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NEVADA RARE DISEASE ADVISORY COUNCIL - SUBCOMMITTEE DRAFT MEETING MINUTES

Date: 01/05/2023

09:32 am – 10:06 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 09:33 am.

1) INTRODUCTIONS AND ROLL CALL

SUBCOMMITTEE MEMBERS PRESENT:

(4) Annette Logan-Parker (*Chair*); Jennifer Millet, *DNP, RN*; Gina Glass (*Vice Chair*); Amber Federizo, *DNP, APRN, FNP-BC* (Quorum = 3)

SUBCOMMITTEE MEMBERS ABSENT:

Not Applicable

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

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

OTHERS PRESENT:

Amber Williams, *Cure 4 Kids Foundation*; Joseph Filippi, *Management Analyst, Director's Office, DHHS*; Craig Vincze, *PhD*; Naja Bagner; Ihsan Azzam, *MD, PhD*; Christina Thielst, *LFACHE, MHA*; Donna Laffey, *Ferrari Reeder Public Affairs*

Roll call was taken and is reflected above. It was determined that a quorum of the Rare Disease Advisory Council - Subcommittee (RDAC-SUBCOMMITTEE, the Council) was present.

2) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comment.

No public comment.

3) INFORMATIONAL ITEM: An introduction to the Strategic Plan Subcommittee. – *Chair Logan-Parker*

Chair Logan-Parker introduced the agenda item of familiarizing the members present with the title and purpose of the present meeting. Chair Logan-Parker recognized the name as the Subcommittee Strategic Planning also known as Strategic Planning Subcommittee Group. Chair Logan-Parker stated this is a trial by error process since individuals on the Council have volunteered additional time to the development of this meeting. Chair Logan-Parker stated the primary objective of the subcommittee, as was voted on, was to work on the Strategic Plan and to advance the Strategic Plan of the Rare Disease Advisory Council (RDAC). Moreover, Chair Logan-Parker stated the subcommittee plans to report all activities participated in to the Main RDAC Council every other month.

Chair Logan-Parker opened the floor for comment.

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

4) INFORMATIONAL ITEM: Review the Strategic Plan Subcommittee schedule. – *Chair Logan-Parker*

Chair Logan-Parker introduced the agenda item to review the Subcommittee schedule. Chair Logan-Parker confirmed the meeting times and dates as meeting every first Friday of the month at 9:30 AM, opposite the main Council meeting.

Chair Logan-Parker opened the floor for comment.

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

5) INFORMATIONAL ITEM: Review and discuss the Nevada Strategic Plan for 2023-2025 that serves as the initial framework for creating a collaborative approach of a comprehensive plan for the management of care of rare disease in Nevada, of the Rare Disease Advisory Council (RDAC). – *Chair Logan-Parker*

Chair Logan-Parker introduced the agenda item to review and discuss the Nevada Strategic Plan for 2023-2025. Chair Logan-Parker read the primary objectives listed in the Nevada Strategic Plan 2023-2025 document. Chair Logan-Parker announced page fifteen as the page which individuals can find the current rare disease areas of focus. Chair Logan-Parker included adolescent and young adult cancers in the statement as well as factor deficient and inherited platelet disorders. All the diseases on the newborn screenings totaled forty-six different conditions. There is ongoing conversation about the forty-seventh condition for newborn screenings. However, until the data compiled is confirmed, updates to this document will be made at the time of confirmation. Chair Logan-Parker stated that when developing the Nevada Strategic Plan 2023-2025 document, a survey was conducted of the cardiac board members and Council members. Chair Logan-Parker stated the survey was conducted within Legislative rules outlining the thirteen duties assigned when taking the survey. Chair Logan-Parker reaffirmed the process of placing the subcategories and voting on the importance of each. Chair Logan-Parker stated this is a refresher as to how the subcommittee formed the documents' structure. Chair Logan-Parker moved the conversation to review page nineteen, which illustrates awareness and education. Chair Logan-Parker

mentioned this is a brief overview to help get the discussion and thought process in the direction of intention. Chair Logan-Parker highlighted the bullet points on page nineteen. Chair Logan-Parker stated the three primary areas of focus as pillars: awareness, education, care and support, research, and data. Chair Logan-Parker stated the focus is on the creation and development of the Council's Awareness and Education Campaign by leveraging the network of RDAC for efficiency and effectiveness. Chair Logan-Parker expressed her interest in hearing from Subcommittee Member Amber Federizo, who has spoken with other RDACs in the country on how to be a successful RDAC. Chair Logan-Parker stated the need for promoting stability and solutions for individuals affected with a rare condition by establishing the creation of a comprehensive state plan. Chair Logan-Parker and the Council will work to develop compiled data sources to one accessible platform statewide.

