Minutes for the Newborn Screening Technical Advisory Committee (TAC)
March 26, 2025
Hybrid Meeting
ASL (or CART) and Spanish interpretation available
Department of Health Town Center 2,
111 Israel Rd. S.E. Tumwater, WA 98501. Room: 153.
Virtual meeting: ZOOM Webinar

Technical Advisory Committee Members present:

Online Participants:

Kelly Oshiro, JD, Board Vice Chair and TAC Co-Chair
Nirupama (Nini) Shridhar, MPH, PhD, TAC Co-Chair
Eric Leung, Washington Chapter of the American Academy of Pediatrics (WCAAP)
Byron Raynz, Parent Advocate
Heather Hinton, MultiCare Yakima Memorial
Joon-Ho Yu, Department of Epidemiology, University of Washington Bioethics, Treuman Katz Center for Pediatric Bioethics and Palliative Care
Priyanka Raut, Yakima Valley Farmworkers Clinic
Krystal Plonski, Naturopaths, Seattle Children's Hospital, and Washington Association of Naturopathic Physicians (WANP)
Peggy Harris, Parent/Child Advocate, Save Babies Through Screening Foundation
Kristine Alexander, Regence Health Plans
Lisa McGill Vargas, Sacred Heart Medical Center Neonatology Intensive Care Unit (NICU)
Taylor Kaminski, Global Perinatal Services
Emily Shelkowitz, Seattle Children's Hospital Biochemical Genetics
Cathleen Ackley, Parent Advocate

Technical Advisory Committee Members Absent:

Roberta (Bobbie) Salveson, Mary Bridge Children's Hospital Biochemical Genetics
Joan Chappel, Washington Healthcare Authority (HCA)
Christina Lam, Seattle Children's Hospital Biochemical Genetics
María Sigüenza, Commission on Hispanic Affairs
Steve Kutz, American Indian Health Association
Tawny Hooley, Parent Advocate

State Board of Health (Board) staff present:

Michelle Davis, Executive Director
Kelly Kramer, Newborn Screening Project Policy Advisor
Molly Dinardo, Policy Advisor
Melanie Hisaw, Executive Assistant
Crystal Ogle, Administrative Assistant
Michelle Larson, Communications Manager
Anna Burns, Communications Consultant

Guests and Participants:

Allegra Calder, Facilitator
Ann Melvin, Seattle Children's Hospital
John Thompson, Department of Health
Julie Walker, Department of Health
Michele Greenwood, Spokane Ear Nose & Throat
Samantha Fuller, Department of Health
Megan McCrillis, Department of Health

1. **Welcome and Introductions**

Kelly Kramer, Board staff, welcomed attendees and noted that the purpose of today's meeting is to complete the review of congenital cytomegalovirus (cCMV).

Kelly K. reviewed the agenda for the meeting and shared that Dr. Ann Melvin and Michelle Greenwood would join to support the discussion.

Allegra Calder, Facilitator, welcomed everyone to the meeting. Facilitator Calder asked TAC members to introduce themselves.

Kelly Oshiro, TAC Co-Chair, described the Board's authority and how conditions are reviewed. TAC Co-Chair Oshiro stated that today's meeting is to review cCMV for inclusion on the Washington Newborn Screening Panel, as directed by Senate Bill 5829.

Nini Shridhar, TAC Co-Chair, shared that the meeting would wrap up the cCMV review with Department of Health presentations, followed by a TAC discussion and vote.

2. **March Board Meeting Recap**

Kelly Kramer, Board staff, shared a brief update from the March 12 Board meeting. The Board reviewed the TAC's discussion on Branched-Chain Ketoacid Dehydrogenase Kinase (BCKDK) Deficiency and decided not to move forward with adding the condition to Washington's Newborn Screening (NBS) panel due to limited data. The Board also approved the NBS criteria, with one small change to rename criterion six to "public health infrastructure readiness" to better reflect its intent.

