Minutes for the Newborn Screening Technical Advisory Committee (TAC)
February 11, 2025
Hybrid Meeting
ASL (or CART) and Spanish interpretation available
Washington State Department of Health, Town Center 1
101 Israel Rd S.E. Tumwater, WA 98501
Rooms 163 and 164
Virtual meeting: ZOOM Webinar

Technical Advisory Committee Members present:

In-Room Participants:

Kelly Oshiro, JD, Board Vice Chair and TAC Co-Chair
Eric Leung, Washington Chapter of the American Academy of Pediatrics (WCAAP)
Tawney Hooley, cCMV Parent Advocate

Online Participants:

Byron Raynz, Parent Advocate
Roberta (Bobbie) Salveson, Mary Bridge Children's Hospital Biochemical Genetics
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)
Joan Chappel, Washington Healthcare Authority (HCA)
Sunpreet Bhangoo, Washington Healthcare Authority (HCA)
Kristine Alexander, Regence Health Plans
Lisa McGill Vargas, Sacred Heart Medical Center Neonatology Intensive Care Unit (NICU)
Rucha Shukla, Sacred Heart Medical Center Neonatology Intensive Care Unit (NICU)
Taylor Kaminski, Global Perinatal Services
Christina Lam, Seattle Children's Hospital Biochemical Genetics
Molly Parker, Provider and Chief Marketing Officer (CMO) of Population Health, Jefferson Healthcare
Cathleen Ackley, cCMV Parent Advocate

TAC Members Absent:

Emily Shelkowitz, Seattle Children's Hospital Biochemical Genetics
Steve Kutz, American Indian Health Association
Peggy Harris, Parent/Child Advocate, Save Babies Through Screening Foundation
Nirupama (Nini) Shridhar, MPH, PhD, TAC Co-Chair
María Sigüenza, Commission on Hispanic Affairs

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
John Thompson, Department of Health
Dr. Ann Melvin, Seattle Children's Hospital, Infectious Disease
Samantha Fuller, Department of Health
Megan McCrillis, Department of Health
Julie Walker, Department of Health
Michele Greenwood, Providence Spokane Ear Nose and Throat

1. **WELCOME & INTRODUCTIONS**

   Kelly Kramer, Board staff, welcomed everyone to the meeting and provided an overview of the two topics that the Technical Advisory Committee (TAC) would cover during the meeting. The topics are reviewing the Board's newborn screening criteria and starting a review of the condition congenital cytomegalovirus (cCMV). Kelly K. added that voting on cCMV would occur at the next TAC meeting in March.

   Allegra Calder, Facilitator, invited TAC members to introduce themselves and reminded everyone to be mindful of their speaking pace to help support meeting interpretation.

2. **JANUARY TAC RECAP**

   Kelly K. summarized the January 14 TAC meeting, focusing on the TAC's discussion about adding branched chain ketoacid dehydrogenase kinase (BCKDK) deficiency to the newborn screening panel. The results of the TAC's vote were shared, with the recommendation not to add BCKDK deficiency to the panel at this time. Kelly K. also reviewed the split vote on proposed changes to the screening criteria. Kelly K. noted that the TAC would review and discuss suggested edits to the Board's criteria provided by the Department of Health's Newborn Screening Program during the meeting today.

3. **WA Criteria Review and Discussion**

   Kelly Oshiro, TAC Co-Chair, introduced the topic for discussion.

   Kelly K. reviewed the first newborn screening criteria, "Available Screening Technology," and the suggestions provided (presentation on file). Kelly K. then opened the floor for discussion.

   Eric Leung, Committee Member, expressed approval of the updates made to criterion one.

   Molly Parker, Committee Member, agreed with Member Leung's comment. Member Parker then suggested wordsmithing the second point and changing it to "potential impact on the families, healthcare systems, and newborn screening program" to emphasize families and patients first.

   Member Leung asked Member Parker to clarify if they just wanted to change the order of the items on point two.

Member Parker said that is correct.

Facilitator Calder asked if we could move forward with the change Member Parker suggested.

TAC Co-Chair Oshiro said that the change is a great suggestion, and we can adopt the change.

Member Leung asked moving forward if we need first or second motions.

Kelly K. answered no.

Kelly K. moved on to the second criterion, “Diagnostic Testing and Available Treatment,” and its suggested changes (presentation on file). Kelly K. opened it up for discussion.