Chair Logan-Parker opened the floor for comment.

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

- 6) **FOR POSSIBLE ACTION:** Review and possible action to approve the While You Wait Campaign rollout. This campaign is a While You Wait campaign, asking participants with rare diseases to help identify the extent of rare disease(s) in Nevada. These survey results will be used to improve quality of care and to advise state agencies on research, diagnosis, treatment, and educational needs relating to rare diseases. – *Council Members*

Chair Logan-Parker introduced the agenda item for the While You Wait Campaign rollout. Chair Logan-Parker stated the campaign is a While You Wait campaign. Chair Logan-Parker confirmed the concept is mirrored and expanded upon from the Pennsylvania State Rare Disease Advisory Council evaluation processes. Chair Logan-Parker reviewed the plan details which include developing the collateral materials which would include posters and brochures in English and Spanish. Chair Logan-Parker outlined that a Quick-response code (QR) code has been established to guide participants to the assessment. Chair Logan-Parker indicated the need to review the material one more time before the assessment is launched to the public for evaluation. Chair Logan-Parker encouraged board members and all individuals who know someone with a rare disease or are a caregiver or representative of someone to complete the While You Wait campaign. Chair Logan-Parker stated that a review should commence at the next subcommittee Council meeting to address any potential hiccups or obstacles which were not identified at the first review. Chair Logan-Parker stated she will follow up with an email to the Council members. Chair Logan-Parker stated everything is set up ready to go including the infrastructure in Redcap, the survey itself, Spanish translation, and QR Codes. Chair Logan-Parker transitioned to discuss with the Council that next steps are to determine how best to disseminate the information gathered to Southern and Northern Nevada, Cure 4 Kids Network, Pediatric offices, Urgent Cares, Emergency Rooms, and Specialty Providers. Chair Logan-Parker announced Shirley Folkins Roberts volunteered the staff at Northern Nevada Cancer Institute. Chair Logan-Parker wants to brainstorm with the Council on ways to get Rural Nevada involved also.

Ms. Christina Thielst spoke, stating a meeting with the Childhood Cancer Foundation took place a couple of weeks ago. Ms. Thielst knows how to get back in touch with this group electronically to gain ideas moving forward. Ms. Thielst also mentioned she would be happy to distribute materials to the

Childhood Cancer Foundation neuromuscular specialist. Ms. Thielst requested a list of other members who may need the material so she may circulate the material appropriately.

Subcommittee member Jennifer Millet spoke, stating intentions of working with the pediatric department at University Medical Center. Ms. Millet believes the outreach department would be a good resource regarding this topic. Ms. Millet inquired about page nineteen on the pillars of success, care, and support, networking platform. Ms. Millet mentioned under the newborn screenings, new mothers typically cannot be located to be notified if a possible condition was found. Ms. Millet suggested to the Council that on the platform an option be created to help track where the parent can be located to notify when something arises. Ms. Millet feels that this will help to make the RDAC platform more valuable to others in the future.

Chair Logan-Parker suggested the colleagues and peers over at newborn screenings along with Dr. Summit Gupta should be invited to the next subcommittee meeting. Chair Logan-Parker stated they would be great resources to help collaborate and find solutions to adding this into the platform. Chair Logan-Parker supported and agreed with Ms. Millet that it is a lot of effort to track down mothers so having a way to minimize the efforts would be beneficial to many.

Dr. Craig Vincze spoke to acknowledge his desire for participation in working with University Medical, Shirley Folkins-Roberts at Norther Nevada Children's Cancer Foundation, and cancer specialists on the While You Wait campaign.