Kelly Oshiro, TAC Co-Chair, said the Board appreciates the TAC's time and commitment to review the criteria and BCKDK Deficiency. TAC Co-Chair Oshiro said the Board was impressed by the level of work and will also share feedback on how the new criteria worked during the congenital cytomegalovirus (cCMV) review.

Eric Leung, Committee Member, noted that some documents still refer to "Five Criteria" and suggested updating them to avoid mentioning a specific number going forward.

Kelly K. responded to Member Leung that they will update all materials and thanked them for bringing that up.

Kelly K. shared an update on House Bill 1697. The bill was related to the Recommended Uniform Screening Panel (RUSP) alignment, and it would have required the Board to adopt all RUSP conditions and shorten the timeframe to review. The bill is not moving forward at this time.

3. **February cCMV TAC Review**

Kelly Kramer, Board staff, summarized the February 11, 2025, Newborn Screening TAC meeting and expressed appreciation to Dr. Ann J Melvin, MD, MPH, Emeritus Professor, Children's Hospital, for the thorough review of the natural history, diagnostic testing, and treatment for congenital cytomegalovirus (cCMV). The minutes for the meeting are in today's packets.

Kelly K. reviewed the discussion today; Parent perspectives; Natural history, diagnostic testing, and treatment; Available screening technology; Early Hearing Detection, Diagnosis, Intervention Program; and Available resources – audiology.

Kelly K. focused on the condition, symptoms, diagnosis and treatment of cCMV (see materials on file). cCMV is an infection passed from a pregnant person to their baby. It affects about 1 in 200 newborns in the U.S. cCMV is a leading cause of nonhereditary hearing loss and can also cause developmental delays, vision problems, seizures, and organ issues. Diagnosis requires testing urine or saliva within 21 days of birth. Antiviral treatments may reduce hearing loss and improve development. Children with cCMV should have regular hearing and vision check-ups.

4. **Update on cCMV Parent Education Materials (Mel)**

Julie Walker, Department of Health (Department), Early Hearing Detection, Diagnosis & Intervention Program (EHDDI), shared updates on Senate Bill 5829 and congenital cytomegalovirus (cCMV) educational materials. The Department has created an informational flyer that discusses preventing cCMV while pregnant and will be translated into 12 languages. Julie discussed upcoming projects, including the Watch Me Grow Washington (WMG) and sending flyers to families in May and June 2025. The Department will do a social media campaign in June for CMV awareness month. Julie highlighted partnerships with the Department of Children, Youth, and Families, the Office of Superintendent of Public Instruction, county resources, and additional external partners for material distribution (see presentation on file).

Peggy Harris, Committee Member, noted that outreach and education in schools of cCMV is wonderful.

Kelly Kramer, Board staff, thanked Julie for this education project and all the work.

5. **Cost-Benefit Analysis- cCMV**

Megan McCrillis, Department staff, reviewed the cost-benefit analysis (CBA) for congenital cytomegalovirus (cCMV). The analysis focused on two screening models for cCMV: ‘no screening’ and ‘urine filter paper.’ The dried blood spot model didn’t meet sensitivity benchmarks, and saliva screening had implementation challenges.

Unlike most screenings aimed at reducing mortality, cCMV screening focuses on the early detection of hearing loss, which can develop later in some infants. Washington sees about 80,000 births annually, with roughly 1 in 244 affected by cCMV. The urine filter paper model shows high sensitivity (99.4%) and is more practical, though some false positives and negatives are expected. (see presentation on file).

Eric Leung, Committee Member, asked what threshold is used to determine a positive result.

Megan was not sure of a specific threshold but noted the feasibility study measured viral loads in dried urine samples. Megan noted that they will have to look at additional research for method development for universal newborn screening (NBS).

