

Joe Lombardo
Governor

Richard Whitley,
MS
Director



Cody Phinney,
MPH
Administrator

Ihsan Azzam,
Ph.D., M.D.
Chief Medical
Officer

NEVADA RARE DISEASE ADVISORY COUNCIL MEETING MINUTES

Date: June 2, 2023

2:30 pm – 3:28 pm

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 2:36 pm.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Annette Logan-Parker (CHAIR); Gina Glass (Vice-Chair); Ihsan Azzam, MD, PhD; Shirley Folkins-Roberts; Valerie Porter, DNP, BSN, MBA; Kimberly Palma Ortega; Naja Bagner; Paul Niedermeyer; Craig Vincze, M.D.; and Christina Thielst (Quorum=9)

COUNCIL MEMBERS ABSENT:

Veneta Lepera; Amber Federizo, DNP, APRN, FNPBC (excused absence); Nik Abdul Rashid, MD (excused absence); Susana Sorrentino, M.D.; Jennifer Millet, DNP, RN (excused absence); and Linetta Barnes, BSN, RN

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

Ashlyn Torrez, *Health Program Specialist I, Office of Public Health Investigations and Epidemiology (OPHIE), DPBH*; Elizabeth Kessler, *Health Program Manager I, OPHIE, DPBH*; Sherry Stevens, *Administrative Assistant III, DPBH*; and Julia Peek, *Deputy Administrator, DPBH*

OTHERS PRESENT:

Penni Echols, *Briza Virgen, Social Services Chief I, Medical Programs, Division of Healthcare Financing and Policy (DHCFP)*; Kaelyne Day, *Social Services Specialist III, DHCFP*; Malinda Southard, *Executive Director, DHCFP*; Brigette Cole, *Assistant Executive Director, Northern Nevada Children's Cancer Foundation*; Kathleen Kingston; and Amber Williams, *Executive Leadership Support, Special Projects, Cure4Kids Foundation*

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.

Ms. Kathleen Kingston introduced herself and stated that she heard about the rare disease council yesterday at the Nevada Governor's Council meeting that she attended. Ms. Kingston stated that her son, John Jack Kingston, has a rare genetic condition called tuberous sclerosis complex (TSC), and Ms. Kingston has been volunteering for the TSC reliance for many years. Ms. Kingston added that she is the Co-Chair of the TSC Alliance of Nevada for the Las Vegas area. Ms. Kingston stated that TSC causes benign tumors to grow major organs such as, brain, heart, kidneys, lungs, and are often causes of seizures and autism, both of which her son John Jack Kingston has. Ms. Kingston added that the TSC Alliance was formed by four mothers in 1974 and has made tremendous strides. Ms. Kingston continued that in 2001, a grandfather of two identical twin girls got the first \$1,000,000 appropriated for medical research and has since grown with lots of advocacy over the years to \$113,000,000. Ms. Kingston stated that TSC Alliance has been a major contributor to the rare disease community as TSC Alliance collaborates with different rare disease organizations. Ms. Kingston commented that the RDAC focus at this time is on specific diseases and due to the Council being new and the lack of funding, Ms. Kingston would love to be a resource. Ms. Kingston commented that she would love to learn for about the Council, come to the Council's meetings, and when a spot opens up on the Council, she would like to put in her application. Ms. Kingston thanked the Council for an opportunity to talk.

Chair Logan-Parker expressed her appreciation for Ms. Kingston joining the Council meeting today, and thanked Ms. Kingston for her interest in the work RDAC is currently doing. Chair Logan-Parker then asked Ms. Penni Echols to speak.

