

Final Minutes of the State Board of Health April 12, 2023

Hybrid Meeting Physical meeting at Labor & Industries Auditorium, 7273 Linderson Way SW, Tumwater, WA 98501 Virtual meeting via ZOOM Webinar

State Board of Health members present:

Keith Grellner, RS, Chair Kelly Oshiro, JD, Vice Chair Patty Hayes, RN MN Tao Sheng Kwan-Gett, MD, MPH, Secretary's Designee Dimyana Abdelmalek, MD, MPH Stephen Kutz, BSN, MPH Melinda Flores Socia Love-Thurman, MD Michael Ellsworth, JD, MPA, Secretary's Designee Kate Dean, MPA

State Board of Health members absent:

Umair A. Shah, MD, MPH Socia Love-Thurman, MD

State Board of Health staff present:

Michelle Davis, Executive Director Melanie Hisaw, Executive Assistant Anna Burns, Communications Consultant Stuart Glasoe, Health Policy Advisor Molly Dinardo, Health Policy Advisor LinhPhung Huỳnh, Council Manager

Guests and other participants:

Michael Ellsworth, Department of Health John Thompson, Department of Health Kelly Cooper, Department of Health Jeremy Simmons, Department of Health Victor Rodriguez, Council Vice Chair Jessica Zinda, Council Member Jo-Ann Huynh, Administrative Assistant Grace Cohen, Department of Health Lilia Lopez, Assistant Attorney General Eric Sonju, Assistant Attorney General

<u>Keith Grellner, Board Chair,</u> called the public meeting to order at 10:01 a.m. and read from a prepared statement (on file). He then detailed operating procedure and ground rules for conducting a hybrid meeting, and asked Board Members to introduce themselves.

1. APPROVAL OF AGENDA

Motion: Approve April 12, 2023 agenda Motion/Second: Member Hayes/Member Kutz. Approved unanimously

2. ADOPTION OF MARCH 8, 2023 MEETING MINUTES Motion: Approve the March 8, 2023 minutes. Motion/Second: Member Hayes/Member Abdelmalek. Approved unanimously

3. PUBLIC COMMENT

<u>Sue Coffman</u>, spoke in opposition to the COVID-19 vaccine, and said there are meaningless studies done to boost safety. Sue said it's not misinformation, but missing information.

<u>Gerald Braude</u>, spoke in opposition to the COVID-19 vaccine. Gerald apologized for the last meeting when he expressed frustration and said since that time, there are more deaths in Washington (WA) State following COVID shots and over 35,000 deaths nationwide reported to VAERS. Gerald volunteers in Jefferson County and talked about Vaccine Adverse Events Reporting System (VAERS) data and the adverse effects of the COVID-19 vaccine.

<u>Christine Zahn, Director of the Arginase Deficiency (ARG1D) Foundation,</u> and grandmother of a child with the diagnosis, talked about how exhausting the disease is and advocated for required newborn screening. Christine talked about the effects of Arginase Deficiency, how it has affected their family and how a simple blood spot and early detection is an easy solution. Christine said there is not a cure, but there is treatment.

<u>Melissa Leady</u>, spoke in opposition to the COVID-19 vaccine and encouraged the State Board of Health (Board) and Department of Health (Department) to be more forthcoming with COVID-19 data.

<u>Natalie Chavez</u>, spoke in opposition to the COVID-19 vaccine and talked about the book, Cause Unknown, the Epidemic of Sudden Deaths in 2021 and 2022. Natalie shared data and statistics on increased deaths and talked about the importance of fact checking.

<u>Mike Johnson</u>, spoke in opposition to the COVID-19 vaccine, and said Switzerland has withdrawn all COVID-19 vaccinations. Mike said the risk vs benefit does not justify the shot. He talked about deaths and data reported to VAERS, saying the shots should halt until causes are investigated.

<u>Dennis Flynn, Spokane resident,</u> spoke in opposition to the COVID-19 vaccine, talked about false COVID-19 numbers reported, why there is mistrust with policy leaders, and the importance of crucial conversations.

