

# Addressing the Clinical Care Crisis in Post-Acute Sequelae of SARS-CoV-2 Infection (Long COVID) along with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) through California Centers of Excellence\*

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**PATIENT-LED  
RESEARCH  
COLLABORATIVE**

## OVERVIEW

We propose the creation of California Centers of Excellence to address the clinical care crisis in post-acute sequelae of SARS-CoV-2, more commonly referred to as Long COVID. Recognizing the acknowledged connection between Long COVID and myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) and the expected onset of ME/CFS following COVID, these Centers would also address ME/CFS and comorbidities common to both Long COVID and ME/CFS (e.g., dysautonomia), along with other post-viral conditions associated with COVID. The Centers of Excellence would perform clinical care, carry out research, and engage in education, training, and outreach. For each \$40 million appropriated, the Centers could treat 10,000 patients per year over 4 years. Hence an appropriation of \$120 million would enable treating 30,000 of the estimated million-plus Long COVID and ME/CFS patients in California and result in an infrastructure capable of knowledgeably treating thousands of additional patients, putting clinical care for Long COVID and other post-viral conditions on par with that of other major diseases.

## THE PROBLEM

### Long COVID and its Connection with ME/CFS

Many COVID-19 survivors are experiencing significant symptoms persisting months beyond resolution of the acute viral infection. These symptoms involve a wide range of organ systems: cardiovascular, pulmonary, neurological, renal, gastrointestinal, immune and more. To address this emerging issue, the National Institutes of Health (NIH) has launched a \$1.15 billion Initiative to study what is now referred to as *post-acute sequelae of SARS-CoV-2 infection (PASC)*, or simply *Long COVID*.

A recent survey of nearly 4000 self-described COVID *long-haulers* found that 65% were still experiencing symptoms 6 months after acute infection, and of those, 80% reported persistent fatigue, 73% post-exertional malaise, and 58% cognitive dysfunction.<sup>1</sup> These symptoms are the three most common among surveyed long-haulers, and all three are primary diagnostic criteria for myalgic encephalomyelitis

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/ chronic fatigue syndrome (ME/CFS), a highly debilitating disease that pre-pandemic affected an estimated 180,000 Californians and cost the California economy roughly \$5 billion annually in medical expenses and lost income.<sup>2</sup> Also highly common to both ME/CFS and Long COVID are forms of dysautonomia<sup>3</sup>, such as postural orthostatic tachycardia syndrome (POTS). Dr. Anthony Fauci has publicly pointed out on several occasions how many COVID long-haulers indeed have symptoms reflective of ME/CFS.<sup>4</sup> A comprehensive study of Long COVID and ME/CFS patients shows a significant overlap of symptoms between the two.<sup>5</sup> Some Long COVID patients have already been diagnosed with post-COVID ME/CFS, with two studies having found an ME/CFS onset rate of 45% among COVID long-haulers<sup>6</sup>.

Referred to by the Centers for Disease Control and Prevention (CDC) as *America's Hidden Health Crisis*<sup>7</sup>, ME/CFS is a chronic, complex disease that is associated with neurological, autonomic, immunological and energy metabolism impairment.<sup>8</sup> The hallmark symptom of ME/CFS is post-exertional malaise: a significant worsening of fatigue and associated symptoms after physical or cognitive exertion. Other symptoms include a substantial impairment in function, profound exhaustion, unrefreshing sleep, cognitive impairment, orthostatic intolerance, widespread pain, flu-like symptoms and sensory hypersensitivities.<sup>9</sup> As many as 75% of cases follow an infection.<sup>10</sup> ME/CFS is highly debilitating, with 25-29% bedbound or homebound<sup>11</sup> and up to 75% unemployed.<sup>12</sup> Some of the challenges faced by people with ME/CFS are listed in Appendix A.

Rates of development of ME/CFS after infection with Severe Acute Respiratory Syndrome (SARS), Middle East Respiratory Syndrome (MERS), West Nile Virus, or Epstein-Barr Virus range from 5-27%<sup>13</sup>. A recent paper by the US ME/CFS Clinician Coalition, an organization representing the collective clinical expertise on ME/CFS in the US, estimates that 10% of COVID survivors will develop ME/CFS.<sup>14</sup> With the number of COVID-19 survivors in California about to surpass 9 million, 10% of them developing ME/CFS would *more than quintuple* the pre-pandemic prevalence of ME/CFS in California. Some of the connections between ME/CFS and COVID are summarized in Appendix B.