Ms. Penni Echols introduced herself, and stated that she lives in Las Vegas with her family. Ms. Echols stated that her youngest daughter was born in 2014 with a complex congenital heart defect and was later diagnosed with CHARGE syndrome. Ms. Echols stated that her youngest daughter just finished third grade and loves to swim, read, and learn about places on the map. Ms. Echols continued that during this week her daughter and herself checked out books from the library about Arizona and the Grand Canyon, and Ms. Echols's daughter was trying to convince her parents into a quick vacation. Ms. Echols stated that she is here in the Council meeting as the Nevada Liaison for the CHARGE Syndrome Foundation and Member of their Board of Directors. Ms. Echols continued that the CHARGE Syndrome Foundation mission is to champion the lifelong potential of people with CHARGE syndrome through outreach, education, and research. Ms. Echols wanted the Council to be aware of the CHARGE Syndrome Foundation's (the Foundation) Medical Travel Assistance Program. Ms. Echols stated that the Medical Travel Assistance Program was created in the spring of 2020 in response to increased needs of families related to the COVID-19 pandemic. Ms. Echols added that the Medical Travel Assistance Program has continued to receive donations, and the program expanded to include supporting families of individuals with CHARGE who need to receive medical care that requires travel out of state or over a long distance. Ms. Echols stated that her volunteer work with the Foundation is to connect Nevada families to the Foundation's programs. Ms. Echols expressed her happiness with assisting an family with CHARGE Syndrome diagnosis through the simple preauthorization process. Ms. Echols expressed that travel for

medical care is a severe strain on Nevada families impacted by rare disease, and causes a heavy financial burden of leaving work even for one or two days, often without pay is only the beginning of what makes traveling for care hard. Ms. Echols expressed that the stress on the child is immense as well as on the families. Ms. Echols stated that her day job is working for Nevada Hands & Voices as a Parent Guide for families identified in the newborn hearing screening process. Ms. Echols added that the etiologies of many rare diseases include hearing loss, and the Early Hearing Detection and Intervention Program that provides the screening process that the program provides allows the families to be alerted to deeper medical or genetic condition with their precious newborn. Ms. Echols continued that she assists newly screened families who are also navigating the rare diagnosis process. Ms. Echols strongly expressed that she sees no improvement over the last eight years in the availability of specialized medical care in Nevada. Ms. Echols commented that families still face long waits for clinic visits with genetics, neurology, and ear, nose, and throat surgeons. Ms. Echols stated that there is extreme anxiety for families and a delay in care for newborns. Ms. Echols added that in the last month, she knows of families who have traveled to Los Angeles, Salt Lake City, and Palo Alto for medical care. Ms. Echols commented that the lack of providers in Nevada is burdensome, dangerous, and in some situation's life threatening. Ms. Echols felt that raising awareness of the needs of individuals living with rare diseases in Nevada is the first step towards improving their quality of life. Ms. Echols thanked the Council for providing a forum for her to raise her concerns. Ms. Echols expressed her appreciation for the Council, and asked the Council to connect with her with any individuals who may benefit from the resources of the CHARGE Syndrome Foundation programs. Ms. Echols stated that a copy of her written copy of her public testimony was provided to Ms. Torrez with her contact information.

Chair Logan-Parker thanked Ms. Echols for her comments, and stated that the Council is pleased to have Ms. Echols on the Council meeting. Chair Logan-Parker asked if there was anyone else that would like to provide public comment.

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

- 3) FOR POSSIBLE ACTION: Approval of minutes from April 7, 2023, Rare Disease Advisory Council Meeting. – *Council Members*

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

Chair Logan-Parker asked the Council if there was any edits needed to the meeting minutes from the last Council meeting. Hearing none, the Council moved on to a vote.

Councilmember Valerie Porter motioned to approve the meeting minutes from prior council meeting dated April 7, 2023. Councilmember Shirley Folkins-Roberts seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

- 4) FOR POSSIBLE ACTION: Discussion and possible action to approve the Strategic Plan updates. – *Council Members*

Chair Logan-Parker introduced agenda item number four, and stated that for simplicity, the strategic plan is built around three pillars, awareness and education, care and support, and research and data. Chair Logan-Parker added that the three pillars are based off the objectives given to RDAC through Senate Bill 315 (SB315). Chair Logan-Parker continued that each of the three pillars will have two priorities associated with each pillar. Chair Logan-Parker added that the strategic plan will also list out some action items that will keep the Council focused and on target over the next couple of years. Chair Logan-Parker asked the Council for a motion to have a discussion about the details of the strategic plan.

Chair Logan-Parker stated that there will be one edit to the strategic plan, to edit the zip code where the strategic plan puts Ms. Ashlyn Torrez as the contact to reach out to for anything related to RDAC, is missing one digit.

Councilmember Dr. Craig Vincze commented that the strategic plan is very well done and the analogy of using a zebra is really powerful.

Chair Logan-Parker thanked Dr. Vincze for his comment.

