

Creating a research home for ME/CFS, Long Covid, and others

Despite the significant disease burden, Myalgic encephalomyelitis (ME), previously known as chronic fatigue syndrome (CFS), lacks effective diagnostics and therapeutics. Emily Taylor, President and CEO of Solve M.E., explains why dedicated research for Infection-Associated Chronic Conditions and Illnesses (IACCI) such as ME/CFS is vitally needed

Despite [over three million Americans](#) disabled by ME/CFS and nearly 40 years of research at the National Institutes of Health (NIH), ME/CFS remains misunderstood. Patients still experience the [lowest quality of life of any disease measured](#), and decades of NIH research have failed to produce a single FDA-approved treatment. The RECOVER Initiative, with \$1.25bn dedicated to addressing Long COVID, is falling flat with no treatments to show. In each of these cases, the NIH has failed to serve a significant patient population because of its antiquated, siloed structure.

An unmet medical need

The NIH's structure, which often favors well-established and broadly recognized diseases, has marginalized less understood and multi-systemic conditions like ME/CFS, Long COVID, postural orthostatic tachycardia syndrome (POTS), and other infection-associated chronic conditions

and illnesses (IACCI). Consequently, IACCI research initiatives remain underfunded, and the medical community is left with limited guidance on diagnosis and management. This institutional neglect perpetuates the suffering of patients, who often experience disbelief and inadequate care from healthcare providers. Furthermore, the bureaucratic complexities within NIH impede the swift allocation of resources and collaboration among researchers specializing in IACCI and disproportionately favor diseases with substantial private financial backing. Advocacy groups and patients have long called for a restructuring of NIH priorities and funding strategies to ensure equitable attention to ME/CFS and similar conditions.

IACCI like ME/CFS are a growing but under-researched health and economic burden. These illnesses – such as ME/CFS, Long COVID/PASC, POTS/Dysautonomia,

fibromyalgia, PANS/PANDAS, persistent Lyme disease, MCAS, and more – severely impact patients' quality of life and ability to work and can often cause a lifetime of disability. Following COVID, major IACCI are now estimated to impact up to [73.3 million](#) Americans. Research into IACCI is [severely underfunded](#) relative to disease burden and is decades behind illnesses with similar levels of severity due to their nature as complex multi-systemic-illnesses that aren't clearly within the domain of any existing medical specialty.

The need for IACCI research

Both patients and experts – including at the [National Academies](#) and the [Federation of American Scientists](#) – have called for more funding and multidisciplinary collaboration for IACCI research, due to extremely high rates of comorbidity between these illnesses and increasing evidence of shared biological underpinnings. The COVID-19 pandemic has further increased the urgency of IACCI research due to long-term COVID affecting up to [56 million Americans](#) (17% of the population) with no established treatments, therapeutics, or research plan off-ramps.

Solve recommends the establishment of a dedicated IACCI research institute at NIH. This institute needs to have 1) the authority to direct research funding and 2) the ability to coordinate multi-disciplinary research and bring in expertise from different parts of NIH. Additional responsibilities include patient engagement and the establishment of clinical trials.

Another solution is the establishment of a special IACCI program under the Office of the Director, which would serve as a hub to coordinate and direct multi-disciplinary research on IACCI across NIH. Funding for this program could be provided through the Common Fund or from a smaller budgetary commitment from Congress. While legislatively a straightforward solution, it would only be temporary and would require future commitments and expansion to actually fulfill its mission.

A third solution, a compromise between the institute and the program, is the establishment of a full office for IACCI research. This would require cooperation and budget commitment from Congress and would advance

research into priority areas – such as diagnostics, therapeutics, and clinical trials. An office would also provide a permanent home for research infrastructure, reducing potential waste and duplication of projects and incentivizing more upcoming researchers and clinicians to specialize in a field that currently has very few dedicated specialists.

We strongly believe that an Office of IACCI Research should be established to accelerate multidisciplinary research into IACCI. We hope that members of Congress will recognize the importance and urgency of establishing this entity and lend their support to making this office a reality.

Solve has co-authored a white paper on this topic. Read the white paper, 'A Home for Infection-Associated Chronic Conditions and Illnesses at the NIH' in its entirety [here](#).

As Congress is reviewing multiple NIH structuring proposals, reforming the NIH structure to address the needs of IACCI is critical to America's health, workforce, and economy. As highlighted, the current NIH framework has failed to provide adequate support and funding for ME/CFS and other IACCI, leaving millions of Americans without effective treatments or diagnostics. Establishing a dedicated IACCI research institute or a specialized office within NIH would ensure focused, multidisciplinary research and facilitate the development of desperately needed diagnostics and therapeutics. Such reforms would not only alleviate the suffering of millions but also address the growing health and economic burden posed by these conditions. With the increasing prevalence of chronic illness and disability, the urgency for NIH to address IACCI is undeniable.

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