### **A Crisis in Clinical Care**

The incidence of Long COVID has yet to be firmly established. A study of nearly 2 million health care claims found 23% of patients still ill 30 days after initial COVID-19 diagnosis<sup>15</sup>, and another study had 33% of patients reporting symptoms 6 months following acute infection<sup>16</sup>. Using the 30% estimate of the American Academy of Physical Medicine and Rehabilitation<sup>17</sup>, which is consistent with that of the Government Accountability Office<sup>18</sup>, this corresponds to 2.7 million Long COVID cases in California. There are currently fewer than two dozen Long COVID treatment centers in California<sup>19</sup>, and patients report long waiting lists and unsatisfactory treatment. Consequently, many patients with Long COVID are going untreated or receiving treatment from uninformed providers.

Obtaining proper treatment promptly is critical and can mean the difference between recovery and ongoing or worsening chronic illness. It is not uncommon for a gradual increase in exercise to be recommended to Long COVID patients. However, long-haulers with ME/CFS symptoms, specifically post-exertional malaise, should be cautioned against such graded exercise, which evidence has shown can result in a permanent, substantial exacerbation of symptoms.<sup>20,21</sup> Instead, long-haulers should be encouraged to pace their activities and build in regular rest periods.<sup>22</sup> The U.S. ME/CFS Clinician

Coalition has issued a letter titled Post-COVID ‘Long-Haulers’ and ME/CFS<sup>23</sup>, emphasizing the importance of considering ME/CFS in the differential diagnosis of Long COVID patients.

An additional challenge is that with standard laboratory diagnostic tests for SARS-CoV-2 often coming back with false negatives and inaccessibility of testing particularly early on in the pandemic, Long COVID patients are often not taken seriously and are told that their symptoms are made up. Such stigmatization is common with post-infection syndromes including ME/CFS.

The large number of ME/CFS patients and the studies performed on them to date, such as the CDC Multi-Site Clinical Assessment<sup>24</sup>, could provide highly useful information for diagnosing and treating those COVID long-haulers who are experiencing ME/CFS-related symptoms such as post-exertional malaise. Repurposed drugs for ME/CFS are one possibility.

ME/CFS itself, though having been around decades, faces its own clinical care crisis. A summary of the *ME/CFS Expert Clinician Summit* that took place at the Bateman Horne Center in Salt Lake City in March 2019 states: “...there are less than two dozen ME/CFS expert clinicians in the entire country and the majority of them are nearing retirement age. This negatively impacts both the ability of patients to access clinical care and also our ability to ramp up research.”<sup>25</sup> There are roughly half a dozen ME/CFS specialists practicing in California. Californians afflicted with ME/CFS often wait up to two years to be examined by a specialist; many never get to see a specialist at all. As health care providers increase their familiarity with ME/CFS, more and more Californians will be diagnosed, thereby exacerbating the clinical care shortage. Furthermore, with each passing day, the window for training new clinicians narrows, as those who are still practicing get closer to retirement.

### **Long COVID in Children**

Over half of children who contract COVID may have lasting symptoms, according to a recent journal article<sup>26</sup>. Addressing Long COVID in children is particularly challenging, as children have a more difficult time expressing their symptoms. Furthermore, many children have not been diagnosed, partly because their acute phase has tended to be milder hence not recognized. With most Long COVID research having been oriented toward adults, and with longer approval times for pediatric studies, there is less information on children. One of the most common, or at least most known, condition among long-haul children is multisystem inflammatory syndrome (MIS-C), a condition where different body parts, including the heart, lungs, kidneys and brain, become inflamed. But there is concern in some circles that other pediatric long-hauler symptoms are being ignored.

### **Long COVID and ME/CFS and the Economy**

A study conducted by the Patient-Led Research Collaborative shows two-thirds of Long COVID respondents have had to reduce their work hours or not work at all due to their illness<sup>27</sup>. While the study may have a sample that has more severe Long COVID, with an estimated 2.7 million COVID long-haulers in California, there are still likely hundreds of thousands of Californians who are not receiving the same income they were before. The figures for ME/CFS are quite similar, with an estimated 75% of those afflicted unable to work<sup>28</sup>. Pre-pandemic, ME/CFS was costing the California economy an estimated \$4-6 billion annually in medical expenses and lost income<sup>29</sup>. With the expected more than quintupling of the ME/CFS population due to COVID, that figure will likely exceed \$25 billion per year.

