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## DEPARTMENT OF HUMAN SERVICES



NEVADA DIVISION of PUBLIC  
and BEHAVIORAL HEALTH



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### NEVADA RARE DISEASE ADVISORY COUNCIL

#### DRAFT MEETING MINUTES

Date: August 01 2025

9:32 AM – 11:21 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 9:32 am.

#### 1) INTRODUCTIONS AND ROLL CALL

##### **COUNCIL MEMBERS PRESENT:**

Annette Logan-Parker (CHAIR); Gina Glass (Vice-Chair); Valerie Porter, DNP, APRN, AG-ACNP-BC, MBA; Ihsan Azzam, MD, PhD; Paul Niedermeyer; Sumit Gupta, MD; Kim Anderson-Mackey; Melissa Bart-Plange; Pamela White; Dr. Verena Samara; Madison Bowe; Amber Federizo, DNP, APRN, FNPBC; Jennifer Millet, DNP, RN; Naja Bagner; and Brigitte Cole

##### **COUNCIL MEMBERS ABSENT:**

Craig Vincze, PhD (excused); Christina Thielst; and Dr. Devraj Chavda

##### **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:**

Dr. Williams Evans, *Cure 4 the Kids*; Sabrina Schnur; Linda Anderson; Cade Grogan; Claire Wells, *Orchard Therapeutics*; Dr. Iljana M Gaffar MD, FAAP; Jaromy Russo, *Cure 4 The Kids*; Judy Akin; Mallory Carvalho; Scott Rosenzweig, *Make A Wish Nevada*; Susheela Jayaraman, *Orchard Therapeutics*; Jen L. Thompson, *OoA (Office of Analytics), Nevada Health Authority, DHS (Department of Human Services)*; Emilia Wilburn; and Meosha Williams

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

## 2) PUBLIC COMMENT

Ashlyn Torrez opened the floor for public comment helping the Chair.

Dr. Ihsan Azzam put into the chat at 9:37 AM: “Hello Everybody and good seeing you all. Unfortunately I will have to drop out at 10:00 am to join another required meeting. Thank you and have a great day/weekend.”

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

## 3) FOR POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from June 6, 2025.

Chair Logan-Parker stated the minutes have been posted on the Department of Health and Human Services (DHHS) [DHHS changed to DHS starting 07/01/25] website and asked the Council for a motion to approve the minutes.

**Councilmember Kim Anderson-Mackey motioned to approve the meeting minutes from prior council meeting dated 6/06/2025. Councilmember Valorie Porter seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.**

## 4) FOR INFORMATION ONLY: Guest Presentation on Metachromatic Leukodystrophy (MLD) Atidarsagene autotemcel (Lenmeldy) & Newborn Screening.

Susheela Jayaraman, Associate Director of Diagnostics in Newborn Screening at Orchard Therapeutics, emphasized the importance of newborn screening for metachromatic leukodystrophy (MLD). She was joined by Claire Wells, Medical Science Liaison for the Western United States and former critical care pediatric nurse practitioner, who presented the clinical background, data, and history of the condition.

Madison Bowe put into the chat at 9:57 AM: “I'm sorry for being late. I hope their *[sic]* will be a recording of this. I didn't realize the time had passed”

MLD was described as a rare, autosomal recessive lysosomal storage disorder caused by a deficiency of the arylsulfatase A (ARSA) enzyme, leading to the accumulation of sulfatides in the nervous system. This buildup resulted in myelin breakdown, progressive motor and cognitive decline, seizures, severe disability, and premature death. The estimated incidence was approximately 1 in 100,000 live births, with higher rates in certain communities.

The disease was classified into late infantile, early juvenile, late juvenile, and adult subtypes. Early-onset forms, occurring before age seven, included the severe late infantile type—accounting for roughly

50% of cases—and early juvenile type. Most early-onset cases were detected through sibling testing after an older sibling's diagnosis.

Without newborn screening, diagnosis typically relied on leukocyte enzyme activity testing, followed by urine sulfatide analysis and genetic testing due to possible pseudo deficiencies. Patients often experienced normal early development, a brief stagnation phase, and then rapid decline.

Late infantile MLD generally presented between ages two and three, progressing quickly to severe disability, seizures, and death at an average age of 4.5 years. Early juvenile MLD presented later, with initial gait or behavioral changes, and often resulted in death between ages 10 and 25.