<u>Bill Osmunson, dentist for about 50 years</u>, talked about Board receiving information for the last two decades that fluoride ingestion is dangerous, saying that 2 out of 3 people

are overdosed with fluoride. Dr. Osmunson said the Washington State Board of Pharmacy states fluoride is a drug, and he requested the Board of Health provide a forum, ad hoc committee, or hearings to consider fluoride danger evidence.

Chair Grellner closed public comment at 10:46 a.m.

4. BOARD ANNOUNCEMENTS AND OTHER BUSINESS

<u>Michelle Davis, Board Executive Director</u> greeted the Board and directed Board Members to materials in their packets.

Ms. Davis provided staffing updates. She said she recently offered the vacant Policy Advisor position to Andrew Kamali, who will join Board staff on May 1. She added that Mr. Kamali's biography would be included as part of the Board's June meeting materials. Ms. Davis said she will hold interviews for the vacant Communications Manager position this week and hopes to fill that position by June. She shared appreciation for Board staff and Vice Chair Oshiro for supporting the recruitment process.

Ms. Davis said the Health Impact Review (HIR) team has been invited to provide information to the House Health Care and Wellness Committee on April 18. She said the presentation would be broadcast TVW. She said HIR staff will update the Board on its work for the fiscal year at the Board's August meeting.

Ms. Davis said Member Kate Dean joined the Board last month and her biography is now on the Board's website. Ms. Davis added that the Governor's Office is continuing its search for another Board position—a city official who serves on a local board of health. Ms. Davis has reached out to the Association of Washington Cities to encourage its members to apply.

Ms. Davis shared that an updated list of future Board meetings, which includes updated meeting locations, is on the Board's website. She said Board staff sent a letter to House and Senate budget leaders, which reflects priorities that the Board would like to see in the state's operating budget. Ms. Davis shared that Board staff have sent a letter denying the petition to consider adding Guanidinoacetate methyltransferase (GAMT) deficiency to the newborn screening panel. She then mentioned that the water recreation variance report, which is required in rule (Chapter 246-260 WAC), relates to rule variances that have been granted by the State Department of Health (Department) and local health jurisdictions for water recreation facilities.

Ms. Davis shared that Board staff have finalized a letter to the U.S. Office of Management and Budget (OMB) working group that is looking at potential updates to federal race and ethnicity data standards. She said multiple Washington state agencies plan to submit comment to OMB. For the comment letter, Board staff drew from work on the Notifiable Conditions rule as well as recommendations on disaggregated data in the Board's State Health Report. She said Board Members will receive the final letter following today's meeting. There were no questions from Board Members.

5. DEPARTMENT OF HEALTH UPDATE

<u>Michael Ellsworth, Department of Health and Secretary's Designee</u>, updated the Board on Department of Health (Department) activities. He reviewed current trends in respiratory viruses, as there is a downward trend in hospitalizations for Influenza, COVID-19 and other respiratory diseases. Data shows that COVID-19 related deaths are still elevated, with high-risk communities having the highest rate of death. High risk individuals are eligible for a new booster. He also provided an update that with the end of the Federal COVID-19 Public Health Emergency, the only change will be data reported standards for states and federal mail order COVID-19 test, as the Department will continue monitoring COVID-19 rates.

<u>Member Ellsworth</u> provided an update on the National Legislative Landscape. The Department requested federal funding for data modernization. He reviewed the presentations the Department gave at the federal legislature.

<u>Member Ellsworth</u> highlighted developments for the Department at the state legislature level, including the release of the Maternal Health Mortality Review Panel report and staff presenting to the Senate Health & Long-Term Care Committee on the Fentanyl Crisis.

<u>Kelly Cooper, Department of Health,</u> provided a legislative session update to the Board, and highlighted one of the main themes for this session was workforce, which for the Department involves discussion of credentials for health care providers, including dental therapists, behavioral health specialists, peer specialist, and music therapists.

She mentioned the following bills as impactful to the Department:

- SB 5236-Hospital Staffing
- HB 1134-988 Crisis System
- SB 5120-23 Hour Crisis Relief Centers
- HB 1724-Reducing Barriers to Licensure
- HB 1470-Private Detention Centers
- SB 5367-Products containing THC
- SB 5536-Controlled Substances
- SB 5263-Psilocybin
- HB 1335-Doxing

She noted that HB 1251 regarding drinking water facilities may require rule making rule making by the Board.