Megan explained that babies who screen positive for cCMV and are symptomatic at birth follow the same path as the no-screening model, which also applies to false negatives who are detected later. Start-up costs for screening aren't included in the cost-benefit ratio, which currently shows a benefit of 72 cents per dollar spent and a net cost to the system. The dried blood spot model performs worse, with lower sensitivity and higher costs. Sensitivity analysis suggests that if cCMV prevalence is higher or if late-onset hearing loss affects 20% of symptomatic babies, costs could break even. Intangible factors like emotional impact and infections prevented were also noted. Follow-up for positives would last six years, with frequent hearing checks. Year one would monitor about 309 infants, growing to around 1,800 by year six. Data from other programs, like Minnesota and Ontario, show challenges with false positives and mild abnormalities, indicating further evaluation is needed.

Cathleen Ackley, Committee Member, appreciated the CBA but noted a different vision was shared in a prior TAC meeting. The question was raised about why the analysis focused on hearing loss instead of other neurodevelopmental conditions.

Megan explained that hearing loss was the focus because more data is available for the CBA, while evidence on other neurodevelopment outcomes is limited. Other benefits might emerge over time if the screening is implemented, but this analysis reflects what can be reasonably measured right now. Megan noted these models probably represent a slim snapshot.

Member Ackley referenced a CBA of cCMV by the Infectious Diseases Society of America (IDSA) that included multiple neurodevelopmental issues in its analysis. The CBA did not include our geographic region. Overall, the CBA was worth it because of the additional things they looked at. Member Ackley said they would be happy to consider looking at other outcomes.

Megan said that for our primary purposes, we must look at changes based on screening. Antiviral treatment helps symptomatic infants detected early, but the model assumes these cases are already identified without screening. While other CBAs exist, they may not apply to Washington's situation, though additional resources are welcome.

John Thompson, Department staff, thanked Member Ackley and expressed interest in reviewing the additional information. John agreed with Megan that the model compares the status quo with the introduction of screening. In the literature that they have found, there is no difference in cost or benefit if they were to model the development outcomes. John emphasized that 15% of babies with cCMV develop late-onset hearing loss and benefit from early intervention. John highlighted that the biggest impact is preventing CMV spread in pregnancy to reduce death and disability. John praised Julie's prevention efforts.

Member Ackley agreed and offered to discuss the ISDA studies further. Member Ackley asked if Minnesota and Ontario were only considering hearing loss and related costs. Were they also considered early intervention and impacts? Particularly in Minnesota, were impacts on the costs of Medicaid and the state budget considered?

Megan stated that they do not have CBAs for Minnesota or Ontario and are unsure if they conducted these.

Member Ackley noted the Chimes study might provide more detailed data beyond hearing loss and include other neurodevelopmental issues that can appear outside the expected timeframes. Member Ackley agreed on the importance of prevention and noted that many people think CMV is like a common cold. Member Ackley emphasized the need for screening options for pregnant people alongside prevention efforts, since CMV is mostly benign until pregnancy occurs.

Megan explained that six years is an example. Subject matter experts are still unsure how long to follow those with cCMV. The CBA focus is on hearing, but neurodevelopmental outcomes can be determined later over time.

John explained that the CBA is a living document and can be updated as new research or treatments emerge. Such as if a new medication shows it saves lives, the model would be revised to reflect that.

Member Leung expressed gratitude to Member Ackley. Member Leung pointed out that Minnesota is the only state that has universal screening. It is challenging to adopt a CBA with targeted hearing screens as an initial method, then proceed to tests for urine or CMV through other methods. Member Leung inquired about the benefits of a two-tier system, such as urine and targeted hearing. Member Leung also asked whether Washington's CBA is specific to oral anti-retroviral or intravenous antiretroviral (ARV). Additionally, was the proposed treatment model for six weeks or six months?

Megan said the model used oral ARV, which is the current best practice. The treatment length was based on the latest Redbook guidance, which is six months for kids with symptoms and hearing loss.

Member Leung stated that the cost of NBS ranges from $25 to $13 to create a ratio equal to 1. But is that assuming that we don't change the cost of screening? Member Leung noted bringing this up, as the Board can recommend the cost of expanding and accommodating the program.

Megan explained that the current NBS fee estimates, based on staffing and test kit costs, range around $3 per baby. To achieve a cost-benefit ratio of 1, the fee would need to be $13 per baby. However, this $13 fee isn't considered realistic now unless new, more efficient technology lowers testing costs.