## **THE SOLUTION**

### **Synergizing Clinical Care and Research**

With information emerging daily about Long COVID and so little known about ME/CFS, it is crucial that there be very close coupling between clinical care and research for Long COVID and ME/CFS. Such is the case at Mount Sinai Hospital in New York, which undertakes research as well as housing the Center for Post-COVID Care. Clinicians need to be aware of the latest research results, researchers need to test their theories in a clinical setting, and clinicians in training require a patient base on which to train. Having an invigorating research program is important to attracting the best and brightest clinicians, faculty, and students.

A further motivation for synergy is that clinicians observe what is helping patients, and their insights can lead to more pertinent research regarding disease mechanisms, and more importantly, areas to pursue clinical trials. While the more traditional approach is to first understand mechanisms and then run clinical trials, one way to help in the shorter term is to start with clinical insights and then conduct clinical trials on those treatments, designing the trials in a way that provides insight into mechanisms.

### **Centers of Excellence**

The needs for clinical care and research can be met through Centers of Excellence, which, in addition to housing a medical center and performing research, would engage in education, training, and outreach (see Figure 1). Classes, webinars, and written material would be provided for physicians and other health care providers. Centers would also provide tele-mentoring, enabling anybody throughout California to participate and benefit. Centers of Excellence would also benefit aspiring physicians by providing material designed for medical school curricula. Clinical care would be provided centrally as well as through satellite clinics and tele-medicine, enabling patients from all over California to be served. Centers would be open to (a) any patient who is experiencing prolonged symptoms following a suspected or confirmed case of COVID, and (b) any patient with an ME/CFS or likely ME/CFS diagnosis, regardless of whether it was initiated by a SARS-CoV-2 infection. Research would be underwritten by multiple sources, with California money targeting California core competencies (e.g., stem cell research) as well as serving as a co-funding source. Ways in which Centers of Excellence will help address the Long COVID and ME/CFS clinical care crises are summarized in Appendix C.

### **Community Outreach**

An important function of a Center of Excellence will be to serve as a resource to the community. Centers will sponsor webinars, conduct classes, and provide written material. Centers will also provide staff to answer questions by telephone and email. Outreach to the community will be enhanced through satellite clinics. Interaction with the community will be two-way. Input from patients, caregivers and other stakeholders will be not only encouraged, but an essential ingredient in the operation of the Centers. To assure the patient voice is heard, there will a direct line of communication between community groups and Center management, with patients and other stakeholders serving in an advisory capacity.

### **Health Equity**

Marginalized populations have worse outcomes from COVID-19, including elevated incidence, hospitalization, and death rates<sup>30</sup>. The Presidential COVID-19 Health Equity Task Force issued a set of recommendations to address these disparate effects of COVID-19, which includes a focus on providing care for people with Long COVID, particularly for those who do not have regular or affordable access to healthcare.<sup>31</sup> Members of Congress also recognize the importance of addressing health equity among COVID long-haulers, as demonstrated in the recently proposed CARE for Long COVID Act<sup>32</sup>.

An important mission of Centers of Excellence will be to achieve health equity among marginalized populations (e.g., BIPOC, LGBTQ+) in California. Ways in which this will be accomplished include strategic community outreach and placement of satellite clinics so that those in low-income urban, rural, and other underserved communities receive needed services. Additionally, efforts will be made to recruit and train BIPOC and LGBTQ+ physicians and other health care workers to increase the engagement rate among these populations and to provide culturally competent care.

### **Dysautonomia and other Common Comorbidities**

ME/CFS and Long COVID not only have a commonality of symptoms, but they share comorbidities. One prime example is postural orthostatic tachycardia syndrome (POTS), a form of dysautonomia that affects a significant fraction of ME/CFS sufferers and was reported by roughly one-third of respondents in the aforementioned Davis, et al. survey of people with Long COVID. The ability to observe and monitor comorbidity onset in this sizable group of COVID long-haulers provides a valuable opportunity to not only learn more about the co-morbidity, but also how the co-morbidity interacts with ME/CFS and Long COVID and explore synergies in treatment approaches.