Lisa McGill Vargas, Committee Member, commented liking how this is laid out. It defines a lot of points of discussion we had.

Member Leung said speaking to criterion two point four, understands the intent, but speaking to accessibility, not sure how we could influence that kind of structure.

Byron Raynz, Committee Member, agreed and wouldn’t want point four to say that we are not going to screen for a particular condition if folks are too far out to get treatment for this. This is what this point seems to allude to.

Member McGill Vargas said it is important to think about how we can influence access to care for some of the very rare diagnoses that do need specialized care. As we are considering our newborn screening, it's not so much for accepting or refusing the criteria, but what is the room for advocating for those families that have difficulties getting into our cities on the west side of the state.

Bobbie Salveson, Committee Member, suggested including something about telemedicine and that would increase the availability.

Heather Hinton Committee Member, said the part that stands out to them in point four is where it says, “considered acceptable.” That seems like it is subjective almost, especially coming from an area where there is difficulty accessing that kind of treatment.

Joan Chappel, Committee Member, agreed that “acceptable” and “proximity” is a vague term. Member Chappel suggested using the word availability.

Member Leung asked if the purpose of point four is to use it as leverage to increase or demand more accessibility from legislators. Does it help us go back to legislators and demand that we improve access?

Megan McCrillis, Department of Health, said the primary goal in spelling this point out specifically is to call attention to the fact that we know in this state there are geographic differences with vastly different resources. Trying to make sure that specific piece about

availability, proximity, and access was specifically addressed in each conversation with each specific condition. Megan discussed from their perspective it was trying to call attention to that issue that we know exists and create conversation around it without putting hard boundaries without it.

Member Leung appreciated that answer and suggested that this point might fit better under criterion number six “Public Health Readiness.”

Facilitator Calder recapped the discussion.

Kristine Alexander, Committee Member, agreed with TAC members that proximity is part of availability and doesn’t necessarily need to be separately stated. Unfortunately, you cannot always guarantee access to something, but the benefit of newborn screening is getting treatment. On the other hand, nothing is perfectly available to everybody.

Facilitator Calder asked TAC members for their thoughts on Member Leung’s suggestion to move this under “Public Health Readiness.”

Member Raynz expressed concerns about being diagnosed versus not being diagnosed. If there was no treatment available regardless of where it was, they would still want to know if their child still had that particular life-threatening condition.

Member Parker appreciates the discussion around this from a rural perspective and agreed to move this point under “Public Health Readiness.”

Cathleen Ackley, Committee Member, agreed with moving it to “Public Health Readiness.”

Facilitator Calder reminded folks that this is for all screening.

Member Leung suggested separating the idea of “available treatment to change the outcome” from the “accessibility for treatment” and redirecting the accessibility part as our state’s goal, moving that to criterion six, which might clarify some of the issues.

TAC Co-Chair Oshiro said to Member Leung’s point, that separating availability and tethering this criterion to four to proximity and frequency would better address Megan's intent in drafting the criterion.

Tawny Hooley, Committee Member, said from a parent perspective living in Spokane, they had to utilize several different doctors to be able to assist us who were not in proximity to our location. Agreed with moving the fourth point to the six criteria and removing the word “proximity.”

Facilitator Calder summarized that there seems to be support for removing proximity and moving this fourth point to the last criteria. Facilitator Calder asked Member Leung if they were separating availability, is that covered in the second point?

Member Leung said that Facilitator Calder was right. Point two speaks to the fact that there needs to be an intervention available to change the course of the disease so that officially separates that type of availability from accessibility.

Christina Lam, Committee Member, agreed.

Facilitator Calder asked Megan if availability and accessibility are somewhat interchangeably used in their thinking.

Megan said yes, but it is up to this committee how they best see it.

Facilitator Calder clarified for this criterion, the available treatment piece is staying, the issue around if it is accessible will move to criterion six, and the word proximity will be removed.

Kelly K. moved on to criteria three, “Prevention Potential and Medical Rationale,” and reviewed the suggested updates (presentation on file). Kelly K. opened it up for questions.

Member Leung posed a question for the genetic specialists on the committee. There are conditions that we screen that may only be unmasked by a precipitating illness and may not manifest in the first year of life or infancy. Does that create a contradiction?

Member Lam answered that point three can address that.