She reviewed the House and Senate Budget, and noted the House budget identified a change to the school rule budget proviso, that may allow the Board to move forward with school rules.

Chair Grellner invited Board Members for questions and discussion.

<u>Patty Hayes, Board Member</u> reflected on the Maternal Mortality Report, suggesting that it may be interesting for the Board to explore further from a public health perspective sometime this year.

<u>Stephen Kutz, Board Member</u> suggested that looking at the under capacity of Obstetrician-Gynecologists (OB-GYNs) and lack access to prenatal visits as an important factor in Maternal Mortality rates. He also asked whether COVID-19 testing would continue to be free, noting there's a difference between coverage and free. <u>Michael Ellsworth, Secretary's Designee,</u> said he will look into it and update the Board. <u>Member Kutz</u> also expressed concern about the Department receiving data from emergency rooms and urgent care, and that the end of the Federal order will mean doctors will no longer use testing equipment. <u>Member Ellsworth</u> stated that the end of the Public Health Emergency is separate from the Food and Drug Administration (FDA) authorization which may continue until October 2024.

<u>Dimyana Abdelmalek, Board Member</u> asked if the President ending the Public Health Emergency affects the state public health acts and <u>Member Ellsworth</u> said it does not.

<u>Socia Love-Thurman, Board Member</u> shared that she is also interested in how the Board can dive more into the Maternal Child Crisis and shared her interest in bringing community voice to the board, especially as Native Maternal work is already happening on a regional level.

<u>Kate Dean, Board Member</u> shared that HB 1515 is a big priority for counties. She also stated that there is confusion about if and when Washington (WA) State residents should be self-reporting even among the most informed WA residents. <u>Member Ellsworth</u> said that the Department has shifted from individual positive tests data collection, especially with the rise of home test kits. The Department is focused on tracking Hospitalization and Death rates, genome sequencing, and national/global trends.

6. HEALTH DISPARITIES COUNCIL REDESIGN

<u>Stephen Kutz, Board Member</u> introduced the Governor's Interagency Council on Health Disparities (Council) and a brief overview of what would be covered during their presentation. <u>LinhPhung Huỳnh, Council Manager</u>, and additional presenters introduced themselves and thanked Board Members for the opportunity to present an update on the Council's work.

<u>Grace Cohen, Department of Health, Council Fellow,</u> provided an overview of presentation topics, which included background on the history and creation of the Council, past focus areas, and current Council redesign efforts. They shared that the Council was created in 2006 through a bill championed by Senator Rosa Franklin, the first African American woman elected to the Washington State Senate. The goal of the Council is to eliminate health disparities among people of color and women in Washington State. The Council's current authorizing legislation also names specific health conditions that the Council should examine, as well as Council authority, responsibilities, and membership. Ms. Huỳnh outlined the relationship between the Council and Board and identified how their work intersects, she noted that state statute requires the Board to provide staffing and assistance to the Council. She shared that the Board has a seat on the Council, conducts health impact reviews in collaboration with the Council, and both aim to ground their work in health equity. Ms. Huỳnh provided a list of topics where the Council has made past recommendations, from education and early learning to reproductive health access, to disaggregating data, etc. Ms. Huỳnh emphasized that throughout the past 17 years, they have heard clearly and loudly from communities that interagency efforts should focus on addressing the root causes of health disparities and inequities—such as racism, discrimination, and other forms of bias and exclusion—and the Council should move upstream when examining these issues across all systems, as these are the things that limit a person's opportunity to health and wellbeing.

<u>Victor Rodriguez, Council Co-Chair</u>, shared that he is one of the community-appointed members of the Council. He provided details about the Council's redesign efforts. Since the Council was established 17 years ago, a lot has changed, and the Council has learned a lot. The Council wants to incorporate these learnings to build together the future agencies and community members want for Washington State regarding health and health equity. Council Vice Chair Rodriguez noted that a significant part of the redesign effort is reimagining the Council's statute and recommending updates to lawmakers, so the Council's authority aligns with their aspirations for the future and is grounded in their foundational truths. The Council will use its vision and operating principles, which emphasize bold action, to guide these efforts. Council Vice Chair Rodriguez also encouraged Board Members to participate in the redesign effort and contribute their vision, hopes, and dreams for what health can look like in Washington.