Member Leung said in the CBA, the cost was higher than the benefit. Member Leung asked what would need to be charged in addition so that the ratio improves?

Megan said the model is looking at the public health system's costs. The increasing fee is to cover the additional costs that are going into the system. If CMV is more common than we thought, then more kids with late onset hearing will reap additional benefit. That improves the benefit-cost ratio from a societal level, which is where our ratio comes from.

Krystal Plonski, Committee Member, thanked Megan and asked if other states are using urine sample testing for screening for cCMV. Are Minnesota and Ontario using dried bloodspot?

Megan said there are some urine screening programs for other conditions that are not CMV. The two programs we referenced are using universal screening with just a dried bloodspot.

Member Plonski asked how many other states are testing for this.

Megan answered that Minnesota was the first state to launch cCMV screening and mentioned that there are additional states that have begun screening or are considering it. The data shared from Minnesota was from 2023-24. Other states that have implemented screening have not conducted it long enough to establish a large enough data pool.

Member Plonski asked if the Recommended Uniform Screening Panel (RUSP) conditions or other conditions under review utilize urine testing?

Megan noted that some conditions can use urine for detection. The MS/MS in our laboratory is an excellent tool for accurately detecting conditions via dried blood spot.

John stated that there are high false positive rates in some conditions being detected by MS/MS. Per conversations with the follow-up supervisor, urine may be a useful secondary test if the Board were to approve this specimen type in newborn screening.

Nini Shridhar, TAC Co-Chair, thanked Megan for the analysis and asked what the current capacity for pediatric audiology is. TAC Co-Chair Shridhar raised concerns about adding 1,800 patients to the system, especially since only a small number might benefit, and questioned how that could affect diagnosis rates.

Megan noted that this may be addressed during the public health readiness section but asked if Julie Walker can provide input.

Julie Walker, Department staff, said the exact numbers aren't available but that Seattle Children's Hospital currently has a two to three-month wait time. Not all audiology clinics in Washington specialize in pediatrics. There are audiology clinics in Washington but not all specialize in pediatrics. Mary Bridge Hospital and Seattle Children's have 8-9 clinics, the University of Washington has nine pediatric clinics, and there are 21 other pediatric audiology clinics.

Kelly Kramer, Board staff, added that Michele Greenwood will join the meeting in the afternoon and can offer further insights.

Member Ackley shared that the CMV Foundation was created in 2014 and that Minnesota started screening in 2021 due to the Vivian Act. There was a powerful New York Times best seller that shared a personal story of CMV that spurred national attention to this issue. Member Ackley expressed support for targeted screening and offered to share additional data to help inform Washington's CBA.

John explained that targeted screening shows no measurable benefit, making it impossible to calculate a cost-benefit ratio. For infants who are asymptomatic at birth but develop hearing loss later, intervention services would still be accessed, so no added benefit could be attributed to targeted screening.

Emily Shelkowitz, Committee Member, asked if there are any studies about siblings at risk and if any program has looked at that data. Is there a reason that Minnesota settled on six years of follow-up?

Megan shared that families could request dried blood spot testing for cCMV if symptoms appear later. But this type of follow-up is uncommon in other programs. The six-year follow-up timeline aligns with when most hearing loss typically emerges. It is unclear when Minnesota plans to conclude follow-up.

Julie shared that at an Early Hearing Detection and Intervention conference, they learned that a six-year timeline is recommended for audiological monitoring. The CMV program is looking at the best timeline to conduct active follow-up by determining if families attend appointments and the types of hearing tests being conducted.

Rucha Shukla, Committee Member, asked what criteria were used for targeted screening. Was it just failed hearing screenings that led to ordering CMV screening? The majority of infected kids can be asymptomatic.

John stated that yes, the model was if the baby failed their hearing screen.

Member Shukla would like to hear the numbers Member Ackley cited for targeted screening.

Member Ackley said the information came from a national infectious disease report that included over seven criteria, including neurodevelopmental concerns.