Member Leung thanked Member Lam and asked if they felt that the way this is written covers all situations adequately.

Member Lam answered that the way it’s written allows us to evaluate conditions appropriately and it’s based on our judgment on whether the goldy locks cases meet the criteria to be screened universally. Despite cases where there is not sufficient time between birth and onset of irreversible harm and cases that are late onset, which may or may not have true treatment or lead to substantial anxiety. That is a question for someone with more ethical expertise to weigh into.

Member Hooley spoke about their personal experience being an advocate for their son and the testing they had to go through.

John Thompson, Department of Health, noted that they would argue in the case of an infectious disease like cCMV, that the onset is the infection itself. So, that would fit within the proposed criteria.

Member Parker asked for clarification on point three. Is the intention to balance the negative impact of detecting later onset or just any impact?

Megan answered that point three is from the historical criteria. You can presume that might indicate a negative impact. It could be interpreted as whatever that might mean for the condition in question.

Member Parker clarified that the sense of bullet three is that the benefits of detecting and treating infantile forms balance the impact of detecting later forms. So, we would choose to select a condition for screening because the benefits of detecting early onset are more important than the negative impacts of detecting later.

John answered that this was a correct interpretation.

Joon-Ho Yu, Committee Member, noted always interpreting it as the benefits of early detection is worthwhile compared to waiting until it gets detected later. So, it's not exactly the negative impact of early detection, but that there is a greater benefit earlier.

Member Lam said there are later onset forms of conditions where there may not be treatment compared to early onset. Detecting these later onset forms of conditions may bring harm to patients and families.

Member Salveson agreed with what Member Lam said but also believes that knowing that there is an underlying condition can avoid much of the diagnostic odyssey that people go through. Knowing that they have this condition they could proceed with palliative treatments instead of being misdiagnosed.

Member Lam said that the impact of detecting later onset forms can be positive or negative. However, we are weighing the negative impacts against the benefits of detecting early onset.

Member Parker said this discussion clarified things for me and doesn't feel the need for changes now.

Kelly K. reviewed criteria four, "Public Health Rationale," and its edits (presentation on file). Kelly K. shared an email from Emily Shelkowitz, Committee Member with feedback for the committee to consider. In the email, Member Shelkowitz asked the committee to consider whether sufficient literature or guidelines inform clinicians on how to monitor asymptomatic individuals and when to consider treatment for our late onset conditions. Member Shelkowitz also noted in the email that this comment might belong under criteria four as there may be public harm that can come from those diagnosed with late onset forms.

Member Lam suggested that this comment applies to what we were just discussing for criterion three.

Member Leung vocalized agreement.

John asked the committee if we need to consider modifying the language in criterion three to reflect Member Shelkowitz's comments.

Member Lam said that in criterion three, under point three point three, the discussion should occur there. Not sure whether that should be laid out as something that should be discussed with every disorder.

Facilitator Calder responded that this reminded them of their discussion during their last meeting. We want enough direction and guidance but also have the flexibility to have discussions. The criteria are universal, but the conditions are all different.

Member Salveson said that point three in criterion three addresses this.

Facilitator Calder recapped the discussion. Based on the comments from Member Shelkowitz, we feel that will happen in criteria three.

BREAK

4. Washington Criteria Review and Discussion Continued

Criterion 5 Cost-benefit and Cost-effectiveness

Megan McCrillis, Department of Health, reviewed the cost-benefit analysis model and explained that short-term finite healthcare costs are included, along with other potential costs or benefits associated with screening for a condition. Megan explained that they are unable to include a dollar amount on hardships placed on families. Informed the group that the changes to this criterion likely won't change the cost-benefit analyses that they conduct but will now call out the complex considerations the TAC considers in their vote.

Christina Lam, Committee Member, liked seeing how we go through cost analysis, but didn't notice a formal way of the costs incurred for detecting late onset conditions or the emotional economic impact of false positives. Curious if there are additional calculations that haven't been displayed at the last meeting.

Megan said historically our cost-benefit modeling sticks to costs associated with diagnostic testing. The Department of Health typically doesn't put costs on the hardships or other costs.

John Thompson, Department of Health, confirmed Megan's answer and talked about the parts to costs. John said all the parts will come out when the analysis is done for any given condition.