Atidarsagene autotemcel (arsa-cel), commercially known as Lenmeldy, was an autologous hematopoietic stem cell-based gene therapy approved for pre-symptomatic late infantile, pre-symptomatic early juvenile, and early symptomatic early juvenile patients with early-onset metachromatic leukodystrophy (MLD). The therapy used a patient's own stem cells, modified to express the ARSA enzyme, which were then reinfused. The integrated analysis included data from phase 1 and phase 2 trials, as well as compassionate use cases, totaling 39 treated patients—two of whom were later reclassified as symptomatic and excluded from efficacy analyses but retained in safety evaluations. The comparison group comprised 49 individuals from natural history and sibling data.

Inclusion criteria allowed pre-symptomatic late infantile, pre-symptomatic early juvenile, and early symptomatic early juvenile patients, with early symptomatic cases requiring an IQ  $\geq 85$  and a GMFC (Gross Motor Function Classification)-MLD score  $\leq 1$ . Exclusion criteria included infectious disorders or severe concurrent disease.

For pre-symptomatic late infantile patients, overall survival at data cutoff was 100% in treated patients compared to 59% in the natural history cohort at six years. All untreated patients achieved severe motor impairment (GMFC  $\geq 5$ ), while treated patients avoided this outcome and maintained cognitive age equivalents. In pre-symptomatic early juvenile patients, overall survival was similar between groups, but 87% of treated patients remained below GMFC 5 up to 10 years of age, with cognitive performance maintained or exceeding age expectations. In early symptomatic early juvenile patients, overall survival was also similar, but treated individuals demonstrated better motor preservation, stronger cognitive outcomes, and higher likelihood of retaining functional speech for caregiver communication.

Across all subgroups, treatment was associated with meaningful preservation of motor skills, cognition, and communication. Safety considerations included the need for conditioning prior to infusion, which carried known risks. The only treatment-related finding was the development of ARSA antibodies, which did not affect long-term outcomes; no polyclonal expansion was observed. Three deaths occurred: one from cerebral hemorrhage unrelated to therapy and two in patients already in rapid disease progression at treatment initiation.

Published guidelines in Europe and the United States addressed newborn screening outcomes, patient management, and long-term monitoring. Five U.S. treatment centers were qualified: University of California, San Francisco (UCSF), University of Minnesota, Texas Children's, Children's Hospital of Philadelphia (CHOP), and Children's Hospital of Atlanta (CHOA). The treatment process—from apheresis to infusion—took approximately six weeks, followed by a recovery period.

Dr. Ihsan Azzam requested clarification on two slides addressing loss of speech.

Claire Wells explained that the green category represented late infantile patients, the darker purple indicated pre-symptomatic early juvenile patients—typically identified through sibling occurrence and carrying a variant expected to present as early juvenile but treated before symptom onset—and the lighter purple represented early symptomatic early juvenile patients, who met trial eligibility with an IQ  $\geq 85$  and a GMFC score  $\leq 1$ . Treated early symptomatic patients demonstrated a notably different outcome curve compared to pre-symptomatic counterparts, with preservation of communication skills identified as the most meaningful long-term outcome relative to the natural history group.

Susheela Jayaraman continued with the impact of newborn screening, referring to a study from a qualified treatment center in the UK that reviewed 17 referrals between February 2022 and February 2023. Thirteen patients did not meet treatment criteria—eleven due to advanced symptoms and two due to late-onset disease. Four met eligibility requirements and received gene therapy, three of whom were presymptomatic siblings of ineligible patients and one who had early symptomatic early juvenile MLD. The study compared treated and untreated siblings within the same families, showing that 86.4% of treated siblings retained independent walking ability, while 81.8% of untreated siblings had lost all gross motor function. These findings supported the need for newborn screening to identify eligible patients earlier.

An international consortium developed a newborn screening algorithm to address the high false-positive rates associated with enzyme-first screening, largely caused by a common pseudo-deficiency. The recommended three-tiered “sulfatide-first” approach began with sulfatide measurement, followed by ARSA enzyme screening if elevated, and concluded with gene sequencing for confirmation. The first prospective pilot in Germany included sequencing ARSA, SUMF1, and PSAP genes—linked to disorders biochemically similar to MLD—and used LC (Liquid Chromatography) tandem mass spectrometry for analysis. Only ARSA deficiencies were reported as screen positive. The sulfatide-first method was highly sensitive, cost-effective, and improved further by measuring two sulfatide species.

