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NIH is Failing the Long COVID Community

The National Institutes of Health (NIH) announced the launch of its clinical trials for Long COVID earlier this month. Our Long COVID and ME/CFS communities are deeply concerned about the direction of RECOVER's clinical trials.

With upwards of 29 million Americans sick with Long COVID, it is a failure that RECOVER is only now trialing a handful of pharmacological treatments, while the other trials will focus on brain exercises, meditation and a forthcoming exercise trial.

"It's fiscally irresponsible to be spending millions of limited funds on soft therapies like meditation and brain training when there are over 50 pharmacological options waiting to be trialed," said Ben HsuBorger, #MEAction Advocacy Director. "RECOVER needs to immediately course correct and begin implementing the recommendations of the patient experts and post-viral research community."

The Long COVID and myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) communities have repeatedly called for RECOVER to study the dozens of drugs that have already shown promise in treating infection-associated chronic diseases, which have been waiting for years to be trialed. Studies show **half of the Long COVID community** has developed the complex, infection-associated chronic disease of ME/CFS, whose core symptoms are also post-exertional malaise, fatigue, cognitive dysfunction and orthostatic intolerance.

Some RECOVER Trials Pose Risk to Patients

RECOVER's decision to prioritize studying brain games and graded exercise shows that its leadership does not have a solid grasp of the pathophysiology of post-exertional malaise (PEM), which is one of the core symptoms affecting people with Long COVID. PEM is a worsening and/or triggering of new symptoms after physical, cognitive and emotional exertion, and is not the same as fatigue. These trials not only contradict the existing scientific evidence on PEM and are a waste of resources; they have the potential to harm patients.

“Prioritizing the study of interventions known to worsen symptoms in people with PEM is the worst possible outcome for RECOVER,” said Jaime Seltzer. “It’s like gradually increasing sugar intake for a person with diabetes, hoping the body will adapt. If the mechanism is broken, pushing to do more of the activity isn’t going to help fix it. We need research focused on interventions that address the underlying pathophysiology.”

NIH has Ignored Disease Experts

RECOVER’s devastating missteps over the past three years are a direct result of its failure to bring in experts from the infection-associated chronic illness research community when designing the initiative, and its failure to adequately incorporate feedback from the community experts serving on RECOVER’s advisory committees.

For the past three years, the Long COVID and ME/CFS communities have repeatedly and clearly communicated the research priorities needed to make RECOVER a success, and they have been summarily ignored resulting in our current situation: only a handful of worthwhile trials coming down the pike after RECOVER has spent close to $1 billion on observational studies. Our communities have continuously called for RECOVER to set up a process that is **accountable to the patient community** at every level where patient advocates are equal partners. NIH routinely says it values the patient voice, but its actions have not matched its words.

“The RECOVER Initiative -- and all NIH research on Long COVID -- must be directly based on a strategic plan for research created by experts in infection-associated chronic illness, including representative patient advocates,” said JD Davids, Co-Director of Long COVID Justice and Strategies for High Impact. “This would avoid the mess we found ourselves in now where researchers are launching trials that are ignorant of the core symptoms of Long COVID or the most promising treatments to address them, despite concerted input from dedicated patient advocates.”

Massive Public Investment is Crucial

RECOVER has run out of money, and the NIH has requested no new funding for clinical trials, and appears to be quietly abandoning the Long COVID community. It is absolutely essential that our federal government makes a **major public investment in Long COVID research,** including the launch of a NIH Long COVID office that is fully funded with budgetary authority across NIH institutes. The fastest route to treatment is repurposing drugs that already show promise for post-viral disease, and public sector money is needed to incentivize private sector investment.

Twenty-nine million Americans are experiencing Long COVID symptoms with more being infected each day. We must reckon with the fallout of COVID-19, and be prepared for the next pandemic to come.