

April 19, 2024

Dear Senator Sanders and Members of the HELP Committee:

On behalf of our 36,000 members, React19 welcomes this opportunity to provide feedback on your draft legislative proposal regarding Long COVID. Our request is simple, we wish to ensure that symptomology resulting from adverse reactions to COVID vaccines be included, rather than excluded, within the definitions of “other COVID-induced conditions” and “infection-associated chronic conditions” targeted in your proposal.

React19 is uniquely qualified to make this request. We are a 501(c)(3) nonprofit grassroots organization of Americans who are suffering lasting – and in some cases, severe, life-altering effects from COVID-19 and COVID-19 vaccinations. Just like those with Long COVID, our members suffer from debilitating neurological syndromes such as dysautonomia, life-threatening cardiovascular conditions including myocarditis and pericarditis, extreme fatigue, brain fog, and neuropathy to name a few. Like Long COVID, these new ill-defined diseases are often disabling, resulting in not only lost income but also insurmountable medical bills. The similarities between Long COVID symptoms and those resulting from COVID vaccine adverse events are such that many in the research community simply refer to the later as “Long Vax.”¹ With both Long COVID and Long Vax, research for a cure is desperately needed.

For this reason, leading Long COVID researchers Drs. Harlan Krumholtz and Akiko Iwasaki included 241 individuals suffering from adverse events after COVID vaccination in Yale’s Listen to Immune, Symptom and Treatment Experiences Now (LISTEN) Study from May 2022 to July 2023. React19 co-founder Brianne Dressen who has both Long COVID and Long Vax and Dr. Danice Hertz who has Long Vax coauthored the study’s official findings which indicated a significant symptom overlap between those suffering from Long COVID and Long Vax.²

¹ Lee, B. Y. (2024, February 20). Largest ‘Long Vax’ study to date on Post-COVID-19 vaccination syndrome. Forbes. <https://www.forbes.com/sites/brucelee/2023/12/03/largest-long-vax-study-to-date-on-post-covid-19-vaccination-syndrome/?sh=46ce26cc4eb6>

² Krumholz HM, Wu Y, Sawano M, Shah R, Zhou T, Arun AS, Khosla P, Kaleem S, Vashist A, Bhattacharjee B, Ding Q, Lu Y, Caraballo C, Warner F, Huang C, Herrin J, Putrino D, Hertz D, Dressen B, Iwasaki A. Post-Vaccination Syndrome: A Descriptive Analysis of Reported Symptoms and Patient Experiences After Covid-19 Immunization. medRxiv [Preprint]. 2023 Nov 10:2023.11.09.23298266. doi: 10.1101/2023.11.09.23298266. PMID: 37986769; PMCID: PMC10659483.

Dr Avindra Nath, lead neurological researcher at the National Institutes of Health, has researched both patient groups and has also observed the considerable overlap between Long COVID and Long Vax.³ In doing so he has expressed concern that there are no agencies tasked with researching interventions or treatments for side-effects to vaccines and has called for collaborative research.⁴ Yet, research for such COVID related illnesses are not funded nor advocated for.

Throughout your proposal, the term "infection-associated chronic conditions" is frequently employed to guide research funding and patient collaborative leadership. However, this term employed in a manner of inclusion of other chronic conditions, dangerously excludes our membership—those who are vaccinated and also a direct collateral damage of the pandemic. Forming patient advocate research advisory committees using federal research funds dedicated to Long COVID patients, plus narrowly including unrelated infectious disease chronic conditions—even for those who disregarded government guidance and remained unvaccinated—while disregarding COVID-related illnesses such as Long Vax, is not just incorrect; it could send a potentially dangerous message to the American public.

Americans need to know that if they support their country in its time of need, it will do the same for them in theirs. Specifically including Long Vax cases within the definition of “other COVID-related conditions” for both advisory boards and research study arms would be an excellent opportunity to convey that crucial message. Again, we are grateful for this opportunity to provide our insight. Should you have any questions regarding our recommendation, please do not hesitate to let us know.

With Respect,

React19 Board of Directors

www.React19.org

³ Safavi F;Gustafson L;Walitt B;Lehky T;Dehbashi S;Wiebold A;Mina Y;Shin S;Pan B;Polydefkis M;Oaklander AL;Nath A; (n.d.-a). Neuropathic symptoms with SARS-COV-2 vaccination. medRxiv : the preprint server for health sciences. <https://pubmed.ncbi.nlm.nih.gov/35611338/>

⁴ A;, N. (n.d.). Neurologic complications with vaccines: What we know, what we don't, and what we should do. Neurology. <https://pubmed.ncbi.nlm.nih.gov/37185124/>