Councilmember Paul Niedermeyer commented that he would like to suggest to add an AI component to the strategic plan. Mr. Niedermeyer stated that in April of 2023, healthcare software giant Epic announced that Epic partnered with Open AI Services, the makers of Chat, GPT, and Microsoft, to integrate GPT 4, which is the latest generation of AI software that is available only now under subscription for \$20 a month. Mr. Niedermeyer added that Epic is incorporating the AI services into the Epic electronic healthcare record (HER) system and chat GPT. Mr. Niedermeyer clarified that GPT is an artificial intelligence system. Mr. Niedermeyer stated that in Northern Nevada Epic EHR is used in Renown, Saint Mary's Regional Medical Center, owned by Primary Healthcare that has a national footprint in 30 to 40 locations such as Carson, Tahoe Health, and other use Epic. Mr. Niedermeyer commented that the several pilot programs with generative AI have already started at USC in San Diego, University of Washington, Standard and Stanford Healthcare. Mr. Niedermeyer commented that if an AI component is added to the strategic plan, what does that mean in practical terms to the RDAC. Mr. Niedermeyer stated that in practical terms, there will be more instances of rare disease will be diagnosed generally and more quickly. Mr. Niedermeyer added that providers will be able to take the full constellation of symptoms assessments that are done themselves or by other practitioners or nurses, and the system in real time will then be able cross reference the patients with all their assessment data, their vitals, and everything. Mr. Niedermeyer recommended that the AI systems may fall within the criteria for the different types of rare diseases that will be specific testing that is done because 80% of the rare disease today is genetic. Mr. Niedermeyer is talking about the Symptomology and what is currently embedded within the electronic health record (EHR) systems. Mr. Niedermeyer mentioned that what is in the patient's current admit profile but everything that is in the HER for that patient for all of their admissions and all the systems that communicate with Epic. Mr. Niedermeyer reiterated that the patients will be diagnosed generally and more quickly. Mr. Niedermeyer commented that RDAC needs to incorporate AI into the strategic plan because it would be simple and deductive. Mr. Niedermeyer added that Epic would use GPT 4 that will analyze patient data as Mr. Niedermeyer mentioned before in EHR and offer the provider probable diagnosis that conformed the collective patient data. Mr. Niedermeyer continued that RDAC needs to be involved in AI now for two reasons, first to ensure that rare diseases of highest incidence and prevalence are readily available in all EHR systems that use AI in Nevada

generally. Mr. Niedermeyer added that RDAC agrees and concurs with the criteria that is used to diagnose each rare disease in the system as the AI systems comes online like chat, GPT or barred. Mr. Niedermeyer clarified that a barred system is a system that is used by Google as he is sure that Google will eventually be partnering with other EHR systems as there will most likely be a great need to develop a diagnostic and statistical manual of rare disease. Mr. Niedermeyer commented that he assumed that the statistical manual of rare disease does not exist as he is not aware of one existing today. Mr. Niedermeyer added that perhaps a good analogy would be the mental illness manual, DSM-5 or The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition by the American Psychiatric Association. Mr. Niedermeyer stated that the process of developing such a manual will take some time, but is imperative that RDAC procures a seat at the table to ensure at a minimum common rare diseases in Nevada and their criteria are recognized. Mr. Niedermeyer added that the National Organization for Rare Disorders (NORD) and others will likely lead the effort of establishing a manual on rare diseases. Mr. Niedermeyer continued that ideally the Council will want to ensure as many rare diseases in Nevada are recognized and receive priority so patients can receive the care they need.

Chair Logan-Parker thanked Mr. Niedermeyer and asked where he felt the suggestion should fall under awareness and education.

Mr. Niedermeyer confirmed that his recommendation would fall under awareness and education. Mr. Niedermeyer added that companies that are using artificial intelligence technology and are providing EHR software are addressing the concerns and needs of Nevada. Mr. Niedermeyer thought it would be appropriate and helpful to have awareness and education on artificial intelligence and what the opportunities would look like for Nevada.

Councilmember Ms. Christina Thielst commented that she agrees with Mr. Niedermeyer. Ms. Thielst added that she was in a position for seven and half month delay on getting a diagnosis for her condition and sometimes for others it takes even longer to get a diagnosis.