BREAK

6. **Public Health Infrastructure Readiness**

Megan McCrillis, Department staff, introduced “public health infrastructure readiness” as the newest criterion for discussion. This criterion had previously been considered informally as part of cost-benefit analyses but was largely addressed behind the scenes rather than explicitly outlined. Megan provided an estimate of the resources required to begin congenital cytomegalovirus (cCMV) testing for the laboratory (see presentation on file).

John Thompson, Department staff, explained that the screening fee would need to be increased to cover these additional resources. Typically, implementation of a new screening begins two to three years after the Board's approval.

Eric Leung, Committee Member, asked whether the model included costs for data analysis over time.

John responded that it did not. While the lab has historically engaged with the community through presentations at the annual newborn screening (NBS) symposium and has occasionally published papers, such activities are not part of their standard duties and thus were not included in the cost model.

Priyanka Raut, Committee Member, raised a related concern regarding data transparency. In clinical settings, information is received for abnormal results but not for normal screenings, which creates ambiguity.

John explained that the follow-up team positions would address this gap. The first Health Services Consultant 2 would contact primary care providers (PCPs) to coordinate diagnostic testing following positive results. The second would manage confirmed cases, ensuring follow-up hearing screenings every three months, at least for the first year, mirroring the Minnesota model. The exact duration of follow-up has yet to be determined.

Member Raut asked how educational materials would be developed to protect siblings following a positive case.

John explained that educational materials, such as referral packets and brochures, would be created in collaboration with experts and distributed to both parents and providers.

Member Leung asked Member Raut to clarify their earlier comment and confirmed that providers should receive both normal and abnormal screening results

Kelly Kramer, Board staff, introduced Michele Greenwood.

Michele Greenwood, Audiology, Spokane Ear, Nose, & Throat, presented on the standard audiological care pathway for infants. This typically begins at six months of age, with screenings every three months until age two. Michelle emphasized the challenges of access for families in rural areas of Washington.

Kelly K. invited Michelle to comment on infrastructure readiness.

Michele raised concerns about limited access to initial Auditory Brainstem Response (ABR) testing and whether providers outside Spokane are ready for ongoing screenings.

Kelly K. asked about current clinic capacity given the rise in patient volume.

Michele said their clinic could likely accommodate the need by establishing a specialized clinical day for cCMV patients. Michele noted uncertainty regarding capacity in other regions.

Rucha Shukla, Committee Member, emphasized the travel burden for families in remote areas and expressed concern over the logistical challenges of requiring multiple long-distance visits for testing.

Member Leung voiced concern about the ability of clinics to handle new diagnoses and suggested that dedicated scheduling might help manage increased demand.

Michele noted that their clinic currently reserves appointment slots for newborns who fail NBS screenings. However, more patient data would be needed to determine the number of additional slots required.

Member Shukla added that estimates should include potential patient numbers from northern Idaho and eastern Oregon. Member Shukla suggested involving clinics in the development of specimen collection training, particularly for urine samples, since many newborns remain hospitalized for 24-48 hours.

John shared insight from a conversation with the director of Quebec's urine NBS program, where families are sent home with a collection kit. The process of collecting and drying urine on filter paper achieves a 99% specimen acceptability rate. John viewed this as a strong indication that a similar model could be adopted successfully.

Heather Hinton, Committee Member, raised concerns about long-term follow-up and access to care for children who may require frequent hearing screenings. Member Hinton asked whether care would remain with PCPs or require ongoing specialist involvement.

Emily Shelkowitz, TAC Member, asked whether any existing programs had factored in the availability of developmental services to support asymptomatic children and prevent progressive hearing loss.

Megan responded that the cost-benefit analysis (CBA) stopped at screening implementation and did not include services such as speech-language pathology (SLP).

Member Leung supported Member Shelkowitz's question, noting that hearing loss often co-occurs with other conditions requiring services like occupational and physical therapy. Member Leung also noted that in many community health systems, pediatricians are considered specialists and refer patients to additional providers as needed.

