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Rochelle Walensky, MD, MPH Director Centers for Disease Control and Prevention Roybal Building #21 Room 12000 Atlanta, GA 30333

Email: director@cdc.gov

Dear Dr. Walensky:

This letter is signed by seventy-five multidisciplinary experts, as well as other key stakeholders in the fight to reduce tobacco-related disease and death. This includes seven individuals who have served as president of the Society for Research on Nicotine and Tobacco. Drawing from our collective expertise, we write to petition the Centers for Disease Control and Prevention to rename "E-cigarette or Vaping Product Use-Associated Lung Injury" (EVALI).

The CDC's website currently states:

"National and state data from patient reports and product sample testing show tetrahydrocannabinol (THC)-containing e-cigarette, or vaping, products, particularly from informal sources like friends, family, or in-person or online dealers, are linked to most EVALI cases and play a major role in the outbreak." <u>CDC, accessed 7/25/2021</u>

Based on this current knowledge, the name EVALI is ineffective and misleading as it does not provide health care professionals or the public with clarity and specificity regarding the sources of risk for these harms. Nor does it make clear what steps to take to reduce the risk of such harms. First, "e-cigarette" as used by the public only refers to nicotine vaping products; no THC user would say they consume it with an "e-cigarette." After the EVALI outbreak and after coverage of the evidence that adulterated THC vaping was responsible, one poll found two-thirds of respondents related the lung disease deaths to use of "e-cigarettes such as JUUL." Only 28% related the deaths to use of "marijuana or THC e-cigarettes." Other research (Dave

et al. 2020) has found similar increases in misperceptions of the risks of nicotine ecigarettes following the EVALI outbreak and communications about the condition.

Given that the CDC has concluded that the primary drivers of the 2019-20 outbreak of serious vaping lung injuries are THC products that have Vitamin E acetate added, it is critical to focus understanding on these basic facts. In contrast, the CDC has not proven that any human developed EVALI due to nicotine e-cigarettes, and there is significant evidence that nicotine e-cigarettes cannot be a cause of EVALI as summarized <u>here</u>.

We believe that Adulterated THC Vaping Associated Lung Injury (ATHCVALI) communicates far more accurate information to the public on health risks, whether the source of adulteration is from Vitamin E acetate or other compounds such as phytol. ATHCVALI is also consistent with World Health Organization guidelines on naming diseases, which discourages generic descriptors (such as e-cigarettes, which is not the source of the problem—harmful adulteration in THC products is). Our suggested name ATHCVALI provides important information to manufacturers and consumers that THC vape products can include harmful adulterants, thus encouraging corrective actions from market forces. We considered other names before recommending ATHCVALI, including Vitamin E Acetate Lung Injury (VEALI), which while an unambiguous improvement over EVALI, is perhaps not sufficiently broad since other adulterants in THC vaping products besides Vitamin E can cause lung injury. We are happy to share other naming options with you as well that improve over EVALI, provide scientific information on known risks, and do not stigmatize people trying to use e-cigarettes to quit smoking.

The naming EVALI is stigmatizing and does not help to prevent its spread. As you know, in the United States, HIV was originally unfortunately termed "Gay-related immune deficiency" (GRID). This was problematic for two reasons: 1) it stigmatized sexual orientation minorities, and 2) it misled heterosexuals into feeling safe. While important particulars are different in this situation, we have concerns that EVALI currently 1) stigmatizes nicotine e-cigarette use, which the CDC itself has recognized offer potential public health benefits (see below) and 2) does not communicate the risks of lung injury from adulterants such as Vitamin E acetate. Similar concerns have been raised by other informally-named diseases, such as the swine flu and West Nile virus, which in different ways both stigmatize and mislead.

The <u>American Lung Association</u> recognizes on their EVALI page that, "We are still learning about this disease, so changes may continue to be made to the terminology." This statement suggests that some public health groups may be looking for the CDC to update terminology as new information becomes available. Other well-meaning public health groups have been confused by the CDC's statement on EVALI; for example, the <u>American Thoracic Society</u> suggests "Juuling" is a practice that can lead to EVALI. Any role that the CDC has in degrading the quality of information released by public health groups is a serious concern with potential long-lasting implications for the trust of experts and science. The CDC has expressed some support for e-cigarette use among adults who cannot or will not quit smoking otherwise. The CDC's website currently states:

"E-cigarettes have the potential to benefit adult smokers who are not pregnant if used as a complete substitute for regular cigarettes and other smoked tobacco products." (<u>CDC, accessed 7/25/2021</u>).

There is concern that the misleading EVALI name, coupled with the inaccurate communication surrounding it from the media and other sources, may be suppressing e-cigarette use by adult smokers who want to quit smoking, because of resulting fears of and/or stigma around using e-cigarettes. There is no reason to let this misconception persist any longer, which likely results in higher prevalence of combustible tobacco product use than would otherwise occur.

CDC co-authors recently <u>wrote</u>, "Importantly, the factors driving EVALI are distinct from those driving the concurrent youth e-cigarette use epidemic in the US," so the desire to reduce youth e-cigarette use should have no bearing on what this disease is named.

President Biden took office pledging to lead with "science and truth." This has been echoed more recently by Surgeon General Dr. Vivek Murthy warning that health misinformation is "a serious threat to public health." Given what we now know about the disease, the name EVALI and doubt-inducing communications are not consistent with this pledge. Refining and improving the communications around this injury would be small but important steps to fulfilling President Biden's commitment. If the CDC allows EVALI to stand, this could have an unfortunate adverse impact of reducing the CDC's credibility among certain groups of people on other things like masks and vaccines.

Renaming the disease should also be accompanied by a press release and awareness campaign regarding the dangers of adulterants in THC vaping products, which will help disseminate correct information. The CDC and other federal health agencies should also immediately discontinue mentioning nicotine vaping product use as a possible culprit in these lung injuries since the evidence does not support this connection.

Thank you for considering our request. We would be pleased to answer any questions you may have or to speak directly with you and/or your colleagues.

We look forward to your response.

Sincerely,

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