Mr. Niedermeyer commented that the reason as to why the AI technology transition is important is because if there is not a general consensus on what a rare disease diagnosis for a specific condition it will be difficult for the patient to get insurance coverage.

Chair Logan-Parker thanked Mr. Niedermeyer and asked if there was any other discussion.

There was none, the motion was put for a vote for possible action.

Councilmember Christina Thielst motioned to approve the Strategic Plan updates. Councilmember Shirley Folkins-Roberts seconded the motion to approve. There were no objections. A quorum voted to approve the Strategic Plan updates.

- 5) FOR POSSIBLE ACTION: Discussion and possible action to merge the Needs Assessment Data Collection and Strategic Plan Subcommittees into one subcommittee and get volunteers who would like to participate. – *Council Members*

Chair Logan-Parker stated that she would like to merge the two subcommittees into one subcommittee that would be the Strategic Plan Subcommittee. Chair Logan-Parker felt that it would be best to have one subcommittee to manage all of the efforts of the Councils' initiatives. Chair Logan-Parker requested a motion to further discussion.

Councilmember Valerie Porter motioned to approve the Strategic Plan updates. Vice-Chair Gina Glass seconded the motion to approve. There were no objections. A quorum voted to approve merging the two subcommittees into one subcommittee, the Strategic Plan Committee.

- 6) FOR POSSIBLE ACTION: Discussion and possible action to attend the Nevada Division of Health Care Financing and Policy (DHCFP) and the Mercer Government Human Services Consulting (Mercer) Discussion of Nevada System of Care for Children with Rare Disease. – *Council Members*

Chair Logan-Parker stated that there are some representatives from Nevada Medicaid here to assist with discussion if needed. Chair Logan-Parker added that the state of Nevada has approved a study to review the Nevada system for care for children with rare diseases, and the study is being conducted with Mercer Government Human Services Consulting (Mercer). Chair Logan-Parker stated that the Council has been invited to participate in the stakeholder interview with Mercer that will be a 90 minute interview per stakeholder. Chair Logan-Parker added that the goal would be to get the perspectives of each stakeholder entity, and those Council members that cannot attend the stakeholder interview can submit a written response via the interview guide template that was sent out to the Council. Chair Logan-Parker felt that the questions were geared towards providers of services and or health facilities for people with rare disease, and some of the members of RDAC the questions are not applicable but will still be able to provide valuable insights. Chair Logan-Parker stated that if the Council is interested in attending the stakeholder interview or if the Council cannot attend to fill out the completed form by June 30th. Chair Logan-Parker asked the representatives from Nevada Medicare to speak on how RDAC can best provide support and valuable information.

Ms. Briza Virgen thanked the Chair and the members of RDAC for their time. Ms. Virgen introduced herself and stated that she works for the Division of Healthcare Financing and Policy (DHCFP). Ms. Virgen introduced Kaelyne Day who is the program manager over physician services. Ms. Virgen stated that Ms. Erin Lynch is the Chief here in the unit at Medicaid and over the Medical Programs Unit, and Ms. Virgen added that Ms. Lynch is apologizes for not being able to join the RDAC meeting. Ms. Virgen stated that Mercer has been contracted with ARPA funds that was given to DHCFP. Ms. Virgen added that Mercer is really here to provide technical support via research and consulting services to address the needs of children with special healthcare needs. Ms. Virgen commented that the goal is to understand the root causes of issues that would be happening with reimbursement for providers providing care for children in need of specialty care. Ms. Virgen felt that understanding how other states address the similar challenges that Nevada faces as well as the other Medicaid programs throughout the states since not every Medicaid program is same. Ms. Virgen thought that working with other stakeholders would allow for indemnification Medicaid policy best practices and potential reimbursement practices for providers providing specialty care. Ms. Virgen stated that Mercer also sent a letter to renowned pediatric cancer car and a hematology clinic. Ms. Virgen added that Mercer is working on trying to get another contact, and asked the Council for a potential contact that Mercer can reach out to get the information.

Ms. Brigitte Cole commented that she sent out an email to Ms. Lynch and connected DHCFP with Dr. Johnston, who oversees the renowned pediatric hematology oncology department. Ms. Cole added that she also connected DHCFP with Larry Duncan who oversees the renowned children's hospital, and Suzanne would be copied on the email is his assistant. Ms. Cole was hopeful that someone would reach out.