### **Why Funding is Needed Now**

One cannot rely on ordinary market forces to relieve the acute shortage of clinicians. In fact, the opposite is the case, as time requirements for diagnosis and treatment serve as market impediments. The situation is exacerbated by continuing stigma and lack of both medical school education and continuing medical education. Hence, funding is needed immediately to start relieving the backlog of untreated patients and to prepare for the tsunami of Long COVID patients.

With each passing year, Centers will employ and train more and more clinicians and contribute to leading-edge research. As post-viral phenomena are increasingly recognized as physiologically-based, and as treatments are viewed as standard medical practice rather than experimental, patients will receive insurance coverage comparable to that for other impactful diseases. With the recognized connection between ME/CFS and Long COVID, we expect medical schools to increasingly include Long COVID and ME/CFS, along with related post-viral conditions, in their core curricula, resulting in a greater supply of physicians familiar with these diseases. The hope is that after some number of years, the necessary education and infrastructure to treat Long COVID and ME/CFS at scale will have been accomplished, and the State will no longer need to underwrite clinical care.

### **Funding Requirements**

Personnel. Funding provided herein for clinical care would cover sub-specialists, physician trainees, and physician assistants, as well as nurses, physical therapists, occupational therapists, social workers, nutritionists, and medical assistants. Clinical care duties would include treating patients (in-person and remotely), tele-mentoring, and medical education support. Research funding would cover the actual

costs of the research as well as coordination of research with clinical care and non-State research sources. A small management team for each Center would be supported as well. Outreach and infrastructure costs would be borne by the institutions and likely offset by patient and insurance payments.

Personnel Costs. Typical annual salaries for UC physicians are in the \$100K-\$300K range, while salaries for nurses, assistants and physical/occupational therapists tend to peak at \$150K. Current UC benefit rates are about 25%, and indirect costs are scheduled to increase to 35% in July 2022. Not knowing the mix of personnel at this time, for purposes of estimation, we use an annual (fully-loaded) FTE cost of \$300K.

Number of Patients Served. COVID long-haulers and people with ME/CFS typically require well-above-average time for evaluation and symptom-management. Factoring in time to be spent on tele-mentoring and community outreach, we estimate that each FTE could serve 400 patients. This is based on roughly 1800 patient-visits per year at roughly 1 hour per patient, with each patient allotted 4 visits per year. Having just 1 million of the more than 2 million California COVID long-haulers seek care would require 2,500 clinical FTE. These figures are not out of line with cancer, where it is estimated there are roughly 21,000 oncologists<sup>33</sup> and 17 million cancer survivors<sup>34</sup> in the United States, which corresponds to 800 cancer survivors per oncologist.

Funding Profile. Three-quarters of the appropriated funds would be allocated to clinical care, along with education and outreach. The remaining one-quarter would be allocated to research and administration. Given the current crisis in Long COVID clinical care, we assume an immediate ramp-up to full funding.

Annual Funding. Centers would receive annual support of \$7.5 million for each 25 FTE of clinical care (together with education and outreach), and a further \$2.5 million for research and administrative costs. These estimates do not account for inflation. These funds would continue for 4 years. Hence, a \$40 million appropriation would support treatment of 10,000 patients a year; a \$80 million appropriation would support of 20,000 patients a year; and a \$120 million appropriation would support 30,000 patients a year.

Number of Centers. Assuming the University of California has primary responsibility for these Centers of Excellence, administration of the multiple locations could come from one main Center that is geographically accessible or two or more main Centers spread throughout the state. Having one main Center would minimize administrative costs, while having two or more main Centers may be more effective at serving different parts of the state and foster more collaboration and discourse of ideas. Administrative, travel, medical education, and outreach costs may change depending on which of these models is chosen.

