vice-Chair Gina Glass*

Chair Logan-Parker skipped this agenda item since Vice-Chair Gina Glass was not present at the meeting. Chair Logan-Parker stated that Vice-Chair Glass will present at the next meeting.

- 11) INFORMATIONAL: Nevada Rare Disease Advisory Council (RDAC) Childhood Cancer Data Collection Efforts update and overview of the current cancer data available in Nevada. – *Chair Logan-Parker*

Chair Logan-Parker updated the Council on the childhood cancer data collection efforts are ongoing progress. Chair Logan-Parker added that the Cure 4 Kid's Foundation has engaged with a consultant to help get the program up and running. Chair Logan-Parker stated that she will then engage with the providers in Northern Nevada and work on collaborating together into one system to provide data efficiently, quickly, and thoroughly to the Nevada Central Cancer Registry. Chair Logan-Parker asked the Council for questions. Hearing none, Chair Logan Parker moved on the next agenda item.

- 12) INFORMATIONAL: Follow up on Cellular and Gene Therapy (CGT) Access Model and the State of Nevada's current position on CGT. – *Chair Logan-Parker*

Chair Logan-Parker stated that there are not any new updates on the CGT Access Model from the Medicaid Office. Chair Logan Parker added that the Cure 4 Kids Foundation did infuse new gene therapy for a particular type of hemophilia and that went well. Chair Logan-Parker asked the Council for questions. Hearing none, Chair Logan Parker moved on the next agenda item.

- 13) INFORMATIONAL: Presentation on an Overview of the Office of Epidemiology Rare Disease Registries Program. – *Ashlyn Torrez, Health Program Specialist I, Office of State Epidemiology (OSE), DPBH*

Chair Logan Parker introduced Ms. Ashlyn Torrez to give a presentation on the Office of State Epidemiology Rare Disease Registries Program.

Ashlyn Torrez presented the NV RDAC Rare Disease Program Overview.

Ms. Torrez wanted to provide a presentation about the Office of State Epidemiology as well as the Rare Disease Program. Ms. Torrez stated that the overall goal of the Office of State Epidemiology is to prevent and respond to a variety of public health issues throughout disease surveillance. Ms. Torrez added that standard data collection, meaningful interpretation, Statewide standards, and centralized guidance to improve health outcomes for our communities. Ms. Torrez introduced leadership on the organizational chart starting with Melissa Peek-Bullock, the Medical Epidemiologist and Jeanne Ruff, the State Epidemiologist, and Kagan Griffin who provides day to day operations support. Ms. Torrez stated that there are numerous grant programs that include Tuberculosis, Sexual Transmitted Diseases (STD), Hepatitis, Epidemiology and Laboratory Capacity (ELC), Hospital Acquired Infections (HAI), Cancer Registry and lastly, Rare Disease. Ms. Torrez discussed the rare disease registries with a primary focus on sickle cell and Lupus. Ms. Torrez stated in additions to managing these registries, the program is the support staff for the Rare Disease Advisory Council, with responsibilities that include assisting the Council with appointments, drafting, and posting meeting agenda and minutes, and supporting the Chair during the RDAC meetings by taking roll call and addressing action items as needed. Ms. Torrez added that the rare disease program is actively seeking out grant opportunities for rare diseases. Ms. Torrez expressed the goal is to ensure that the data collected is meaningful and not only to us in Nevada, but

also to other states, both sickle cell and lupus registries will function as passive surveillance system. Ms. Torrez thanked the Council for their time and asked the Council if there were questions.

Chair Logan-Parker thanked Ms. Torrez and asked are the REDCap forms up on the Office of State Epidemiology (OSE)Website.

Ms. Torrez replied that the forms will be finalized and on the OSE Website by October.

Chair Logan-Parker asked if the REDCap forms will allow for bulk data uploads.

Ms. Torrez commented that with an email to her she can setup calls one-on-one with those requesting bulk data uploads to match-up data variables in excel format.

Chair Logan-Parker asked if there was an approval process or anything from the Division to do some social media posting. Chair Logan-Parker added that a lot of physicians follow Cure 4 Kids Foundation and would love to promote the REDCap forms out to the rare disease community.

Ms. Torrez commented that she would need to reach out leadership and see about approval for social media posting.

Chair Logan-Parker thanked Ms. Torrez and opened the floor for Council members.

Council member Pamela White asked how death records would be collected.

Ms. Torrez stated that normally the cause of death would not list sickle cell or lupus but some complication. Ms. Torrez added that if the patient was ever seen or did a Medicaid reimbursement claim for sickle cell or lupus then the death record would be counted for either sickle cell or lupus.

Council member Ms. White thanked Ms. Torrez.