<u>Jessica Zinda, Council Member</u>, introduced the Council's draft intent and purpose statement (available in English and Spanish), which serves as a high-level unifying purpose statement that the Council believes will evolve throughout the redesign process. Council Member Zinda also identified various areas of exploration the Council will look at. She invited Board Members to join them in building a new vision and narrative around health in Washington.

Ms. Huỳnh wrapped up the presentation by sharing opportunities to engage with the Council and stay connected to their work (see presentation on file).

<u>Member Hayes</u> asked presenters if they could share the differences between the areas of exploration the Council is looking at in its redesign and the Council's current authority. <u>Member Hayes</u> noted it would be interesting to have a side-by-side visual comparison of the two as work progresses. She also asked about what accountability looks like for the Council. Ms. Huỳnh responded that the Council is exploring statute updates that meet the moment now, and that focus on addressing upstream factors and the underlying causes of disparities Washington is seeing across its systems. Council Vice Chair Rodriguez added that the Council can develop and share materials to show the differences between current statute and where the Council wants to go. He also reinforced that in government we have new language and a new understanding about health equity and health disparities, and that this redesign process will include thinking about how to better frame these topics. Council Vice Chair Rodiguez addressed the question of accountability and shared that there is not a simple answer, but the Council aspires to be accountable to those disproportionately impacted by health inequities in Washington. He noted that there's a need to engage these communities in an ongoing way, deepen our relationships, and encourage a more participatory democracy.

<u>Member Dean</u>, inquired if the Council works exclusively with the governmental public health system, or if it also expands its work to the health care system. Ms. Huỳnh responded that in the Council's statute, they are required to promote collaboration across state agencies, as well as the public and private sector, which would include health systems and organizations that promote social determinants of health. She shared that the recommendations the Council makes typically focuses on what government can do, as they make recommendations to the legislature and the Governor, and government is a vital part of service delivery and how agencies can either perpetuate or eliminate health inequities in Washington. <u>Member Dean</u> shared insights and lessons from bringing new membership to their local board of health, including her hope that moving forward, the local board can ensure an equitable and participatory process without barriers to participation, as Victor touched on during this presentation.

<u>Kelly Oshiro, Board Vice-Chair</u> shared ideas for community members and agencies that the Council could engage in its redesign efforts. <u>Vice Chair Oshiro</u> noted the importance of engaging the Attorney General's Office and public defense groups as well as those whose work relates to the built environment, such as the Department of Transportation.

<u>Member Kutz</u> provided an example of a past topic area where the Council's voice has had impact. Several years ago, members of the community spoke to the Council about poor conditions and health and safety concerns at the federal government detention facility out on the tide flat. Council members listened to these public comments, but felt limited by the Council's current statute. The Council decided to write a letter to [the federal government] detailing community members' concerns and calling for action, which <u>Member Kutz</u> felt led to state legislation this session granting the Washington State Department of Health (Department) some oversight of these facilities.

<u>Keith Grellner, Board Chair</u>, thanked Council Members and staff for their presentation and said the Board will keep an eye out for the legislation to change the Council's statute, and the Board will be there to support these efforts.

The Board recessed for lunch at 12:10 p.m. and reconvened at 1:10 p.m.

7. BRIEFING/UPDATE – NEWBORN SCREENING, <u>ORNITHINE</u> <u>TRANSCARBAMYLASE DEFICIENCY (OTCD)</u>, CHAPTER 246-650 WAC

<u>Dimyana Abdelmalek, Board Member,</u> Thurston County Health Officer, gave some brief background on the Board's authority around newborn screening, ornithine transcarbamylase deficiency (OTCD) as a hereditary condition, and where the Board is in its process of adding OTCD as a new condition for the state's newborn screening panel (see memo).

<u>Molly Dinardo, Board Staff</u>, gave a quick presentation on the condition and provided an update on the Department's funding request to add OTCD to the state's screening panel (see presentation on file).

<u>Member Hayes</u> said the lack of funding is disappointing and asked if staff knew the reason why the Governor did not include funding for OTCD in the budget.