Ms. Virgen thanked Ms. Cole and added that she was hoping to work with the Cure4Kids Foundation. Ms. Virgen asked the Council if there was any recommendations of anyone else to reach out to.

Chair Logan-Parker commented that she sent an email with a long list of recommendations for people to include in the stakeholder interview. Chair Logan-Parker added that her recommendations included all the of the sub-specialists that treat children with rare diseases in both northern and southern Nevada. Chair Logan-Parker continued that she had quite a few people that come off the top of her head that could provide good insight on care for children with rare diseases within the community.

Ms. Virgen stated that would be wonderful to get all the recommended folks contact information. Ms. Virgen asked Ms. Kaelyne Day to put Ms. Virgen's, Ms. Erin Lynch's, and Ms. Kaelyne Day to put their emails in the chat.

The following was put into the chat by Ms. Kaelyne Day (recording timestamp 00:35:40):
"Briza Virgen bvirgen@dchfp.nv.gov"

The following was put into the chat by Ms. Kaelyne Day (recording timestamp 00:35:46):
"Kaelyne Day Kaelyne.day@dchfp.nv.gov"

The following was put into the chat by Ms. Kaelyne Day (recording timestamp 00:35:56):
"Erin Lynch erin.lynch@dchfp.nv.gov"

Ms. Virgen commented that the interview guide are tailored to the clinics and providers that work directly with the families, but if the Council is able to review the questions before the stakeholder interview. Ms. Virgen stated that Mercer and DHCFP are working on developing a separate guide question for the Northern Nevada Children's Cancer Foundation. Ms. Virgen stated that the interview could be a lot shorter than the time limit of 90 minutes if some of the questions does not apply. Ms. Virgen was hopeful to complete the stakeholder interviews by the end of June. Ms. Virgen stated that Mercer will do research within other states and will report back to DHCFP by the end of December.

Chair Logan-Parker recommended that Northern Nevada Childhood Cancer Foundation questionnaire gets sent to some of the folks in south that is similar to the Northern Nevada Child Cancer Foundation, specifically Jeff Warden is the CEO in the south. Chair Logan-Parker added that Candlelighters Childhood Cancer Foundation of Nevada in the south and provides a lot of services for children with cancer, particularly Kimberly Kindig, CEO. Chair Logan-Parker continued that she would get the contact information over to Ms. Virgen.

Ms. Cole with the Northern Nevada Children's Cancer Foundation, commented that there are many patients that are seen for rare diseases and are seen at centers of excellence such as Stanford, UC David

Children's Primary, but live in Nevada. Ms. Cole thought it would be beneficial to look into those centers of excellence to capturing everything. Ms. Cole added that if the centers of excellence take Medicaid for service that is accepted at Stanford as well as Children's Oakland, and there may be some Medicaid managed care organizations are accepted into Utah. Ms. Cole continued that she would pass along the contact information if Ms. Virgen was interested.

Ms. Virgen thanked Ms. Cole, and stated that she was interested. Ms. Virgen added that for the out of state providers there are different reimbursement methodologies that can be assessed. Ms. Virgen continued that if the out of state providers are reimbursed in a similar way to Nevada then DHCFP will want to have a discussion with those providers. Ms. Virgen commented that if the methodology are different with letters of agreement or something similar, then that would a separate than how Nevada reimburses providers.

Ms. Cole commented that she would not be able to speak on how the out of state providers are being reimbursed. Ms. Cole added that she would provide a list of other foundations in Northern Nevada that also serves rare disease patients.

Ms. Virgen commented that the list would great to have to be able to cross reference and get what DHCFP needs.

Chair Logan-Parker asked if there was anyone else in the Council who would like to comment.

Hearing none, Chair Logan-Parker thanked Ms. Virgen for their time. Chair Logan-Parker moved on the net agenda item.

- 7) FOR POSSIBLE ACTION: Discussion and possible action to get volunteers to attend National Organization for Rare Disorders (NORD) RDAC Leaders Meeting with Chair Logan-Parker. – *Council Members*

Chair Logan-Parker stated that NORD will be hosting an RDAC leadership meeting in person in Washington, DC on October 15, 2023. Chair Loga-Parker added that she was planning on being in attendance, and thought that NORD might have some funds to provide coverage for the travel and hotel for two members of each RDAC across the country. Chair Logan-Parker commented that she will be covering her own travel that could either open up two spots for the Nevada RDAC to attend but she was not certain. Chair Logan-Parker stated that she has emailed and called to get confirmation but has not received an answer yet. Chair Logan-Parker felt that the RDAC leadership meeting would be a great opportunity to build relationships with other RDACs and to see what other states are doing and get involved. Chair Logan-Parker stated that those that are interested in attending email Ashlyn Torrez.