Joon-Ho Yu, Committee Member, discussed recognizing the limits of cost benefits and analysis. Member Yu wondered if emotional could be substituted for psycho-social. Also, there's a lot of work on broadening and detaining our understanding of benefits, whether personal, psychological, social, and somewhere in-between.

Molly Parker, Committee Member, talked about the data on false positives and it is not condition specific, which is a negative outcome from false positives.

Eric Leung, Committee Member, appreciated the consideration of negative impacts on families that receive false positives. In more recent conditions, the testing techniques (e.g. Arginase), the screening test is the diagnostic test. That may fit more with the future on how we are testing. There are going to be some errors, and we always need to consider when trying to minimize negative impacts.

Allegra Calder, Facilitator, summarized Member Leung's comments.

Member Leung supports Member Yu's comment to replace emotional with psycho-social and doesn't suggest any additional change.

Heather Hinton, Committee Member, also supported this change.

Criterion 6 Public Health Readiness (new addition).

Byron Raynz, Committee Member, said the word identified is intentional. The spirit of why we are using is identified in both these cases. Megan confirmed yes.

Priyanka Raut, Committee Member, elaborated on the second point on the resources. Megan said in general this work has always happened, it just happened after the TAC made a recommendation and it was confirmed yes, to screen for a condition. The original intent was for the newborn screening program and sometimes we might need extra staff to address some conditions.

Member Raut would love to learn more from the group, maybe adding a dot point on the readiness point.

Member Leung talked about accessibility and suggested dot point two said "Resources, including accessibility, have been considered." It might not need its own dot point, but it's part of the resource consideration.

Member Lam likes "the accessibility" as a separate bullet.

John Thompson, Department of Health, appreciated the comment and thinks there is a value to having the separate dot point. John discussed XLD, from the Department of Health perspective, needed to purchase an expensive piece of equipment and form new protocols, and from a clinical standpoint, a need for the baby boys diagnosed, periodic adrenal function scans, brain MRIs, and more. It was a long-term plan that needed to be established. There are different spheres of influence to consider. Member Leung appreciates the new criteria and leading into Public Health.

Member Parker spoke to Member Raynz comment, asking for specifics around before or after conditions are discovered. Megan spoke to rough estimates and the work already happening, saying more details will be addressed once a condition is confirmed.

John said another benefit of the Public Health Readiness Criterion is it allows the Department, to work with the Board and government on timeframes scoped out in advance.

Kelly Kramer, Board staff, said we will vote on each piece.

Facilitator Calder talked about moving the accessibility piece, support for emotional to psycho-social. Staff will update this before voting.

Member Leung talked about other processes in the emails, such as the function of committee and asked if these are being considered separate from the sixth criteria.

Kelly K. clarified Member Leung's question about process and criterion. Kelly K. said the Board has already decided on the process, and now we are voting on the criterion changes.

Member Leung wanted to raise questions about the process adopted by the Board.

Member Leung talked about two legislative bills, House Bill (HB) 1697 and Senate Bill (SB) 5668. They challenge the process, and place demands on the committee that undermine the work we are doing. The proposed legislation stipulates we stick to the Recommended Uniform Screening Panel (RUSP), that currently exists as of January 2025. Last committee meeting we discussed aligning or considering our own condition to the RUSP. Member Leung finds this comes at a difficult time and asks staff how to respond.

Kelly K. said HB 1697 has a public hearing on Friday, February 14, at 8 a.m., and will testify and lay out those concerns. The Board appreciates the work of the legislators and the rare disease coalition that helped lay out the language on these bills and is currently working on this.

John said the Department has formally responded and made comments known to the committee.

Joan Chappel, Committee Member, said there is a fiscal note, and they have concerns that have passed along to the committee.

Bobbie Salveson, Committee Member, asked if this bill is in addition to the TAC work on the process and criteria. John said the bill as proposed would overturn some of the work this Committee has done, but ultimately the legislature can change the law.

Member Leung discussed the fees to fund screening and follow-up. It is $8.40 a birth for follow-up. For a state with 80,000 births, we are talking around more than $600,000 for programs that follow-up.

5. **Vote**

NBS Criteria Voting Results: Microsoft Forms

Criterion 1

Allegra Calder, Facilitator, said there is a large approval of 93.8%. One person would like to omit or suggest something else. An anonymous commenter said they appreciate the criterion.

Criterion 2

The proposed changes received a 100% approval from all TAC members.