Ms. Dinardo said there were four items that the Department included in its funding request to the Governor's Office this year related to newborn screening, one of which was for a fee increase to include OTCD. She shared that at this time, the only service fully funded in the Governor's and House and Senate Budgets was the overnight shipping courier service. <u>Member Hayes</u> then asked if the Board included funding for newborn screening as part of its legislative priorities, and said if we did not, she recommends making sure to include it in the legislative statement next year. Ms. Dinardo stated her agreement and shared that a challenge is that if funding for newborn screening isn't included in the Governor's budget, the Board cannot take additional action. The Board's position is guided by what's included in the Governor's budget.

<u>Member Kutz</u> inquired about the Department's four funding requests and the estimated annual cost of adding OTCD as a condition for screening. He stated that there aren't only costs related to screening, but also to the health care system if these conditions aren't detected early. He also inquired about the screening cost per test.

Ms. Dinardo said the cost to add OTCD is roughly 105k per year for testing, which would be \$1.26 per baby.

Ms. Davis added that the \$1.26 per baby covers the cost of the newborn screening test. It doesn't cover increased Medicaid coverage and asked John Thompson, Director of the Newborn Screening Program to confirm. She also asked if there might be a separate request that comes through the Health Care Authority (HCA) that covers potential other costs associated with the care of these children.

John Thompson, Director of the Newborn Screening Program at the Department of Health (Department), said he wasn't aware of separate HCA requests. He also stated that approximately 40% of babies born in Washington are eligible for Medicaid coverage, and the screening fee per baby covered by Medicaid needs to be in the HCA's budget. When the Department makes a funding request to the Governor's Office through the decision package process, they let the HCA know that this is what they are requesting. Dr. Thompson also stated that when the legislature grants the Department the ability to increase the newborn screening fee, they also receive the authority to spend that additional funding.

<u>Member Love-Thurman</u> asked as the Board moves forward with considering other potential tests for the state's panel if we should combine these requests together or keep them separate. Dr. Thompson asked if Dr. Love-Thurman was referring to the upcoming technical advisory committee (TAC) to review guanidinoacetate methyltransferase (GAMT) deficiency, and if the committee and Board decide to recommend adding the condition, if this new request should be included with the request for OTCD.

<u>Member Love-Thurman</u> confirmed that this was correct, asked what the best strategy would be moving forward with future conditions, and if a certain approach might be easier for the Governor's Office. Dr. Thompson recommended combining future requests. He also stated that the legislative session is not over and there are still ways that line items can change. Dr. Thompson said if OTCD isn't funded, he would like to strategize the messaging for OTCD and any upcoming conditions that the Board makes decisions on so that it is clear what the Department is asking for. He said in past sessions there was less willingness to increase fees in the second year of the biennium (short session), but those things can be overcome with careful planning and communication.

<u>Chair Grellner</u> asked if staff were aware of a champion who could help to get this topic addressed in this session or if there is something that the Board can do.

Ms. Dinardo said that there's a parent advocate, who was involved in the TAC and has been doing advocacy on their end. Ms. Davis reminded Board Members that the dilemma for the Department and the Board is that funding was not included in the Governor's budget, so we are limited in what we can do.

<u>Chair Grellner</u> thanked staff for the update and said we will keep our eyes on this issue as it goes forward.

8. EMERGENCY RULEMAKING – ON-SITE SEWAGE SYSTEMS, WAC 246-272A-0110, PROPRIETARY TREATMENT PRODUCTS AND SUPPLY CHAIN SHORTAGES

<u>Chair Grellner</u> introduced Department of Health (Department) staff. <u>Michael Ellsworth,</u> <u>Department of Health and Secretary's Designee</u>, said the Department is asking the Board to consider a fourth emergency rule to amend WAC 246-272A-0110 to allow manufacturers to make written requests to use replacement components in proprietary treatment products during supply chain shortages and other manufacturing disruptions. The Board has considered the request previously and the Department is proposing the same language in this fourth request.

Jeremy Simmons, Department of Health summarized the need for the emergency rule and implementation to date, noting that his remarks are reflected in meeting materials and the same request in past meetings. He explained the request stems largely from a shortage of ultraviolet (UV) bulbs caused by closure of Salcor Inc. in April 2022 and other supply chain disruptions associated with the COVID-19 pandemic. Mr. Simmons said use of substitute bulbs has been successful and allowed thousands of septic systems across the state to continue functioning. The last emergency rule was filed February 9 and limited to 120 days, therefore the Department is requesting adoption of a fourth emergency rule to ensure septic systems can continue using replacement components based on Department approval for needed maintenance and repairs. Mr. Simmons said the Department is addressing the issue in the permanent rulemaking to allow use of substitute parts in situations of supply chain shortages and other manufacturing disruptions.