Member Shukla added that all children diagnosed with cCMV would be eligible for early intervention programs, significantly increasing the load on those services. Member Shukla emphasized the strain this would place on eastern Washington, which already faces substantial shortages in healthcare access.

Cathleen Ackley, Committee Member, shared an informational resource that may address Member Shelkowitz's question regarding developmental services.

7. Washington Criteria Review for cCMV and Discussion

Kelly Kramer, Board staff, reviewed criterion one and opened it up for questions.

Rucha Shukla, Committee Member, asked about Dr. Melvin's presentation. Does Washington have a higher prevalence of cytomegalovirus (CMV) than other states?

Dr. Ann Melvin, Seattle Children's Hospital, said no, the papers cited aren't from mass screening data, so hard to say for sure.

Kelly K. reviewed criterion two and three and opened it up for questions.

Eric Leung, Committee Member, said this is a unique condition and doesn't fit well within criterion three.

Kelly K. reviewed criterion four and opened it up for questions.
Member Leung noted that this was a particularly difficult point when this topic was reviewed several years ago. Dr. Melvin's presentation updated the TAC on research and shared several resources that helped address previous concerns.

Dr. Melvin explained that there isn't an effective risk-based screening since simply being born poses a risk, making it challenging because many infants show no symptoms.

Kelly K. reviewed criterion five and opened it up for questions.

Member Leung pointed out that congenital Cytomegalovirus (cCMV) screening appears to lose money, but emphasized the difference between cost-benefit and cost-effectiveness. They weren't sure if the group had discussed cost-effectiveness much.

John Thompson, Department staff, stated the analysis was a cost-benefit analysis, not a cost-effectiveness analysis.

Dr. Melvin asked what a cost-effectiveness analysis is.

John explained that cost-effectiveness analyses include quality of life when measuring benefits. Their current cost-benefit analysis looks only at dollar costs and savings. John noted drawbacks in the current system, especially for babies without symptoms.

Member Shukla asked about data on early versus late onset and diagnosis of hearing loss.

John stated that Megan did include that information in the model. There are benefits for early identification of hearing loss, estimated at 2.4 million worth of benefit per year.

Michele Greenwood, Audiology, Spokane Ear Nose & Throat, shared that there are social and developmental lags from hearing loss, including language skills. Michele discussed the emotional impact on families of false positives. In the past, many providers were not onboard with universal hearing screening due to the fear of causing trauma in families.

Kelly K. reviewed criterion six and opened it up for questions.

Heather Hinton, Committee Member, asked how accessible antiretroviral (ARV) treatment is for families.

Dr. Melvin noted that most families are unfamiliar with cCMV, which can make treatment decisions difficult. In their experience, insurance coverage for treatment has generally not been a barrier. Regarding the cost to families, Dr. Melvin explained that the initial appointment typically occurs with a pediatrician and questioned whether that visit would provide a significant benefit. However, much of the follow-up care can be conducted virtually via telehealth. Given the expected number of affected individuals, Dr. Melvin suggested that capacity concerns may be minimal.

Member Shukla raised similar concerns in the previous meeting. It was noted that some infant care providers offer initial consultations through telemedicine. Broadening access and identifying a wider network of specialists, particularly within hospital systems, could help streamline care pathways. Knowing whom to contact within those systems could improve efficiency for patients and families.

Member Leung asked Dr. Melvin whether treatment could be easily protocolized, especially involving ARVs, in a way like how treatment for HIV in newborns had previously been

handled. Member Leung brought up past efforts in disseminating HIV treatment protocols statewide and inquired whether similar processes could be developed using blood tests, liver function tests (LFTs), and other standard measures.

Dr. Melvin stated that they are considering this suggestion.

Member Shukla asked whether data exists showing long-term benefits of early intervention, particularly over several years. The question focused on whether benefits accumulate over time, possibly leading to cost neutrality or even long-term cost savings following initial stabilization.