Criterion 3
Facilitator Calder asked for comments.

Lisa McGill Vargas, Committee Member, discussed being confused about the wording of but chose to approve the changes.

Eric Leung, Committee Member, had comments but is ok overall with the changes.

Criterion 4
The proposed changes received a 100% approval from all TAC members.

Criterion 5
Most TAC members voted to approve the changes to the criterion. One to two TAC members voted against the second and third additional dot points but provided no additional comments.

Criterion 6
Most TAC members voted to approve the new criterion.

Member Leung asked about changing the wording from availability to accessibility in the third point in Criterion 6.

John Thompson, Department of Health, suggested when we moved it to Criterion 6, the proposal is to say remove the words availability and proximity to accessibility. John asked how we'd like to vote and decided on a hand raise.

TAC members voted unanimously for the change. No objections.

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6. **Discussion and Next Steps**
   Kelly Kramer, Board staff, walked through the voting results and highlighted the incorporated changes from the previous discussion. Kelly K. then informed TAC members of the next steps. Kelly K. will present the recommendations to the Board at the March 12 meeting. The criteria updates will not be adopted and applied to conditions under consideration until the Board has approved of the proposed changes.

7. **Overview Congenital Cytomegalovirus (cCMV)**
   Kelly K. gave an overview of the legislative mandate to review cCMV for consideration for the state newborn screening panel and the results of the 2022 newborn screening technical advisory committee meeting. Kelly K. summarized the voting breakdown that resulted in the recommendation to reconsider cCMV at a future date. At that vote in 2022, most TAC members felt cCMV did not meet Criterion 2, were split as to whether it met Criterion 4, and voted with mixed results regarding the cost-benefit analysis.

   Kelly K. then introduced the two parent representatives that will share their experience with cCMV.

8. **Parent Perspective**

Tawny Hooley, Committee Member, thanked the group for discussing cCMV and shared a personal experience with cCMV as an occupational therapist at Sacred Heart in Spokane, WA. Member Hooley discussed treating a patient who had CMV while pregnant and later learned their son was diagnosed with cCMV. Member Hooley was one of the few patients diagnosed with cCMV during pregnancy and felt that providers were not prepared to provide appropriate care. Member Hooley received care at the University of Washington who performed amniocentesis and ultrasounds. Providers warned that the baby may need NICU care, antivirals, and additional treatment. Member Hooley was aware that most babies with CMV are ok, but it can be fatal. Member Hooley began to look for expert care elsewhere and found a doctor in Texas from the CMV Foundation website. This provider gave virtual guidance to Member Hooley's care team.

Once Member Hooley's child was born, their care team found hearing loss at six months and diagnosed them with sensorineural hearing loss (SNHL) at nine months, with rapid progression. Member Hooley discussed connecting with a clinical trial and received antivirals for six months with weekly blood work and growth checks. Member Hooley noted the lack of resources in Spokane. Member Hooley discussed that their child's hearing is now in the normal range, no longer needs hearing aids, and is meeting all developmental milestones with some speech therapy. Member Hooley emphasized that without early intervention, there could have been so much more medical care. Member Hooley said that if we can screen children at ages two and three before they start talking could significantly improve outcomes for both individuals and society. Member Hooley acknowledged the costs of screening but stressed the positive outcome from providers willing to try different treatments and noted educating pregnant friends and family about CMV prevention.

Cathleen Ackley, Committee Member, shared a different experience from Member Hooley. Member Ackley explained that their second child was born healthy but began to have rapid and deteriorating hearing loss due to cCMV. Member Ackley said they felt early prevention could have prevented the hearing loss and that providers could have done more to warn about cCMV.

Member Ackley then presented on costs and benefits related to early identification of cCMV. Member Ackley shared statistics, such as "1 in 200 babies are born with CMV" and 10% are symptomatic at birth. While the number may seem small, Member Ackley emphasized the significant costs, noting that vigilance is crucial for asymptomatic babies. While Washington would need to pay for the costs of education and screening for cCMV, the state is already paying the costs of late diagnoses. For example, special education costs can be $300-500k per child over 18 years and the cost of lifelong care can be $3-5 million. Member Ackley said that testing babies for cCMV could cost between $10 to $50 per baby and that for every $1 spent on screening, $10 would be saved. The annual cost of universal screening would be $809k - $4 million. Member Ackley said that the benefits of early detection would be to initiate antiviral treatment to reduce neurological damage and hearing loss. Parent education prevents emergency medical costs and unnecessary emotional impacts. Member Ackley concluded by stating that Washington needs to act now, and universal screening is cost-effective.