<u>Chair Grellner</u> re-stated that this is the fourth request for this emergency rule. <u>Vice Chair</u> <u>Oshiro</u> asked for an update on the timeline of the permanent rulemaking. Mr. Simmons said the Department had planned to do a final briefing in June but is now aiming for August followed by the public hearing. <u>Vice Chair Oshiro</u> asked if the Board will receive a request for a fifth emergency rule. <u>Stuart Glasoe</u>, <u>Board Staff</u>, said he thought a fifth emergency rule would be needed, likely addressed in August alongside the briefing on the permanent rulemaking followed by public hearing on the proposed rules tentatively scheduled for November.

Motion: The Board directs staff to file a fourth CR-103E, Emergency Rulemaking Order, upon expiration of the third emergency rule, filed as WSR 23-05-055, to amend WAC 246-272A-0110 to help ensure on-site sewage system proprietary treatment products continue to function properly without negatively impacting treatment, operation, or maintenance during supply chain shortages or other manufacturing disruptions.

Motion/Second: Member Kutz/Member Dean. Approved unanimously

9. RULEMAKING PETITION – NEWBORN SCREENING, REQUEST TO ADD ARGINASE 1 DEFICIENCY (ARG1D) TO <u>CHAPTER 246-650 WAC</u>

<u>Chair Grellner</u> introduced the agenda item and invited <u>Board Member</u>, <u>Dr. Love</u> <u>Thurman</u> to provide further information.

<u>Dr. Socia Love-Thurman, Board Member,</u> reviewed the Board's petition for rulemaking policy, including the responsibilities of state agencies when they receive petitions. <u>Member Love-Thurman</u> shared that on March 29, the Board received a petition for rulemaking to include Arginase 1 Deficiency (ARG1-D) as a required condition in the Board's newborn screening rule under Chapter 246-650 WAC. <u>Member Love-Thurman</u> provided a brief description of ARG1-D. She then directed <u>Molly Dinardo, Board staff</u>, and <u>John Thompson</u>, <u>Director of the Newborn Screening Program at the Department of Health (Department</u>) to provide an overview of the Board's process for adding a condition, the petition request, and a brief overview.

Ms. Dinardo and Dr. Thompson presented the ARG1-D petition. Ms. Dinardo reminded Board Members of the process for considering new conditions for the newborn screening (NBS) panel, including the three guiding principles and the five newborn screening criteria. Ms. Dinardo shared that in the petition the Board received, the petitioner stated that a diagnosis of ARG1-D at birth allows for immediate treatment. Dr. Thompson provided a high-level overview of ARG1-D, its symptoms, and its treatment. Dr. Thompson directed Board Members to review the family stories located in the meeting materials packet, which provide personal testimonies of what families must go through to get a diagnosis for their loved ones.

Ms. Dinardo mentioned several other considerations for the Board as they discuss the petition request, such as ARG1-D is listed as a secondary condition on the Federal

Recommended Uniform Screening Program (RUSP), Washington is one of the few states that do not currently require testing for the condition, and the Washington Newborn Screening lab has been running the ARG1-D blood testing for Idaho since 2021. Ms. Dinardo then asked Board Members to discuss how they would like to proceed with this petition.

<u>Vice Chair Oshiro</u> commented that she is interested in the NBS program's current testing in Idaho and is curious about what it would be like to do the NBS testing for ARG1-D for Idaho and Washington, and what the cost would be to scale it up. Dr. Thompson responded that for ARG1-D, they are looking for a high concentration of Arginase in the blood, which is done using a specific technology called tandem mass spectrometry. The Department currently has this capability in its laboratory now. Adding ARG-1D testing would be a minor change to their process, as processing specimens would be like what they do in their contracted work with Idaho. Dr. Thompson stated it would also mean a modest number of repeat tests they would need to conduct, and for the babies with a positive result, it would mean more follow-up. The cost difference would be minimal for ARG1-D – they don't have an exact cost estimate, but if Dr. Thompson had to guess, he shared that it would be about \$1 or less due to the infrastructure already in place.