### **Center of Excellence Candidates and Funding Mechanism**

The requirements of a Center of Excellence to include a medical center, research program, and affiliated medical school might appear at first sight to limit the number of candidates. However, a Center need not be a single institution; it could be a consortium that would bring together the finest expertise in treatment, research, and education. Several of the University of California campuses house medical centers and medical schools and are now treating Long COVID patients. In the private sector, Stanford University has been addressing ME/CFS for two decades and now houses a Long COVID clinic. Various

hospitals and medical networks (e.g., Kaiser, Cedars-Sinai) have begun to treat Long COVID. A funding mechanism should be utilized that minimizes State administrative costs while assuring that the funds are allocated to the candidate institutions that can maximize the return on investment and most benefit the California population. One possibility would be to allocate the funds directly to the University of California, with some fraction of the funds stipulated to be spent by non-University entities but under University supervision (e.g., grant program managed by UC). In addition to receiving State funds through this proposal, the Centers should utilize federal, local, and private funds to expand capacity and further their reach.

### **Addressing Long COVID and ME/CFS Synergistically**

The high volume of Long COVID patients with symptoms reflective of ME/CFS provides a unique opportunity to investigate the actual mechanisms of post-infection ME/CFS onset, which could lead to a much better understanding of the disease. This point was recently underscored by Dr. Anthony Fauci when addressing the American Academy of Neurology<sup>35</sup>.

Dr. Francis Collins, Director Emeritus of NIH, recently stated in a House of Representatives hearing: “My hope would be that as we study Long COVID and look at those comparisons with chronic fatigue syndrome (CFS), we'll learn a lot about both of them. We'll figure out how they are similar, how they are different and how, if we can identify interventions, they might work for both of those groups because there's a lot, lots and lots of people with chronic fatigue syndrome (CFS) who we're still waiting for something that's going to help them.”<sup>36</sup>

California has the opportunity to play a vital role with Long COVID patients, existing ME/CFS patients<sup>37</sup>, and those COVID-19 long-haulers who experience ME/CFS onset. With the rapidly increasing number of Long COVID patients and consequential cases of ME/CFS onset, there is no time to waste.

### **SUPPORTING ORGANIZATIONS AND INDIVIDUALS**

The following organizations and individuals endorse this proposal. Support letters are at the end of this document.





David Kaufman, MD, Center for Complex Diseases, Mountain View, CA.