In the Hanover, Germany pilot, more than 100,000 dried blood spots were screened, identifying three MLD cases—two early-onset and one late-onset. Consensus guidelines outlined screening, diagnosis, and care pathways, with confirmatory testing performed at the QTC (Quality, Timeliness and Customer Service) in Germany or at local specialty clinics in other countries. Subtype prediction was based on genotype, family history, and clinical or biochemical evidence. Recommendations included pretreatment monitoring and preparation for ARSA cell therapy for early-onset cases, pretreatment monitoring and possible stem cell transplant for late-onset cases, and ongoing observation for uncertain phenotypes.

Consensus guidelines established a pretreatment monitoring schedule, with approximately 80% of patients expected to have a known phenotype based on genetic mutations. A recent publication provided standard operating procedures for first- and second- tier screening methods, noting that the sulfatide screen was relatively straightforward to implement, while the ARSA enzyme screen was more complex. Some laboratories opted to outsource the second-tier test due to low expected sample volumes. Global newborn screening efforts included retrospective analyses, the German prospective pilot, and additional pilots in New York and Tuscany, Italy. In New York, MLD screening was incorporated into the SCREENPLUS pilot and was set to transition to statewide implementation under an NICHD IDIQ (National Institute of Child Health and Human Development) (indefinite delivery/indefinite quantity)

grant. The Tuscany pilot screened more than 40,000 dried blood spots, detected no new cases, but confirmed feasibility within Italy's public health system. Based on German data, MLD incidence was estimated at approximately 1 in 40,000, explaining the absence of detected cases in the Italian cohort. Norway became the first country to implement nationwide screening in the previous year. In the United States, Illinois, Minnesota, and Pennsylvania had added MLD to their statewide panels, with New York preparing to follow. The MLD Newborn Screening Alliance, an international consortium of experts, continued to meet annually to share data, address challenges, and support global expansion of MLD screening.

Dr. Summit Gupta asked about the timeframe between tier-one and tier-two testing, as well as the interval from receiving a positive result to referring a patient to a genetics or metabolic specialist, noting that newborn screening results were typically returned within a couple of weeks.

Susheela Jayaraman compared MLD with Krabbe disease, explaining that while Krabbe requires referral for transplant within 30 to 45 days of a positive screen, MLD follows a different treatment timeline.

Claire Wells elaborated that pre-symptomatic late infantile patient typically needed to reach approximately 8 kilograms, around eight months of age, before a line could be placed and therapy administered. Earlier treatment yielded better outcomes; however, once symptoms began, patients were no longer qualified. This made timely action essential but less urgent than the strict 30-day window required for Krabbe disease. The process was recommended to proceed efficiently, without a rigid day-by-day deadline.

Chair Logan-Parker inquired about national efforts to add MLD to newborn screening panels. After clarification, she noted that in Nevada, either legislative authority or increased laboratory capacity would be necessary. She asked whether there were groups that could advise on successful strategies used in other states.

Susheela responded that a small but active MLD advocacy community, largely composed of parents of affected children, had driven screening expansion efforts. In Illinois, a 2023 bill added MLD to the state panel; in Minnesota and Pennsylvania, the condition was under advisory committee and legislative review. New York advanced toward statewide screening through an NICHD grant, and advocacy foundations were available to support similar legislative initiatives elsewhere.

- 5) FOR INFORMATION ONLY: Guest presentation on a new development of a statewide program for northern and rural Nevada patients through Make-A-Wish Foundation which includes expansion of their referral criteria to include more rare diseases.

Chair Logan-Parker introduced Scott Rosenzweig, who presented the history, mission, and operations of Make-A-Wish Nevada. Founded in 1980 in Arizona after a young boy with leukemia named Chris was granted his dream of becoming a police officer, the organization had grown to 57 U.S. chapters, representation in 50 countries, and more than 585,000 wishes granted to children with critical illnesses. In the mid-1980s, eligibility expanded to include children with life-threatening conditions, most of whom went on to live full lives.

Naja Bagner put into the chat @ 10:18 AM: "Sorry guys my phone is acting crazy. Sorry for being late earlier."



The Nevada chapter, the second established, reunited its northern and southern offices in September 2024 to serve the entire state from a 7,000-square-foot donated office on Allegiant Airlines' campus, with employees volunteering in wish preparations.