Chair Logan-Parker commented that she wanted to know about how providers can go about reporting a death that is associated with sickle cell or lupus. Chair Logan-Parker added that Ms. Torrez and herself can chat about this offline.

Ms. Torrez agreed to continue the conversation offline. Ms. Torrez added that in the REDCap forms a data variable can be added to report death of patient as it relates to sickle cell or lupus. Ms. Torrez noted that on the Division side the death records data from vital records and collected on REDCap from providers could be cross-referenced.

Chair Logan-Parker wanted to clarify that the current rare disease registries are passive data collection and there will not be abstracting charts like Nevada Cancer Registry. Chair Logan-Parker asked if the rare disease program will ever evolve into something larger than a passive registry.

Ms. Torrez clarified that the current rare disease registries are passive data collection. Ms. Torrez felt hopeful that with more funding the program could work towards chart abstractions and going into that level detail that Nevada Cancer Registry does.

Chair Logan-Parker thanked Ms. Torrez and asked if there were any other questions. Hearing none, Chair Logan Parker moved on the next agenda item.

14) INFORMATIONAL: Overview on the Newborn Screening Bill Draft Request (BDR) for the 83rd (2025) Legislative Session. – *Chair Logan-Parker*

Chair Logan-Parker stated for the newborn screening BDR 123 the Cure 4 Kids Foundation has been working with Ophelia at the Newborn Screening Program. Chair Logan-Parker added that Ophelia had presented to RDAC at one of the recent meetings, and gave a good overview of the newborn screening program. Chair Logan-Parker stated that Senator Julie Pazina is sponsoring with a co-sponsor Senator Fabian Doñate. Chair Logan-Parker stated that the primary goal of the BDR is to increase from \$81 per live birth per newborn screening to \$150 per life birth per newborn screening.

Chair Logan-Parker added that Cure 4 Kids Foundation will be uploading information on the Nevada RDAC website as it becomes available. Chair Logan-Parker opened the floor to Council members for any questions. Hearing none, Chair Logan-Parker moved on to the next agenda item.

15) INFORMATIONAL: The RDAC Needs Assessment Campaign as highlighted in the Department of Health and Human Services (DHHS) June 2024 Weekly Newsletter. – *Chair Logan-Parker*

Chair Logan-Parker stated that the media campaign for the Needs Assessment is successful as there are an increasing number of surveys submitted during outreach to the community. Chair Logan-Parker expressed interest in sending out QR codes, links, and posters to some of Council members for refreshers to keep outreaching to the community and reach all of Nevada.

Council member Christina Thielst asked if the Department of Health and Human Services (DHHS) newsletter is public newsletter or internal.

Chair Logan-Parker stated that the DHHS newsletter is internal. Chair Logan-Parker was hopeful that the other programs will learn about the needs assessment and will promote it within their Divisions and programs.

Councilmember Ms. Thielst stated that if the DHHS newsletter is public she was going to share to her social media.

Chair Logan-Parker states that with the rare disease month coming up in February, they will be doing a lot of information and promoting the needs assessment through the Cure 4 Kids Foundation's different networks. Chair Logan-Parker stated that all that information to disseminate out to the Council members networks will be provided. Chair Logan-Parker asked the Council for any other questions or comments. Hearing none, Chair Logan-Parker moved on to the next agenda item.

- 16) INFORMATIONAL: The Act4Kids and A&J Patient Advocacy Foundations sharing posters and flyers in their respective organizations for the Needs Assessment Campaign. – *Chair Logan-Parker*

Chair Logan-Parker stated she was combining agenda item number 17 and 18.

Chair Logan-Parker introduced Act4Kids as a parent focused group in Southern Nevada and the A&J Patient Advocacy Foundation are sharing their posters and flyers with their representatives in the state to help us promote the needs assessment.

- 17) INFORMATIONAL: Nevada Rare Disease Advisory Council (RDAC) Subcommittee on the Strategic Plan Update to the Council. – *Chair Logan-Parker*

Chair Logan-Parker stated that there is no update on the Rare Disease Advisory Subcommittee since the Subcommittee has not had a chance to have a meeting since earlier this year due to scheduling conflicts.

- 18) INFORMATIONAL: Council member information sharing announcements – *Council Members*

Chair Logan-Parker opened the floor to Council members who had an announcements. Hearing none, she moved on to the next agenda item.

- 19) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comment.

Meeting timestamp 10:28 AM Councilmember Brigette Cole put into the chat: “I have to leave. Thank you so much, everyone, for all the hard work this council does!”

Chair Logan-Parker thanked Council member Brigette Cole and asked if there was anyone else wishing to give public comment. Hearing none, Chair moved to adjourn the meeting.

- 20) ADJOURNMENT – *Chair 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 10:32 am.