Megan responded that the modeling work focused on a one-year birth cohort, tracking children with and without late-onset hearing loss. The model estimated economic benefits based on early identification. Megan offered to provide a publication that explains how the benefit values were calculated. While long-term benefits were considered, further study would be required to explore that dimension more fully.

John added that the model did not assess cumulative effects across years. Each analysis provided a snapshot of a single year's birth cohort, measuring costs and benefits over six years. This process is repeated for each new cohort, resulting in discrete, year-by-year evaluations rather than a continuous, long-term analysis.

Member Leung emphasized that startup costs are typically one-time expenses. Member Leung noted the importance of factoring in longer-term infrastructure implications.

Member Shukla highlighted that early diagnosis can lead to earlier interventions like cochlear implants and speech therapy. These may improve long-term outcomes even if those benefits are hard to quantify.

Cathleen Ackley, Committee Member, affirmed the previous comment and shared that *Listen and Talk*, a school on the east side, supports children born with hearing loss, especially those affected by CMV. The school's robust early education program ends at kindergarten, aligning with key stages of language and cognitive development. The hope is that early intervention allows children to thrive in public education afterward. Member Ackley stressed that while these benefits are hard to measure, they are critical to child development and long-term success.

Allegra Calder, Facilitator, asked for any final questions or comments. It was noted that members could vote "unsure" if needed. Comments submitted during the vote would be discussed and forwarded to the Board to capture areas of consensus and divergence. Input remains valuable and welcomed.

Member Shukla directed a question to John and Megan, requesting a clear summary of the expected financial cost if urine spot screening were implemented. The request focused on understanding annual cost implications and emphasized the importance of hearing this clearly before voting.

John explained that, from the Department's perspective, the benefit-cost ratio from the urine screening model was approximately 0.72. Shared that in Minnesota, 75% of children

were not receiving proper diagnostic follow-up 75% of children were not receiving proper diagnostic follow-up and that ratio dropped to around 0.58. In other words, for every $1 spent, the estimated return could range between 58 and 72 cents. John acknowledged that the model does not include intangible benefits which are difficult to measure but still impactful. Committee members were encouraged to consider these nuances when making decisions on behalf of families and the broader community.

Peggy Harris, Committee Member, reflected on the emotional difficulty of remaining unbiased and shared a personal experience involving the diagnosis of a child.

8. **Vote**

Allegra Calder, Facilitator, introduced the voting section of today's meeting.

Peggy Harris, Committee Member, discussed how it's hard not to be biased through this and thinking about those who are affected more than those who are not.

Facilitator Calder appreciated Member Harris' comments and emphasized that it's important to vote for what you think based on what you know.

Member Shukla said it would be nice to compare some of the other conditions that are on the newborn screening (NBS) panel and compare their costs.

John Thompson, Department staff, shared a table that provided additional information of the current conditions on the NBS panel and their benefit-cost ratio.

Kelly Kramer, Board staff, provided additional information to TAC members on how to vote. The first vote is for the cCMV condition evaluation with the Newborn Screening Criteria. Once the first vote is completed, the TAC will move to a second vote to determine overall if they think cCMV should be added to the NBS panel.

Kelly K. reviewed the initial vote from the TAC members. For criterion one, most TAC members agreed that cCMV meets the criteria. For criterion two, half of the TAC members felt it met the criteria, while the other half were either unsure or disagreed. For criterion three, most TAC members believed it met the criteria. Similarly, for criterion four, the majority felt it met the criteria. For criterion five, half of the TAC members agreed it met the criteria, while the other half were either unsure or disagreed. Finally, for criterion six, half of the TAC members believed it met the criteria, while the other half were either unsure or disagreed.

Facilitator Calder reminded TAC members that we do not need consensus for these votes.

Kelly K. introduced the second voting ballot. This vote is to ask TAC members for their overall recommendation of cCMV to the NBS panel. While TAC members voted, the TAC went into a break.

LUNCH

9. Discussion and Next Steps

Eric Leung, Committee Member, said this has been one of the most difficult discussions in the last five years and reminded everyone that it is okay to be unsure.