Vice Chair Gina Glass commented that she has gone to the NORD RDAC meeting once or twice before with her organization Dreamsickle Kids Foundation. Vice-Chair Glass added that she used the travel scholarship that the organization applies for each year to attend. Vice-Chair Glass continued that she would not need the funds so if other council members are interested, those members can go.

Chair Logan-Parker thanked Vice-Chair Glass. Chair Logan-Parker stated that if any members are interested in attending to email Ashlyn Torrez.

8) INFORMATIONAL: Update on the Needs Assessment platform. – *Chair Logan-Parker*

Chair Logan-Parker stated that the needs assessment has been built into RedCap, the system that the Council agreed to use. Chair Logan-Parker was hopeful that she would have a preview and final approval for the Council at the next meeting in August. Chair Logan-Parker added that she was getting the needs assessment translated to Spanish, and found that the RedCap server has additional languages available of which is being explored. Chair Logan-Parker felt a safe time frame to roll out the needs assessment campaign and survey by the end of January. Chair Logan-Parker added that she wanted to work out the bugs in the platform before publishing. Chair Logan-Parker opened the floor to the Council for any comments, questions, or concerns.

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

9) INFORMATIONAL: Update on the Sickle Cell and Data Collection (SCDC) grant and for the sickle cell and lupus regulations LCB File No. R107-22 and R108-22 as it relates to the building the data registries for the respective rare diseases. – *Ashlyn Torrez, Health Program Specialist I, Office of Public Health Investigations and Epidemiology (OPHIE), DPBH*

Chair Logan-Parker introduced Ms. Ashlyn Torrez and opened the floor to Ms. Torrez.

Ms. Torrez thanked Chair Logan-Parker. Ms. Torrez stated that she going to provide an update on the data registries for lupus and sickle cell. Ms. Torrez announced that the Legislative Council Bureau (LCB) File No. R107-22 and R108-22, both of these bills are to establish a system of reporting for lupus and sickle cell and their variances was presented to the Board of Health this morning and were both approved. Ms. Torrez expressed her excitement on getting the registries up and running for Nevada. Ms. Torrez added that the Sickle Cell Data Collection grant was submitted to the Centers for Disease Control and Prevention back in May. Ms. Torrez expressed her gratitude towards the Chair and the Council for their time and support in both the grant and the bills. Ms. Torrez asked if there was any questions or comments.

Chair Logan-Parker thanked Ms. Torrez and expressed her appreciation in Ms. Torrez's work in submission of the grant and getting the data registries where they need to be. Chair Logan-Parker asked the Council if there any questions for Ms. Torrez.

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

10) INFORMATIONAL: Council member information sharing announcements. – *Council Members*

Chair Logan-Parker stated that she had two items to share with the Council. Chair Logan-Parker continued that the Governor's Council on Developmental Disabilities invited RDAC to speak at their meeting on June 1st and some folks joined RDAC as a result. Chair Logan-Parker commented that she

presented about the efforts that RDAC is doing. Chair Logan-Parker continued that the newborn screening program was also in attendance of the Council of Developmental Disabilities meeting and felt the newborn screening program was very informative. Chair Logan-Parker felt that her presentation went well and both RDAC and Council of Developmental Disabilities have agreed to keep each other informed in the future. Chair Logan-Parker stated that the second item she wanted to inform the Council about is the RDAC website getting their first inquiry. Chair Logan-Parker added that someone found them on social media and went to the RDAC website and sent an email with some questions. Chair Logan-Parker felt the process worked well and felt excited about the RDAC efforts are being seen and having a positive impact. Chair Logan-Parker asked the Council if there was anything they would like to share.

Hearing none, Chair Logan-Parker moved on to public comment.

11) PUBLIC COMMENT

Chair Logan-Parker opened the floor for public comment.

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

12) 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 3:28 pm.