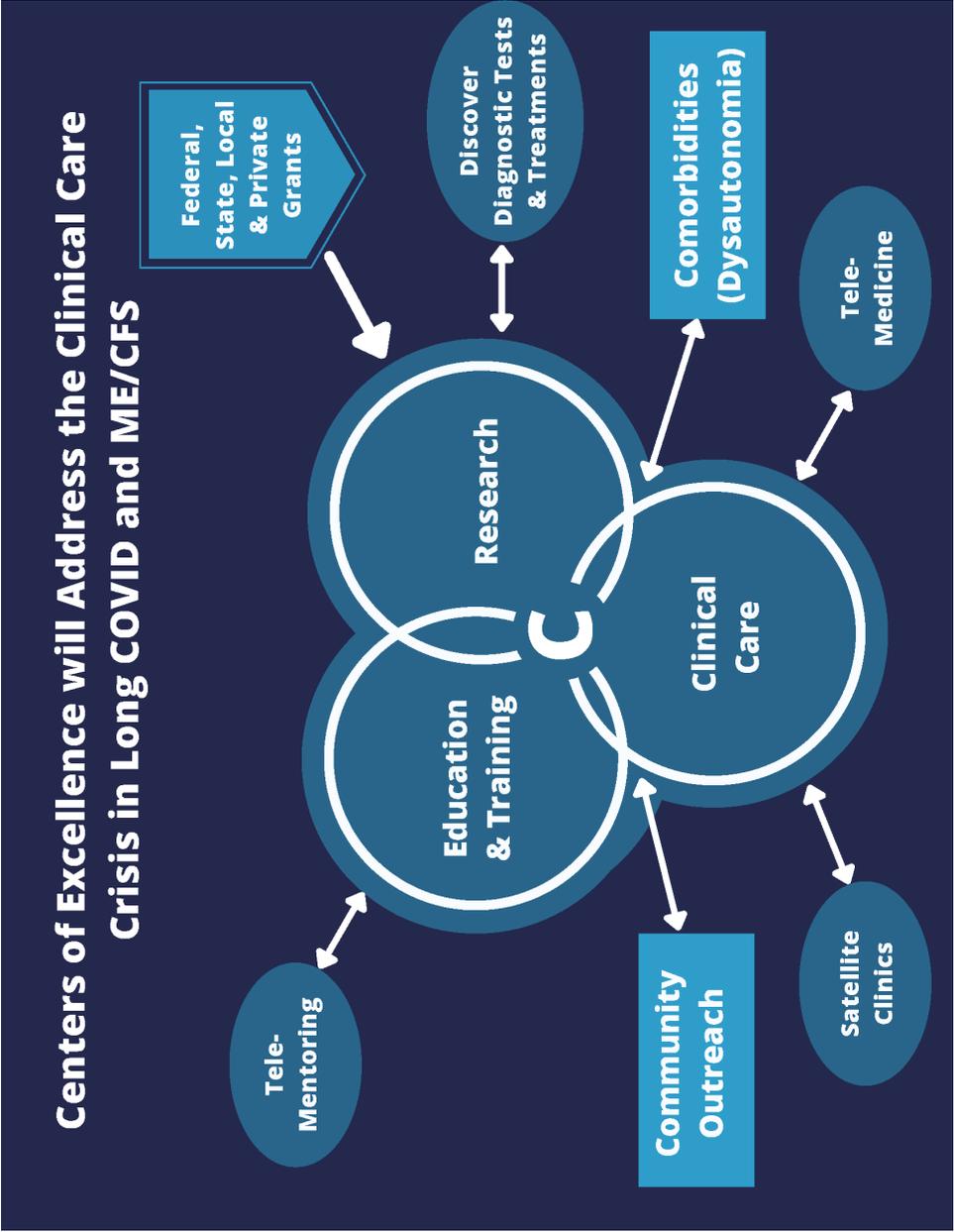


Figure 1. Schematic of California Centers of Excellence in Long COVID along with ME/CFS.

(Figure courtesy of Allison Dykens.)

## **Appendix A**

### **Unique Set of Challenges in Myalgic Encephalomyelitis /Chronic Fatigue Syndrome (ME/CFS): Why Comprehensive Action is Needed Now**

#### **Unfairly Stigmatized**

False characterization as psychogenic, influenced by gender bias, led to decades of neglect, misinformation, misdirection, and harmful treatment protocols

Persistent lack of medical education has led to generations of health care providers unfamiliar with the disease

#### **Bad Science Fuels Misinformation**

Incorrect and harmful guidance from now-debunked 2011 study still persists on medical websites

#### **Invisible Epidemic**

Vast majority of patients are undiagnosed or misdiagnosed

Over 25% bedbound/homebound, up to 75% unemployed, most never recover

Lowest quality-of-life compared with other diseases; people are disabled for decades

#### **Everybody is Vulnerable**

No vaccine or known preventative measures; no officially recognized biomarkers

No FDA-approved drug or treatment

14% of adolescents with infectious mononucleosis are diagnosed with ME/CFS 6 months later

Major disease – affects roughly 180,000 Californians and has disease *burden* double that of HIV/AIDS and over half that of breast cancer

With only half a dozen specialists in California, obtaining appropriate care is difficult, if not impossible.

#### **The Stricken have been Abandoned and Mistreated**

Federal research funding roughly 7% that of similarly burdensome diseases, with no increase planned

No strategic plan in place or in process

Not being treated with urgency

Many in medical community have marginalized the disease

## **Appendix B**

### **The Close Connection between COVID-19 and ME/CFS**

- A survey of nearly 4000 self-described COVID long-haulers indicates that 65% are experiencing symptoms 6 months after acute infection, and of those, 80% report persistent fatigue, 78% post-exertional malaise, and 58% cognitive dysfunction.<sup>38</sup>
- These symptoms are the three most common among surveyed long-haulers, and all three are primary diagnostic criteria for ME/CFS.
- Dr. Anthony Fauci has publicly pointed out on several occasions how many long-haulers indeed have symptoms reflective of ME/CFS.<sup>39</sup>
- Rates of development of ME/CFS after infection with SARS, MERS, West Nile Virus, or EBV range from 5-27%<sup>40</sup>.
- A study of several hundred SARS survivors in Hong Kong showed 27% experiencing ME/CFS onset<sup>41</sup>.
- A paper by the US ME/CFS Clinician Coalition, an organization representing the collective clinical expertise on ME/CFS in the US, estimates that 10% of COVID survivors will develop ME/CFS.<sup>42</sup>
- With the number of COVID-19 survivors in California about to surpass 9 million, 10% of those survivors developing ME/CFS would *more than quintuple* the pre-pandemic prevalence of ME/CFS in California.

