NEVADA RARE DISEASE ADVISORY COUNCIL

DRAFT MEETING MINUTES
Date: April 04 2025
9:33 AM – 10:14 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 9:33 am.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:
Annette Logan-Parker (CHAIR); Ihsan Azzam, MD, PhD; Paul Niedermeyer; Christina Thielst, LFACHE, MHA; Kim Anderson-Mackey; Pamela White; Verena Samara, MD; and Madison Bowe (Quorum=10)

COUNCIL MEMBERS ABSENT:
Melissa Bart-Plange (excused); Brigette Cole (excused); Sumit Gupta, MD; Naja Bagner (excused); Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA (excused); Jennifer Millet, DNP, RN (excused); Gina Glass (Vice-Chair); Amber Federizo, DNP, APRN, FNPBC (excused); Craig Vincze, PhD; and Devraj Chavda, MD

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:
Ashlyn Torrez, *Health Program Specialist I, Office of State Epidemiology (OSE), DPBH*; and Kevin Dodson, *Administrative Assistant III, OSE, DPBH*

OTHERS PRESENT:
Chelsea Bishop, *Nevada Cancer Coalition*; Kathryn Beardshaw; David Frye, *Cure 4 The Kids Foundation*, Amanda M Lattin; Kristen Hackbarth; Chanelle Lochan, *Cure 4 The Kids Foundation*; Katie Sennhenn; Amber Williams, *Cure 4 The Kids Foundation*; and Regan Wood, *Cure 4 The Kids Foundation*.

Roll call was taken and is reflected above. It was determined that there not a quorum of the Rare Disease Advisory Council (RDAC, the Council).

Quorum was not identified, and all action items were skipped.

2) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comment

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

10) INFORMATIONAL ITEM: Guest presentation on the available clinical trials available at the Cure 4 the Kids Foundation. – *Chanelle Lochan, Clinical Research Associate, Cure 4 The Kids Foundation; and Regan Wood, Clinical Research Associate, Cure 4 The Kids Foundation*

Chair Logan-Parker introduced Chanelle Lochan and Regan Wood with the Cure 4 The Kids Foundation and opened the floor to Chanelle Lochan.

Chanelle Lochan, a clinical researcher at Cure 4 The Kids Foundation, introduced the clinical research website to highlight the clinical trials available to patients, families, and healthcare providers. The site, which is found here (https://cure4thekids.org/clinical-studies/) featured four primary categories of trials: hematology, oncology, rare diseases and disorders, and behavioral health. Selecting the hematology section revealed all currently active trials, offering a clear representation of how newly added studies would appear as they became available at the facility. The website served as a comprehensive resource for investigators, physicians, and parents, providing detailed information about each trial, including the sponsor, therapy type, duration, and whether it involved a placebo or medication.

Additional trial data included start and completion dates, enrollment numbers, reported adverse events, global trial sites, and specific eligibility criteria. The oncology section featured IND trials, Expanded Access Programs (EAPs), and compassionate use programs, which were critical for offering investigational treatments to patients with limited or no standard options. These trials aimed to support patients by providing access to potentially life-saving medications that had not yet received full regulatory approval. Further down the site, a section focused on patient education, delivering essential information for those unfamiliar with clinical trials and emphasizing that all medications, from over-the-counter remedies to advanced therapies, required rigorous research before public use.

The site also underscored the role of clinical trials in evaluating the safety and effectiveness of new medications, medical devices, and healthcare procedures. To further support education, the next section linked to the Children's Oncology Group (COG) (https://www.childrensoncologygroup.org/) and Nevada National Community Oncology Research Program (NCORP) (https://sncrf.org/)websites, offering users an opportunity to explore each organization's mission, trial locations, active studies, and areas of research focus.

Interventional trials were primarily designed to evaluate the safety and efficacy of medications, often involving both an active drug and a placebo, and were commonly used in pharmaceutical research.

These trials operated under strict regulatory oversight, with patient safety monitored by study physicians, principal investigators, research teams, laboratory personnel, the FDA, and Institutional Review Boards.

Compassionate use, also known as CUP, referred to the administration of investigational treatments outside of clinical trials for patients with serious or terminal conditions when no approved therapies were available. Participation in these programs required additional regulatory approvals to maintain patient safety, mirroring the standards upheld in interventional trials. When interest in trial participation arose, a comprehensive medical history review was conducted, followed by in-depth discussions with both patients and their providers to ensure full understanding and appropriate trial selection.

Informed consent served as a fundamental requirement in clinical research, ensuring that no procedures were initiated without documented approval from patients or their legal guardians. The process involved a comprehensive and often intricate form detailing the purpose of the trial, potential benefits and risks, confidentiality measures, compensation, alternative treatment options, and contact information for questions or concerns. This document clearly outlined participant rights and responsibilities, emphasizing that enrollment in any clinical trial was entirely voluntary and that participants could withdraw at any time without penalty.