9. cCMV: Natural History, Diagnostic Testing, and Treatment

Dr. Ann J Melvin, MD, MPH, Emeritus Professor, Children's Hospital, reviewed the natural history, diagnostic testing, and treatment for cCMV (see presentation on file).

Allegra Calder, Facilitator, asked the committee for questions.

Eric Leung, Committee Member, thanked Dr. Melvin. Member Leung was struck by a couple of things; the proliferation of data in the last few years. Children that were considered asymptomatic and distinguishing between symptomatic and asymptomatic with deeper investigation. Member Leung asked about their stance on the universal screening program. Dr. Melvin personally feels universal blood spot testing is probably the most cost-efficient, but they are admittedly biased. There are so many steps that are outside of the screening program.

Member Leung asked further questions about Utah screening. Member Leung said Utah requires two failed newborn hearing screening tests. Member Leung said in Washington after two failed tests, then a referral to an audiologist. Some large areas only have one audiologist, so access is difficult.

Rucha Shukla, Committee Member, asked about pregnancy testing and consistent education. Dr. Melvin couldn't find any but wanted to dig deeper.

Tawny Hooley, Committee Member, spoke to their own perspective in Spokane. Member Hooley had been IGG tested and shared their results with their pregnant sister and friend. One of their providers said no need to test, another one said yes to test for CMV.

Julie Walker, Department of Health, said most hospitals in Washington technically do two hearing screenings, and then return in three weeks.

Bobbi Salveson, Committee Member, said this sounded like a concern and asked about other states' blood spot tests.

Dr. Melvin said Connecticut, Minnesota, and other states do targeted hearing screening.

Julie Walker said there is information online.

Molly Parker, Committee Member, talked about universal screening and false positives being so high that it didn't merit screening and cost benefit factors.

Kelly K. forwarded to TAC members the American College of Obstetricians and Gynecologists on cCMV that Member Parker shared.

Facilitator Calder thanked Dr. Melvin.

10. Available Screening Technology

Kelly Kramer, Board staff, introduced the criteria review (see presentation on file). Kelly K. reminded TAC members that recommendations will not be reviewed or approved until the March 12 Board meeting.

Megan McCrillis, Department of Health, reviewed the available screening technology criterion for Congenital Cytomegalovirus (cCMV) and the pros and cons of the biological specimen types used to screen newborns for cCMV. The options include a dried blood spot test, saliva swab, and dried urine paper filter (see presentation on file).

Dr. Ann Melvin, Seattle Children's Hospital, asked if the dried blood spots were mailed.

Eric Leung, Committee Member, said that is correct. The blood spots must dry first before we mail them. The same would be applied to the urine filter paper. Member Leung asked how these specimen types can be used in combination. It seems like even if you use dried blood spots and a saliva swab in combination, you're not going to get the sensitivity or specificity with urine.

Molly Parker, Committee Member, spoke from their observation working in a birth center. Any of these processes would be simple to implement, especially if the dried blood spot was combined in the same packaging as the urine filter paper. The biggest issues may be at the lab receiving end.

Joan Chappel, Committee Member, asked if we currently have the infrastructure at the lab to test dried urine filter papers. Member Chappell agreed with Member Parker's comments.

John Thompson, Department of Health, said we have the expertise on staff who are familiar with the techniques.

Member Leung clarified with Member Chappel if they were asking if hospital sites can test for cCMV and urine samples themselves.

Member Chappel responded that they were just concerned about the lab.

11. Overview: Early Hearing Detection, Diagnosis, and Intervention (EHDDI) Program

Julie Walker, Department of Health, introduced the Early Hearing Detection, Diagnosis, and Intervention (EHDDI) program and what they do for CMV. The program's goal is for all infants to receive a hearing screen by one month of age. Infants who do not pass two hearing screenings will have a diagnostic evaluation before reaching three months old. Infants identified as deaf or hard of hearing (D/HH) have a follow-up within six months. The EHDDI does a lot of work in a short time.

Julie noted that Washington is only one of three states that don't require universal screening, but all birth hospitals provide screenings. The program supports 63 midwives with equipment. One to three infants per 1,000 are identified as D/HH each year. Julie listed the risk factors for hearing differences or loss.