## **Appendix C**

### **How Centers of Excellence will Help Solve the Clinical Care Crisis in Long COVID and ME/CFS**

- Centers of Excellence (CoE) will provide clinical care, perform research, provide specialty training, and engage in community outreach
- CoE will include, at a minimum, a medical school, medical center, and research presence
- Several CoE will be located throughout California
- CoE will consist of a single institution or a consortium
- CoE will encourage collaboration with physicians throughout the State
- CoE will provide satellite clinics so that patients do not have to travel as far
- CoE will facilitate close coupling between clinicians and researchers (this is critical in a field where the state-of-the-art is likely to quickly evolve)
- CoE will train specialists-to-be
- CoE will mainstream Long COVID and ME/CFS knowledge into the physician community, with tele-mentoring as a primary enabling technology
- CoE will facilitate treating co-morbidities in an integrated manner
- CoE will facilitate creation of a population of co-morbidity specialists who are familiar with Long COVID and ME/CFS
- CoE will provide up-to-date information to Continuing Medical Education (CME) providers
- CoE will include Long COVID and ME/CFS in their (medical school) core curriculum
  
- **There is presently no mechanism to perform the above functions**
- **Nobody is training Long COVID or ME specialists**
- **ME/CFS physicians will generally not contract with insurance companies because the time and level of care required is not covered**
- **Patients have limited options. State support is desperately needed**
  
- **After 4 years, we hope to have**
  - **significantly increased the number of Long COVID, ME/CFS and other post-viral specialists in CA**
  - **significantly increased the number of health care providers who are familiar with Long COVID, ME/CFS, and other post-viral conditions**
  - **created an environment that attracts expert clinicians and researchers**
  - **facilitated the inclusion of Long COVID and ME/CFS education in the core curriculum of all CA medical schools**
  - **established a resource for all CA health care providers**

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Gavin C Newsom, Governor  
Dr. Richard Pan, Chair, Senate Committee on Health  
Jim Wood, Chair, Assembly Committee on Health



February 24, 2022

Dear Sirs:

We are writing to express the enthusiastic support of [Body Politic](#) for the proposal of [#MEAAction](#) and the [Patient-Led Research Collaborative](#) for the State of California to establish Centers of Excellence in Post-Acute Sequelae of SARS-CoV-2 (Long COVID) along with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS).

Body Politic is a patient-led organization [at the forefront of the Long COVID movement](#) with over 15,000 global patient and caregiving members - many from within the state of California, and many also receiving a ME/CFS diagnosis. We were the first COVID-19 support group to [research](#) and advocate for this serious illness, regarded as the largest mass-disabling event in modern history.

Long COVID is a new and highly debilitating [multi-organ impacting illness](#) that's estimated to effect [at least 37% of all COVID-19 survivors](#), regardless of acute illness severity, and irrespective of a person's prior health before their exposure to COVID-19. Due to the serious nature of this new chronic illness, [Congress provided \\$1.15 billion in funding](#) to the NIH for Long COVID research, President Biden issued guidance on Long COVID as a disability under the [ADA, Section 504, and Section 1557](#), and the WHO released its [clinical case definition](#) of Long COVID.

Long COVID has no treatment, no known prognosis, and with over [86.2% of surveyed patients reporting being mildly to severely unable to work](#), and many battling mental health challenges as a result of the lacking medical and societal support, it's a crisis that extends far beyond the hospital setting and is one that state and local governments mustn't overlook.

Closely connected to Long COVID, and with decades of history and research setting a close-precedent for the new infection-initiated illness, ME/CFS is a highly debilitating disease with no FDA-approved treatment, afflicting [nearly 200,000](#) Californians, [at least 25%](#) of whom are bed-bound or housebound, with [75% of afflicted persons unable to work](#), and with only a [5% recovery rate](#). The COVID-19 pandemic further threatens to more than quintuple the Californian ME/CFS caseload to over one million individuals, as experts estimate [10% of COVID patients](#) will develop ME/CFS, which is unsurprising given that other viruses, including the SARS coronavirus, have led to ME/CFS onset in [5-27% of affected patients](#).