Subcommittee member Gina Glass spoke to inquire if anyone knew of a Rare Disease Day or week. Ms. Glass mentioned she recalls in 2019 or 2020 at the Grant Sawyer Building it was well attended by medical providers, personnel, and politicians. Ms. Glass believes this is an opportunity for the While You Wait campaign to be shared in the community to the right peer groups who understand and could benefit from the platform.

Recording timestamp 33:55 (09:49 AM) Naja Bagner put into the chat: "Yes Gina it did turn out nice that year and we had food."

Chair Logan-Parker reiterated that she would send out an email survey to the Council members requesting a few posters the RDAC would like to supply. Chair Logan-Parker would like to have as many individuals as possible go out to the communities to visit the big players in person as this will be the most helpful way to spread the word.

Joseph Filippi Recording timestamp 38:24 (09:53 AM) Joseph Filippi put into the chat: "It might be worth speaking with Nevada Rural Hospital Partners who represent the thirteen critical access hospitals in rural Nevada. <https://nrhp.org/contact/>."

Chair Logan-Parker thanked Mr. Filippi for his comment. Chair Logan-Parker stated this is the plan, and she will be doing a final headcount and then get posters printed. Chair Logan-Parker mentioned that 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 Rare Disease Advisory Council. Chair Logan-Parker

welcomes all individuals who want to add any information or data into this project by emailing her directly. Chair Logan-Parker mentions she participated in a conversation on January 4, 2024, with Lindsey from National Organization for Rare Diseases (NORD). Chair Logan-Parker introduced Lindsey as an individual who has been with the NORD organization for the last six months. Chair Logan-Parker stated Lindsey is responsible for helping the 26 western RDACs that are either in the process of getting established in legislation or have been established. Chair Logan-Parker spoke with Lindsey about the 'While You Wait' campaign and Lindsey said she is willing to use the NORD network within the area to help capture the correct audience. Chair Logan-Parker expressed her excitement for the launch of the While You Wait Campaign addressing two things, one being education regarding activities of the RDAC, and the purpose of being interested in data collection from the community.

Amber Williams Recording timestamp 40:00 (9:55 AM) Amber Williams put into the chat: "Lindsey Viscarra."

Chair Logan-Parker stated that since the Council was discussing the While You Wait campaign, there is nothing to be voted on at this time. Chair Logan-Parker asked the Council for any other comments.

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

7) FOR POSSIBLE ACTION: Discussion and possible action to survey each Rare Disease Advisory Council's (RDACs) that are a part of the National Network of RDACs. – *Council Members*

Chair Logan-Parker introduced the agenda item to introduce and discuss the National Network of RDACs. Chair Logan-Parker asked Amber Federizo if she was willing to share her experience since Ms. Federizo was in the Chair position at the time of reaching out to different RDACs. Chair Logan-Parker asked Ms. Federizo how her time spent may have impacted the National Network, data process or altogether if anything was identified through the process of surveying.

Subcommittee member Amber Federizo commented on her experience. Ms. Federizo stated that she originally reached out to NORD and at the time, NORD was holding webinar meetings which included all newly formed RDACs. The NORD meetings were collaborative meetings between any of the National RDACs who were interested. Ms. Federizo found this immensely valuable to see what other RDACs were doing and how they are structured. Ms. Federizo found that very few RDACs were created, however, unless there was a fiscal note. Other states' legislators didn't push their RDAC through their legislative process unless there was funding behind it. Many of the other states RDACs were created and had the funding to be successful. That was one of the glaring differences between many of the different States and the State of Nevada. Ms. Federizo stated additionally there are many RDACs who had varying levels of structure, so their states had informal meeting structures. Ms. Federizo stated that other states RDACS did not have to follow public body laws that the state of Nevada has, and other states RDAC was able to meet without needing to provide a 72-hour notice. Therefore, these Councils could come together in a quick fashion for situations that would arise with late notice rather than a 72-hour notice. Ms. Federizo stated the biggest differences were that many of the RDACs were given a legislative bill draft request (BDR) to submit every year and had full support from the legislature. Ms. Federizo added that if the Council can get reconnected with NORD to gain support when reconnected with legislature to get on those meetings would be best. Ms. Federizo does not know

how frequently the meetings are being held. Ms. Federizo stated when everyone was telecommuting during COVID things seemed to go smoother. Ms. Federizo found her time immensely valuable and believes her synopsis highlights what the other states are doing and what Nevada needs to do to stay current and valid in legislature by attaching the monetary fiscal note to the RDAC. Ms. Federizo told the Council that she does not want this to be a press release opportunity, rather she hopes it is an ongoing process where support is gained on an ongoing basis.