Kely Kramer, Board staff, reviewed the second vote and the anonymous comments submitted.

Member Leung expressed uncertainty about whether generating demand would lead to the necessary infrastructure being developed. They cautioned that this approach might be overly optimistic.

Rucha Shukla, Committee Member, shared a similar concern. While supportive of including congenital cytomegalovirus (cCMV), they worried that the system may not be able to meet the demand, even if it exists, and could become overwhelmed.

Member Leung added that funding pediatric systems across the state has long been a challenge, noting that children have consistently been a vulnerable population. The high costs involved contribute to skepticism, yet do not deter them from advocating. They voted yes, emphasizing that despite consistent failures in securing adequate funding for children's care, persistent advocacy remains essential.

Peggy Harris, Committee Member, agreed and thanked Member Leung for their comments.

Emily Shelkowitz, Committee Member, shared feeling somewhat uninformed but noted that the rationale for adding cCMV, though different, sparked reflection. They found it valuable to consider infrastructure and capacity, which in the case of cCMV, seemed more robust compared to other conditions. They speculated whether this was influenced by current global or societal conditions and invited other members to share thoughts on that comparison.

Member Leung appreciated the perspective and remarked on the difficulty of comparing this condition to others already on the panel, noting that those conditions differ.

Member Harris added that when considering previous additions to the panel, there had been fewer concerns about infrastructure and more comprehensive information available on the respective conditions. This situation felt different.

Member Shelkowitz said their second observation regarding the discussion on hearing loss therapeutics. They noted the absence of a TAC member from the Deaf or Hard of Hearing community and suggested that this is a perspective that should be included on the panel.

Cathleen Ackley, Committee Member, said part of their advocacy here is to represent that community.

Priyanka Raut, Committee Member, acknowledged the diversity of perspectives on the committee and echoed Member Shelkowitz's earlier point, expressing optimism that the group would continue to become more inclusive.

Member Harris said community groups are important. Just need to keep building on those groups.

Member Leung asked Member Raut whether the Farmworkers Clinic has access to community health workers who help connect them to services.

Member Raut confirmed that such programs exist, including partnerships with Seattle Children's Hospital. They emphasized the importance of those initiatives.

Kelly K. will present the TAC's recommendations of cCMV at the April 9 Board meeting.

Kelly Oshiro, TAC Co-Chair, explained that urine screening can't move forward without legislative approval. Rulemaking likely wouldn't begin until July 2026, and the Board may not revisit the condition until urine collection is formally added.

Member Leung asked whether the Board must go through the full process of drafting new RCWs to make these changes.

TAC Co-Chair Oshiro confirmed that review of RCWs would be necessary.

Member Leung shared that they had reviewed the RCWs themselves and were unsure about the level of legislative involvement required for the Board to carry out its responsibilities. They questioned whether modifying the wording of an RCW constitutes a lengthy legislative process.

TAC Co-Chair Oshiro asked whether other Recommended Uniform Screening Panel (RUSP) conditions utilize urine samples, noting that it is a consideration.

Member Leung explained that these legislative challenges were part of why they previously testified in opposition to House Bill 1697. Member Leung wanted to clarify the extent of the process involved, based on how transparent the requirements currently appear.

Molly Dinardo, Board staff, confirmed that the issue will need to be discussed at a Board meeting.

Kelly K. said that the TAC will review the condition of Wilson Disease in either late May or early June.

Member Leung noted that the TAC has historically met as an ad hoc committee; this is the first time we have done a standing committee.

Kelly K. said we will assess this at the Wilson Disease committee. At the next TAC meeting, we can discuss if this group would like to move forward working together through the biennium.

John Thompson, Department staff, thanked TAC members for their time and perspective.

ADJOURNMENT

Kelly Oshiro and Nini Shridhar, TAC Co-Chairs, adjourned the meeting at 2:30 p.m.

WASHINGTON STATE BOARD OF HEALTH

_____

Kelly Oshiro, TAC Co-Chair and Nini Shridhar, TAC Co-Chair