Rosenzweig described the referral process, emphasizing that receiving a wish did not indicate a terminal prognosis. The national medical affairs team determines eligibility for children aged 2½ to 18 with qualifying conditions and no prior wish from another organization. The MD (Medical) Wish website provides condition-specific guidelines, and referrals can be submitted online by medical professionals, family members, or others familiar with the child's medical history. The process required family consent, professional and facility details, and medical information.

Dr. Iljana M. Gaffar put into the chat @ 10:22 AM: "@scott Rosenzweig I would love to connect. I'm an international pediatric (& adult) surgeon.

Linktr.ee/IMpediatricsurgery  
[GAFFAR.IIJANA@GMAIL.COM](mailto:GAFFAR.IIJANA@GMAIL.COM)  
+1(913)636-6243"

Madison Bowe put into the chat at 10:25 AM: "I now wish my mom would have known about this when I was a baby after everything I have gone through with my illnesses."

Dr. Iljana M. Gaffar MD put into the chat at 10:26 AM: "Who are the other wish granting organizations?"

Rosenzweig noted that in Nevada, the BallerDream Foundation serves older children, and similar groups exist nationwide. The national office verified which organizations qualified as true wish-granting entities to prevent duplicate wishes. Certain medical conditions, such as active cancer treatment, automatically qualified a child, while others required further verification. Physicians completed both diagnosis and wish clearance forms, with travel wishes requiring re-clearance 30 days before departure.

Dr. Iljana M. Gaffar MD put into the chat at 10:29 AM: "Thank you for clarifying. Almost all of my favorite patient populations would qualify. Neonatal/infant surgery and ped surg oncology."

Dr. Iljana M. Gaffar MD put into the chat at 10:29 AM: "Scott are you based onsite at the Make A Wish building? I'd love to come visit."

Naja Bagner put into the chat at 10:29 AM: "I was granted a wish at 10 for Disneyworld and it was amazing"

Madison Bowe put into the chat at 10:30 AM: "I think I was just too young to be granted a wish because I wasn't 2. But I'm happy to be alive now.

I would definitely love to help or get involved with Make a Wish."

Dr. Iljana M. Gaffar MD put into the chat at 10:32AM: "Grat question Naja!"

Dr. Iljana M. Gaffar MD put into the chat at 10:33 AM: "do you work with/partner with RMH?"

Dr. Iljana M. Gaffar MD put into the chat at 10:33 AM: “[Baller Dream Foundation | Uplifting Young Warriors | Battling Cancer](#) found this it's for adults as well maybe chatgpt can be helpful”

Naja Bagner put into the chat at 10:37 AM: “Was the RMH question for me Naja?”

Brigitte Cole put into the chat at 10:38 AM: “Make a Wish is wonderful partner and we, at NNCCF, work closely with the team as well!”

Dr. Iljana M. Gaffar MD put into the chat at 10:38 AM: “what NNCCF”

Pamela White put into the chat at 10:39 AM: “Hi this is Pam with Bridging the Gap can Organizations refer a child?”

Brigitte Cole put into the chat at 10:40 AM: “Northern Nevada Children's Cancer Foundation (NNCCF)”

Dr. Iljana M. Gaffar MD put into the chat at 10:41 AM: “I would love to connect. I’m an international pediatric (& adult) surgeon but home base is Nevada. [Linktr.ee/IMpediatricsurgery](#) [GAFFAR.ILJANA@GMAIL.COM](mailto:GAFFAR.ILJANA@GMAIL.COM) +1(913)636-6243”

Brigitte Cole put into the chat at 10:43AM: “Thank you, I will reach out 😊”

Dr. Iljana M. Gaffar put into the chat: “the invitation is open to everyone. I'm brand new her and looking to learn the landscape and how I can be helpful. I also have 2 really amazing huskies I'd love to get therapy trained if anyone has recommendations for trainers, I'm at zip 89103 in Vegas. Then we could do Virtual Pet Therapy too.”

Rosenzweig explained that Make-A-Wish serves only children within the eligibility age range, focusing on experiences that brought hope rather than providing housing or transportation. Other organizations address those needs, and warm introductions could be arranged.

Kim Anderson asked about second wishes for children still living with serious conditions.

Rosenzweig confirmed the one-wish-per-child policy, citing a recent example, and emphasized that wishes were determined by the child with volunteer guidance.