Chair Logan-Parker appreciated Ms. Federizo's guidance and insight into her experience. Chair Logan-Parker also mentioned that she is not surprised by these findings as in the previous Rare Disease Advisory Council Meeting in December when the Annual Report was discussed the underfunding was a main topic of interest. Chair Logan-Parker expressed that the RDAC survey showed the interests of the Council Members and the need to evaluate rare diseases in the state of Nevada. Chair Logan-Parker continued that the evaluation of rare disease through the 'While You Wait' Campaign will be able to take the data collected and present to other states RDAC on a national level that could be imperative to change the state of Nevada's RDAC in the 2025 Legislative Session. Chair Logan-Parker stated this information can be used to determine if this was something the Council members would want to consider or not. Chair Logan-Parker greets Dr. Ihsan Azzam.

Recording timestamp 46:00 (10:01 AM) Ihsan Azzam put into the chat: "Hello Everybody - Sorry for joining late. I had to deal with an emergency this morning."

Dr. Ihsan Azzam greets the Council and apologizes for his tardiness.

Chair Logan-Parker notified Dr. Ihsan Azzam that the Council members are reviewing the strategic plan and are planning how to establish the While You Wait campaign processes. Chair Logan-Parker stated she does not think the Council necessarily need to vote on anything currently. Chair Logan-Parker went on to state that in the Main Council meeting a discussion took place that a vote will occur in the future on how to move forward with the obstacles which may be faced during the process of getting together the survey instrument. Chair Logan-Parker would like to work on having questions prepared and a survey instrument by the March Subcommittee meeting date so that the Council can vote on it at that time. Chair Logan-Parker asked if everyone agrees with the March timeline then this can be the plan moving forward.

Chair Logan-Parker opened the floor for comment.

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

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

Chair Logan-Parker introduced the agenda item for announcements. Chair Logan-Parker announced her role as Chief Executive Officer (CEO) of Cure 4 Kids Foundation has changed to take on a different role of advocacy and innovation within the community where a higher level of strategic planning can take place. Chair Logan-Parker is giving the day-to-day operations to Christine Tonn, the new CEO for Cure 4 Kids Foundation.

Recording timestamp 48:56 (10:04 AM) Naja Bagner put into the chat: “Stepped out for the bathroom. Sorry.”

Chair Logan-Parker won the State Advocacy Award also known as the Rare Voice Award, Every Life Foundation. The State of Nevada was recognized at the federal level where Chair Logan-Parker was recognized for the RDAC Council by Every Life Foundation. Chair Logan-Parker stated that the Council was up against Pennsylvania, Ohio, and Texas. Chair Logan-Parker mentioned it was an honor to represent the State of Nevada. Chair Logan-Parker was given the award as a result of [SB 221](#) of the 82nd Legislative session, which is a Senate Bill that Cure 4 Kids Foundation has been working on. Chair Logan-Parker mentioned the primary sponsors for SB 221 are Senator Fabian Doñate (D), Senator Jeff Stone (R), and Senator Carrie A. Buck (R). Chair Logan-Parker mentioned she feels it was great to represent and it is her opinion that Nevada rarely gets recognized at the national level, so this was an exciting venture.

Subcommittee member Gina Glass and Chair Logan-Parker plan on going to the Rare Disease Week, taking place in Washington DC, February 25, 2024.

Chair Logan-Parker opened the floor for comment.

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

9) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment.

Hearing none, Chair Logan-Parker moved to adjourn.

10) ADJOURNMENT – *Chair Logan-Parker*

Chair Annette Logan-Parker moved to adjourn and expressed appreciation for everyone on the Council.

Chair Annette Logan-Parker moved to adjourn the meeting at 10:06 am.