Member Kutz, asked if his assumption is correct, that if roughly 33 states already screen for ARG1-D, it seems that the efficacy of screening has been recognized by most of the states in the country. Dr. Thompson responded no, not necessarily. Member Kutz then asked if it was related to the ease of testing. Dr. Thompson responded that maybe, but that it is more complicated than that. Dr. Thompson then provided some background historical context. He shared that back in 2002, the Board was looking at a condition that would require tandem mass spectrometry, which was newer technology at the time. The technical advisory committee (TAC) and the Board at that time had discussed opening tandem mass spectrometry to test everything, but the decision was made to be more focused and to develop a process to evaluate candidate conditions. This was the TAC that helped develop the Board's current five newborn screening criteria. Dr. Thompson noted that other states at that time also brought on tandem mass spectrometry, and, depending on their decision-making, either opened mass spectrometry screening broadly or narrowed its application like Washingtons approach. Dr. Thompson states that for the 33 states we know are screening for ARG1-D, they are looking at all primary and secondary conditions on the tandem mass spectrometry, it may be for ease, but ultimately unsure of what decisions were.

<u>Member Hayes</u> states that one of the compelling things for her is the key to early identification and treatment and agreed with Dr. Thompson that the petitioner's story had been compelling and gave a good background for her. She states that in the last meeting, a TAC had been requested to be formed on a different disorder, and questioned for the sake of efficiency, if the Board moved forward directly to a TAC if the committee could review both disorders during the same committee meeting. Dr. Thompson responded yes and that if the Board decides to move forward with a TAC he recommends moving forward in this way for efficiency. He notes that gathering a multidisciplinary group of stakeholders in NBS is challenging, so discussing the disorders together makes sense. He also states that the specialists on the TAC could

speak to both conditions and thinks that speaking on them together in one day can happen.

Member Dean asked Dr. Thompson to explain what a secondary condition on the RUSP is and if there is any sufficient data coming from different states that have chosen to do this testing that would help to inform the Board's decision-making. Dr. Thompson explained that RUSP is a list of conditions recommended by the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children that reports to the Secretary of Health and Human Services. He said RUSP was originally a survey of NBS interested parties in the early 2000s and at that time, the group said here is the list of recommended conditions. They then scored each condition based on a certain threshold. If a condition scored above a certain threshold, it was considered a primary target, and below the threshold, it was considered a secondary target. Over time that moved into being called the RUSP, so back in the early 2000s, if a condition at that time did not have good treatment or wasn't to be known to be a problem or be of clinical consequence, it likely didn't score high numbers to pass that threshold. Dr. Thompson shared that for the conditions that didn't make it on this list, there is a separate process where members of the public or providers can make a nomination to the RUSP, so some conditions that have been categorized as secondary or haven't been added as primary or secondary can be nominated onto the formal RUSP. Dr. Thompson asked Member Dean to repeat her second question. Member Dean asked if there is data from either the RUSP process or other states that have implemented screening on the effectiveness of catching ARG1-D. Dr. Thompson referred to a publication submitted by the petitioner that shows in the United States that of the 33 states that have been screening for ARG1-D, about 29 million babies have been screened, and 22 cases have been identified, so the prevalence is pretty rare. Dr. Thompson said that if the Board decides to move forward, Department and Board staff can learn more about those cases and find the answer to her question.

<u>Member Love-Thurman</u> said the discussion was great and she appreciated the stories the petitioner provided and although a rare disease, it does sound like something that if caught early could make a big difference. Member Love-Thurman offered a motion.

Motion: The Board declines the petition for rulemaking to add ARG1-D as a condition for newborn screening in Chapter 246-650 WAC, but directs staff to work with the Department of Health to move forward with convening a technical advisory committee to evaluate both ARG1-D and previously decided upon GAMT deficiency using the Board's process and criteria to evaluate conditions for inclusion in WAC 246-650-020 and then make a recommendation to the Board.