Dr. Gaffar inquired about partnerships with Ronald McDonald House and similar organizations.

Rosenzweig stated that partnerships exist with groups such as Candlelighters, the Tyler Robinson Foundation, and Ronald McDonald House chapters. Outreach efforts focus on raising awareness that wishes were for children with life-threatening illnesses, not only terminal cases, to encourage community referrals at the time of diagnosis. Partnerships with Touro University, UNLV (University of Nevada, Las Vegas), and UNR (University of Nevada, Reno) educated medical students on the wish process; Rosenzweig welcomed potential collaboration with the College of Southern Nevada.

Rosenzweig described the welcome call process, golden ticket presentation, and wish discovery sessions, which could occur virtually or in person and often required multiple visits to ensure the child expressed their true wish without pressure. Restrictions include guns, cash, primary transportation, or housing, and the focus was on taking the child out of their medical journey. Planning and enhancement events are handled locally, with volunteers ensuring progress. Referrals can come from anyone with knowledge of the child’s medical history.

Rosenzweig highlighted research from Israel and Ohio showing that wish recipients adhered to treatment more effectively, recovered faster, and maintained long-term health, with significant

emotional benefits for families. Medical professionals described wishes as integrative therapy, reducing stress and fostering resilience. In Nevada's current fiscal year, beginning in September, 201 referrals had been received—the highest in state history—with Cure 4 The Kids Foundation as the leading referral source. The 2025 prevalence and incidence report identified 243 potentially eligible children statewide, of whom only 149 were reached, leaving 94 without wishes. Data were compiled by the national Medical Advisory Committee using insurance and medical records without violating HIPAA (Health Insurance Portability and Accountability Act) and would be updated annually.

Madison Bowe asked about eligibility for children reaching 2.5 years while living with serious medical conditions. Rosenzweig confirmed that eligibility lists are reviewed every two weeks with referral partners and that the age requirement ensured the child could fully experience the wish.

Two recent Nevada wishes were shared: Jaden, a 10-year-old with a rare blood disorder, fulfilled his dream of acting at the Smith Center with support from the cast of *Tina: The Tina Turner Musical*; and Zariah, a 4-year-old with multiple hospitalizations, enjoyed a petting zoo birthday celebration with friends, family, and animals. Both demonstrated strong community collaboration.

Melissa Bart-Plange expressed gratitude for her child's wish and asked about obtaining new Make-A-Wish shirts for growing children.

Rosenzweig confirmed replacements are always available. He also noted that all wish families were invited to the annual *Walk for Wishes* each April, with free registration and a VIP tent for gathering. Pamela asked if nonprofit organizations could make referrals; Rosenzweig confirmed that referrals could be made by anyone.

Pamela later asked if Make-A-Wish could be present at a caregiver's respite retreat on September 20.

Rosenzweig requested direct contact via email.

Chair Logan-Parker asked about training availability for Northern Nevada and rural areas;.

Rosenzweig explained that orientations were offered in person in Las Vegas and virtually, with several local participants already trained.

Dr. Iljana M. Gaffar put into the chat at 10:48 AM: "How do you find those numbers?"

Dr. Iljana M. Gaffar put into the chat at 10:57 AM: "When is the next volunteer training orientation/event you all will be at?"

Valerie Porter put into the chat at 10:57 AM: "Hi I have to step away for a minute I will be right back."

Dr. Iljana Marjorie put into the chat: "I can't get the QR to work. Can I have another way to get in touch with you Scott? What would be the best way for a surgeon like me to be involved with Make A Wish? Or any physician/healthcare professional."

Madison Bowe put into the chat at 10:59 AM: "Is the best way to get you the information about CSN to your actual QR code if I can obtain it? I would also love to volunteer."

Scott Rosenzweig put into the chat at 10:59 AM: "[scott@nv.wish.org](mailto:scott@nv.wish.org)"

Madison Bowe put into chat at 11:00 AM: "Is it make a wish .org you said?"

Iljana Marjorie put into the chat at 11:02 AM: "so we can dual recruit those here and who wants to come here/



Iljana Marjorie put into the chat at 11:02 AM: “Amazing. Can't wait to align.”

Scott Rosenzweig put into the chat at 11:02 AM: “wish.org/nv”

Rosenzweig confirmed it was acceptable and directed volunteers to wish.org/nv for opportunities. He also clarified that out-of-state children could have wishes fulfilled in Nevada if referred to through their local chapter.