Many research trials focused on pediatric populations, although adult participants were occasionally included. Consent procedures varied by age: individuals over 18 signed a standard consent form, while those under 18 received an assent form crafted to suit their comprehension level. Assent forms typically featured simplified language and visual elements to assist younger participants—usually between the ages of 7 and 17—in understanding the trial. In certain cases, trials were opened specifically for individual patients when a suitable study was identified, ensuring access to necessary treatments even if the trial was not yet active at the facility.

Cure 4 The Kids frequently ranked among the first institutions to enroll participants in clinical trials, including being the first site in the United States to enroll a patient aged 7 to 13 in an immune thrombocytopenia study. Chanelle Lochan then opened the floor for questions; none were asked.

Chair Logan-Parker remarked that the National Community Oncology Research Program (NCORP), a program of the National Cancer Institute (NCI), was affiliated with the Children's Oncology Group (COG) and played a key role in administering both NCI and COG clinical trials. These studies were made available throughout Nevada, including both Southern and Northern regions, with detailed information accessible via the NCORP website and its affiliated platforms. Chair Logan-Parker concluded by thanking Chanelle and Regan for their efforts.

8) INFORMATIONAL ITEM: Update on the Council's response to SB 78 (BDR 18-301) of the 83rd Legislative Session (2025). – *Chair Annette Logan-Parker*

Chair Logan-Parker then turned to the bill under discussion, which proposed revisions to the governance of boards, commissions, councils, and similar entities by centralizing oversight under the Department of Health and Human Services. The bill required that administrative services—such as legal and IT support—be provided by the department, while restricting boards from maintaining independent

websites or contracting services independently. It also placed the Rare Disease Advisory Council (RDAC) under review, with the possibility of dissolving or integration into another council depending on the final interpretation of the legislation. The bill remained under consideration, with active discussions surrounding the potential exclusion of the RDAC due to its unique role and proven effectiveness.

10) INFORMATIONAL ITEM: Update on the Rare Disease Dashboard, an overview of the list of rare conditions to be added to the dashboard. – *Chair Annette Logan-Parker; and Ashlyn Torrez, Health Program Specialist I, Office of State Epidemiology (OSE), Division of Public and Behavioral Health (DPBH)*

Chair Logan-Parker provided an update on the status of the state dashboard, noting that it was originally focused on sickle cell, lupus, and childhood cancer but had been expanded to include a broader range of rare diseases following approval from Jen and Ashlyn. A soft launch was scheduled for June, after the conclusion of the legislative session, to allow time for the integration of newly added conditions and final adjustments. The state compiled rare disease data primarily by cross-referencing listed conditions with Medicaid billing records. Additional case data, including those from Cure 4 The Kids for patients without Medicaid, were also set to be included, while the Office of Epidemiology continued exploring alternative methods to capture diagnosis-specific data more comprehensively.

Chair Logan-Parker then asked Ashlyn Torrez for an update on the progress. Ashlyn Torrez reported that a SAS (Statistical Analysis System) code was being developed in collaboration with Jen and her team to compile all relevant ICD-10 (International Classification of Diseases, 10th Revision) codes for the included conditions, with a more detailed update anticipated by the next meeting.

Chair Logan-Parker noted that significant progress had been achieved in childhood cancer data collection following the acquisition of the (CNEX) cancer registry platform by Cure 4 The Kids. This advancement enabled the electronic submission of cases directly to the Nevada Central Registry, streamlining a previously manual and labor-intensive process. A total of 120 cases had already been submitted, with a target to complete and submit all 2023 and 2024 cases by July. In addition, work had begun on entering sickle cell and lupus cases dating back to 2019 using REDCap reporting templates developed by Ashlyn and her team, although some final corrections were still pending.

Ashlyn Torrez added that approvals for the updated sickle cell form, designed to align with the REDCap database, were under review. The process had experienced delays due to recent staff turnover and absences, with an anticipated update expected by mid-April.

Chair Logan-Parker acknowledged that community sickle cell providers were still able to use the current form despite minor typographical errors, viewing them as a temporary issue. The transition to electronic transmission significantly improved data collection efficiency, particularly for childhood cancer cases submitted to the Nevada State Registry. Notable advancements were also made in building the necessary infrastructure for sickle cell and lupus reporting, recognizing that full implementation required time following earlier legislative efforts.

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

Chair Logan-Parker opened the floor for Council members to share information.

Hearing none, Chair Logan-Parker moved on.

13) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment.

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

14) 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 10:14 am.