Motion/Second: Member Love-Thurman/Member Hayes. Approved unanimously

10. LEGISLATIVE UPDATE

<u>Michelle Davis, Board Executive Director</u>, said she appreciated the legislative update by Kelly Cooper. She said the request for \$50 million for each fiscal year is included in all the budgets, there's just a difference in the way the Senate approaches the dollars. She said the House amended the budget proviso that suspends the School Environmental

Health and Safety rules, that essentially allows us to update the suspended rules. The Board wouldn't be able to implement the rules until the following legislative session. Ms. Davis sent a note to the budget writers stating the Board's preference for the House budget.

Ms. Davis said several Local Health Jurisdictions (LHJs) have set up School Environmental Health and Safety programs. She commented that there should be a uniform standard for inspection across all LHJs. She noted that with the expansion of school programs, there may be a checkerboard of varying approaches for regulating those schools. The standards should be something we can rely on, a safe and clean environment.

Ms. Davis said she would send a final legislative report out to the Board. She announced the Health Impact Review (HIR) team is presenting before House Health Care & Wellness committee next week on work including HB 1169, concerning legal financial obligations; HB 1562, reducing risks of harm associated with gun, gender-based violence; and SB 5365, preventing use of vapor and tobacco use by minors.

Ms. Davis reminded Board members that 2023 is year one of a two-year biennial budget process. She said next year's budget will focus on what's needed to fund the rest of the biennium. She noted that any bill that died this year can be resurrected next year, and said the team would continue to examine legislation against the Board's legislative statement, and noted that next year's statement needs to include Newborn Screening.

<u>Member Kutz</u> said the school rules are more than 20 years old, and the moratorium has been in place for a long time. He asked about the possibility of sending comments to the Governor's office to at least begin working on these rules. <u>Chair Grellner</u> said we've discussed it over and over again, we've gotten some attention. Ms. Davis said we've heard from Rep. Pollet in January, and his reflection on drinking water testing in schools from legislation two years ago. She said the Board cannot do this work in a vacuum, it takes a significant engagement with partners. We have learned a lot about indoor air quality over the last couple years. When the Board adopted rule in 2010, was relying on studies from 2004, and we've learned a lot since that time. <u>Member Kutz</u> said there may be less obvious things lurking we don't even know about. Just because you change the rules, doesn't mean they will be put into effect w/out funding. Maybe this needs a little push to move forward, it's a multi-year process.

<u>Member Hayes</u> said this is such a unique situation where we've had a standing issue and the rule as amended has problems. The Board should look for opportunities to have more exploration with the Governor's office and find solutions. <u>Chair Grellner</u> commented on these good ideas, saying they are like what we've been doing. Because of the legislative commitment to Foundational Public Health Services (FPHS), even though the new rule has been suspended, the old rule is still in place which is better than nothing. He said local health can now gear up to use those FPHS dollars to do the inspections. He said it would be great to have modernized rules, but at least FPHS is growing the number of counties participating which are little glimmers of movement.

Ms. Davis commented that it would be helpful for the Board to hear from partners in local health and those closest to the schools. She said she would raise this topic for our

new Policy Advisor joining our staff and said she looked forward to having someone with fresh eyes and new perspective.

Ms. Davis said the FPHS Steering Committee will be deciding how the funds will be allocated and noted that the number of proposals exceed available funds. She reviewed the Board's request, which includes continued funding for a Community Engagement Coordinator, and Administrative Assistant. She said the Board was also seeking new funding for a position focused on Equity and Social Justice, and Tribal Relations. She noted the request also includes funding for a additional Communications Consultant and funding to continue work with interpretation and translation for meetings, including TAC's. She said the Steering Committee will be considering the requests and discussing them in May and June.

<u>Chair Grellner</u> said that four people on the Steering Committee are connected to the Board, so we are in a good place.

11.BOARD MEMBER COMMENTS

Keith Grellner, Board Chair called for any comments.

<u>Member Hayes</u> said she will miss the June meeting due to family and graduation events.

<u>Chair Grellner</u> thanked Board staff, saying the meetings are really dialed in now and are running smooth. He is glad to have interpreters and commented they did a great job.

ADJOURNMENT

Keith Grellner, Board Chair, adjourned the meeting at 2:30 p.m.

WASHINGTON STATE BOARD OF HEALTH

Keith Grellner, Chair

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