Iljana Marjorie put into the chat at 11:03 AM: “i see. i hold licenses all over the world. child life specialists and hospice can be helpful. the cortisol crash”

Valerie Porter put into the chat at 11:06 AM: “Both presentations fantastic!”

In response to a question from Naja Bagner about eligibility for children experiencing significant grief, Rosenzweig explained that grief alone was not a qualifying condition, as wishes were limited to physically life-threatening diagnoses. For certain wishes, such as those involving horses, ongoing costs for the first year were covered to avoid financial hardship.

Rosenzweig concluded by thanking Annette and Ashlyn, sharing his contact information, and encouraging collaboration to reach every eligible child in Nevada.

- 6) FOR POSSIBLE ACTION: Discussion and possible action to approve the Provider Needs Assessment survey to 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 proposed creating a needs assessment using the same platform and concept as the previous version but with questions tailored to healthcare providers treating patients with rare diseases.

Jeromey Russo, from Cure 4 The Kids, reported collaborating with Annette to develop the survey on the REDCap platform, a system widely used by educational and research institutions nationally and internationally. The [survey](#) was designed to function across desktop, mobile, and tablet devices, with accessibility features such as adjustable font sizes, links to [nvrdac.org](#), and an email contact option. The landing page included introductory information for providers, estimated completion time, and instructions allowing participants to skip non-applicable questions. The fourth page began the survey, structured similarly to the previous needs assessment with both multiple-choice and open-ended questions. Participants could save progress by entering their email to return later if interrupted.

Iljana Marjorie put into the chat at 11:07 AM: “Sounds like a cool survey. I'd love to get more involved with this council - who would I connect with? [Gaffar.iljana@gmail.com](mailto:Gaffar.iljana@gmail.com)”

Naja Bagner put into the chat at 11:09 AM: “Have to go nice chatting leaving for sickle cell treatment”  
“Ashlyn I was in the hospital for 12 days so I don't know if missed anything Can you email me”

Iljana Marjorie put into the chat at 11:11 AM: “Great idea!”

Ashlyn Torrez put into the chat at 11:11 AM: “@Naja yes I can”

Madison Bowe asked whether the survey could be completed by patients' PCPs (Primary Care Physician), nurses, doctors, and facilities, and if it would be publicly available.

Chair Logan-Parker responded that Council approval was required before launch, after which the survey would be open to all and posted on the websites, with Council members notified once active.

Kim Anderson-Mackey inquired whether a brochure or handout would be available for patients or families to share with providers.

Chair Logan-Parker confirmed that collateral materials, similar to those used for the previous needs assessment, would be created and distributed to pediatricians' offices, hospitals, and other locations to ensure broad accessibility.

Chair Logan-Parker emphasized that the survey's purpose was to collect data to help lawmakers, policymakers, and Medicaid better understand the experiences of patients, families, and providers. She requested a Council motion to approve the survey and begin implementation.

**Vice Chair Gina Glass motioned to approve the survey and begin implementation. Councilmember Kim Anderson-Mackey seconded the motion to approve. There were no objections. A quorum voted to approve the survey and begin implementation.**

Madison Bowe asked if the next slide of the survey could be shown to preview the provider questions.

Jaromy Russo explained that Section two began with a confidence rating, asking providers to assess their ability to manage certain patients on a scale from "very confident" to "not applicable." The section included multiple-choice items, top three ranking exercises, and checkbox questions with selection limits. Some required prioritizing responses by rank, while others restricted the number of options per column. Additional questions allowed broader input, including selecting all applicable answers or providing free-text comments. The format was designed to collect both quantitative rankings and qualitative insights from providers.

Valerie Porter put into the chat at 11:15 AM: "Lowv *[sic]* this as well"

## 15) PUBLIC COMMENT

Ashlyn Torrez opened the floor for public comment.

Madison Bowe inquired about Council Member announcements.

Ashlyn Torrez stated that the Deputy Attorney General had requested all announcements from Council Members be placed on the agenda for approval in advance. Any announcements will need to be tabled

until the next meeting, and members were asked to email them in advance so they can be added to the agenda.

16) ADJOURNMENT- *Ashlyn Torrez on behalf of Chair Logan-Parker*

**Ashlyn Torrez on behalf of Chair Logan-Parker moved to adjourn the meeting at 11:21 am.**

DRAFT