From: nychavez@aol.com Sent: 8/7/2024 11:06:20 AM To: DOH WSBOH Subject: Public Comment for SBOH Meeting 8/7/24

External Email

Good Morning SBOH Members:

Unfortunately, I am currently in attendance at this meeting and was not called on to make a Public Comment (for which I submitted a registration and received a confirmation).

If community members cannot attend and speak via Audio (which I have done at a prior meeting) then please remove that option from the SBOH email 'Ways To Join This Webinar' in the future. Otherwise, it's disrespectful to community members who register for these meetings and take the time to prepare a Public Comment.

My Public Comment for this meeting is as follows~

Hello, my name is Natalie Chavez. Thank you for listening to Public Comments this morning.

A lot has happened since the last BOH meeting on June 12th~ in regards to COVID vaccine-related lawsuits with positive outcomes and settlements, with more COVID vaccine-related lawsuits filed, more COVID vaccine-related studies published, more COVID-related NIH emails released, more investigative journalism into the COVID-19 vaccine debacle, and with over 3,250 physicians, RNs, medical investigators, and other expert volunteers who continue to analyze the hundreds of thousands of pages of internal Pfizer and Moderna documents that have been released under Court Order.

People are Waking Up. The COVID cards are continuing to collapse, along with the 'COVID Narrative' that was propagated by the FDA, CDC, on social media, and the mainstream news. Unfortunately, a lot of Washingtonians (among others nationally and globally) have suffered COVID vaccine-related injuries and many have died.

The CDC's Vaccine Adverse Event Reporting System (VAERS) recent data specifically relating to the COVID-19 Vaccines~ shows that post-vaccination Adverse Events include over 37,000 reports of deaths, over 70,000 cases of Permanent Disability, and nearly 310,000 serious injuries through May 31, 2024.

## I encourage you all to review the websites

https://React19.org and https://Covid19CriticalCare.com. And I hope that you will also consider watching the short documentary called 'Unsafe and Ineffective' which features a few of the COVID vaccine-injured individuals who are part of the React19.org group. You can watch the documentary for free at the website https://UnsafeAndIneffective.com.

Thank you for your time.

From: Sarah Schwartz Sent: 8/7/2024 12:10:53 PM To: DOH WSBOH Cc: Subject: Wilson Disease Newborn Screening (8/7/24)

External Email

To whom it may concern,

I signed up to speak on behave of the importance of infant screening for Wilson Disease. I am a bit confused on the time the meeting started due to time difference and didn't want to join zoom and interrupt. So I will submit my comments here.

Hello,

My name is Sarah. I myself am not a Wilson Disease patient, However, my husband was. His name was James and he had passed away (at age 27) from complications (horrible ones at that) over 13 years ago from having Wilson Disease. When I met James he was 14 years old and seemed to be a healthy teenage boy. Over the years I heard stories from his family about how he was sick with fevers which the doctors couldn't explain (at age 7). Well, as time passed when he was 24-25 I noticed he was losing balance, had excessive saliva, tremors and more. As months went by he became aggressive and seems to be way out of norm with his emotions. The only thing that made since was getting him tested for Wilson's Disease, because his older brother (Bill) had Wilson Disease too. After many times of being told James didn't have Wilson's Diease, he was diagnosed.

By the time James was diagnosed it was too late. His mental state and body functions were out of control and I was constantly told he was okay and I said "No he is sick!". I begged for help from law enforcement and doctors to help me. Because many medical professionals didn't know what Wilson Disease was and the tests, which were ran for years kept saying he didn't have Wilson Disease. The only reason a diagnosis was given was because he ended up bed ridden at the hospital with uncontrollable shaking and loss of the ability to walk. This is when we found out his entire brain was covered in copper which was the reason the tests wouldn't come back with high levels of copper.

So, for 14 months the only thing that anyone could do was treat symptoms. His 3 young children and myself (age 26) watched and tried to care for him at home once he was released from the hospital. He passed back in 2011 being bed ridden where his body twisted and dislocated as he stayed 100% coherent.

I tell you a brief description of what I have experienced on a personal level with Wilson Disease for educational purposes from an inside look of a care giver. And to express loudly as the importance of Wilson's Disease being added to the newborn screening test given at birth. Not only because I myself have 3 children who I found out weeks after my husband and their father passing, are also carriers, not just one but all three of them. This is terrifying as a parent to fear my grandchildren could receive not only one but two genes if their other partner has the gene as well. One of the best ways to know is for the baby to be screened at birth so that treatments can start right away. This being one of the best ways to prevent horrible experiences due to Wilson Disease. Because no one should have to live with the horrible side effect Wilson Disease can do to the individual and their family.

I am here to express again for not only myself or my children, but for ALL the children and their parents, to add the Wilson Disease testing to the newborn screening.

Early intervention is the key!

Thank you for your time and for listening,

Sarah Schwartz (Hendrix)

"POWER IN NUMBERS WE CAN HELP MANY"

"DO ON TO THOSE THAT YOU WOULD WANT DONE TO YOU"

From: nychavez@aol.com Sent: 8/7/2024 11:27:59 AM To: DOH WSBOH Cc: Subject: Re: Public Comment for SBOH Meeting 8/7/24

External Email

Yes, I am currently on now as a Phone Caller and put in the ID# 682856 after the Webinar Meeting #. No worries, I appreciate your reply email Michelle. Thank you for forwarding my email to Board Members.

On Wednesday, August 7, 2024, 11:11:33 AM PDT, DOH WSBOH </br/>wsboh@sboh.wa.gov> wrote:

Natalie, Good morning.

We are looking at our attendees online and did not see your name listed during public comment (or now). Are you one of our phone callers? We do not have names associated with those numbers.

I deeply apologize that you were unable to give your input this morning as we value your voice.

I will make sure all of our Board members receive your email below in our update.

Michelle Larson

SBOH Communications Manager michelle.larson@sboh.wa.gov

From: nychavez@aol.com <nychavez@aol.com> Sent: Wednesday, August 7, 2024 11:05 AM To: DOH WSBOH <WSBOH@SBOH.WA.GOV> Cc: Larson, Michelle L (SBOH) <Michelle.Larson@sboh.wa.gov> Subject: Public Comment for SBOH Meeting 8/7/24

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<a>https://gcc02.safelinks.protection.outlook.com/?url=https%3A%2F%2Funsafeandineffective.com%2F&da</a>

Thank you for your time.

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From: Sara Sayles McCarthy Sent: 8/7/2024 1:22:06 PM To: DOH WSBOH Cc: Subject: Public Comment

## External Email

Thank you very much for allowing me to speak about my experience regarding Wilson's Disease (WD) as the Board considers adding WD to the newborn panel. I am excited that you all will be moving forward with a technical advisory committee. As I am not sure of what information and resources you already have, I wanted to reach out to encourage you to get in touch with some of the experts in the field. I believe you all were referencing Sihoun Hahn (apologies for such little knowledge on my part, was split attention with my 3 year old), but other experts I would highlight would be Michael Schilsky (Michael.schilsky@yale.edu <mailto:Michael.schilsky@yale.edu>) who is a pioneer in the field or Dr. Rima Fawaz (focuses on pediatrics, rima.fawaz@yale.edu <mailto:rima.fawaz@yale.edu>). All of these doctors are members of the Wilson's Centers for Excellence, and I am sure they could help with the information that the committee will be seeking.

Thank you, Sara