Julie explained that when a baby receives a hearing screen, the risk factors are reported to EHDDI on the hearing screening card. However, the risk factors are vague and don't specify if an in-uterine infection is CMV. It is hard to know how many moms with CMV are being reported. Julie went on to review the EHDDI program and how infants with cCMV are being followed (see presentation on file).

Julie discussed the cCMV bill that passed last legislative session, in which the EHDDI program is responsible for educational materials for cCMV. Julie explained that they are working on a short one-pager that focuses on how to prevent cCMV when pregnant. It will be translated into the top 11 languages in Washington and French. The EHDDI team will also launch a social media campaign. Kelly K. will help disseminate this information as well.

Dr. Ann Melvin, Seattle Children's Hospital, thanked Julie and noted that there may be even more cases of CMV. Instead of 30% of kids, it is likely to be 70%.

Tawny Hooley, Committee Member, asked about the flyer and suggested including Dr. Melvin's graph about the first trimester being the highest risk factor for cCMV. Member Hooley also suggested sending this information to primary care providers. It can take 8-12 weeks for a pregnant person to be seen for a check-up.

Julie responded that EHDDI began to work with SETNET that looks at cCMV data. They have created a flyer specifically for cCMV. The American Academy of Pediatrics should also distribute this information to pregnant people. Explained the other avenues EHDDI is exploring in terms of distributing the flyer to help prevent cCMV.

Rucha Shukla, Committee Member, thanked Julie and asked if there is literature regarding a child with CMV who has had normal hearing screenings for a long time. Member Shukla wondered if these kids will continue to be followed or if there is a way to determine if a child is at low risk for hearing loss. Member Shukla discussed concerns due to the lack of resources and the likely overwhelming number of kids needing follow-up. Member Shukla asked about older children on treatment and if other risk factors cause additional hearing loss.

Julie requested Dr. Melvin answer this question due to their expertise.

Dr. Melvin answered that in utero CMV infections get into the middle ear, which they aren't seen postnatally. CMV is still detected in patients with cochlear implants in the middle ear. This may be due to reactivation of the virus. There is limited study for risk stratification at this point.

Member Parker suggested that EHDDI looks at the Washington Academy of Family Physicians when they are distributing information as they work a lot with rural families and pediatrics. Member Parker also suggested the Washington State OB Community which includes any birth center or delivery provider.

BREAK

12. Available Audiological Resources and Access

Michele Greenwood, Audiologist, Providence Spokane Ear Nose & Throat, presented on the shared Pediatric Audiology Assessment, the challenges, clinic resources in eastern Washington and other considerations (see presentation on file). .

Heather Hinton, Committee Member, recently talked to a parent advocate about audiology and the lack of pediatric audiologists in the area and shared that there was a mobile audiology clinic, through Center for Deaf and Hard of Hearing in Washington State. Michele said this is a great solution for older kids and that pediatric audiology takes a lot of energy.

Julie Walker, Department of Health, said the Mobile unit was sitting at the Educational Service District 123, for two years and up. Believes that the mobile unit was being moved.

Rucha Shukla, Committee Member, talked about every child tested that requires follow-up, and the resources needed for pediatric support. Lack of resources on the east side falls to the resources on the west side of the state.

13. Discussion and Next Steps

Kelly Kramer, Board staff, reminded folks that the review of cCMV will continue to a virtual meeting on March 26. We will hear a presentation on the cost-benefit analysis for cCMV and will then move to a vote on the recommendation for inclusion to the newborn screening panel. Also, we will present the criteria recommendations to the Board on March 12. An update on the Board's decision will be shared at that meeting as well.

Kelly Oshiro, TAC Co-Chair, shared gratitude for all participants, the presentations, and the attention to detail from our TAC participants. Looking forward to the Board meeting and sharing recommendations from the TAC.

Eric Leung, Committee Member, asked John about someone within the lab who manages requests from dried bloodspots for cCMV testing. Might help in terms of collection and records estimates.

John Thompson, Department of Health, said we do have that information and can look into it and pull numbers for the next meeting.

ADJOURNMENT

Kelly Oshiro, TAC Co-Chair, adjourned the meeting at 3:20 p.m.

WASHINGTON STATE BOARD OF HEALTH

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