Many physicians and other healthcare providers have at best rudimentary familiarity with ME/CFS, and likely little-to-no experience with recognizing or supporting persons with Long COVID as well. Typical recommended therapies for COVID recovery, such as exercise, [can be extremely damaging to](#) those experiencing both Long COVID and ME/CFS onset, particularly patients with post-exertional malaise. Proper diagnosis and treatment will not only limit the severity of Long COVID and ME/CFS, but will result in coping strategies, thereby reducing both its societal and economic burden.

While we are encouraged by [federal investment](#) into Long COVID research, one area that has received scant federal attention is clinical care. There are currently [fewer than two dozen](#) Long COVID treatment centers in California. Patients encounter long waiting times and uninformed providers. This comes about from the historical lack of federal investment in post-viral conditions. The same can be said of ME/CFS, which has approximately half a dozen practicing specialists in California and which has been excluded from most medical school curricula. With roughly a third of COVID long-haulers expected to be diagnosed with ME/CFS, we have a true crisis in clinical care.

**California must grasp this opportunity to address the Long COVID clinical care crisis through Centers of Excellence**, which in addition to treating patients, will train medical personnel, carry out innovative research, and provide public outreach. These Centers will support satellite clinics to serve rural areas and disadvantaged populations and will engage in tele-medicine and tele-mentoring.

**California, with its six UC medical campuses, has the finest public university health care system in the country, as well as several world renown private institutions.** California is uniquely qualified for this undertaking. **With more and more long-haulers being diagnosed every day, many of whom on their way to experiencing post-COVID ME/CFS, there is no time to waste.**

With both Long COVID and ME/CFS being a life-changing devastating disease for many individuals, it is critical that clinicians, public health personnel and patients have access to the best health care available.

We appreciate your consideration and public health support of the California population, and are happy to discuss further if more information is needed in support of this critical, urgent government action.

Respectfully,



**Angela Meriquez Vazquez**  
*President*



**Lauren Nichols**  
*Vice President*



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Linda Tannenbaum  
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January 26, 2022

Gavin C Newsom, Governor

Dr. Richard Pan, Chair, Senate Committee on Health

Jim Wood, Chair, Assembly Committee on Health

Dear Sirs:

I am writing to express the enthusiastic support of [Open Medicine Foundation](#) for the proposal of [#MEAction](#) and the [Patient-Led Research Collaborative](#) for the State of California to establish Centers of Excellence in Post-Acute Sequelae of SARS-CoV-2 (Long COVID) along with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS).

[Long COVID](#) refers to the more than one hundred [symptoms](#) people have experienced four or more weeks after initial infection with COVID-19. The American Academy of Physical Medicine and Rehabilitation estimates that [30%](#) of COVID survivors develop Long COVID, meaning more than 2.2 million cases in California to date.

[Studies](#) have shown that many COVID long-haulers experience primary symptoms of myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS), a highly debilitating disease that (pre-pandemic) affected nearly 200,000 Californians and cost the California economy roughly \$5 billion annually in medical expenses and lost [income](#). Experts predict that [10%](#) of COVID survivors will develop ME/CFS, which will more than quadruple the California ME/CFS caseload and increase yearly costs to over \$20 billion.

Open Medicine Foundation has been relying on private donations to spearhead innovative research into complex chronic conditions such as ME/CFS. With the recognized connection between Long COVID and ME/CFS, we have launched an [international study](#) to investigate the conversion of Long COVID to ME/CFS. OMF currently supports six collaborative research centers, including ones at Stanford and Harvard.

While we are encouraged by [federal investment](#) into Long COVID research, one area that has received scant federal attention is clinical care. There are currently [fewer than two dozen](#) Long COVID treatment centers in California. Patients encounter long waiting times and uninformed providers. This comes about from the historical lack of federal investment in post-viral conditions. The same can be said of ME/CFS, which has approximately half a dozen practicing specialists in California and which has been excluded from most



medical school curricula. With roughly a third of COVID long-haulers expected to be diagnosed with ME/CFS, we have a true crisis in clinical care.

**California must grasp this opportunity to address the Long COVID clinical care crisis through Centers of Excellence**, which in addition to treating patients, will train medical personnel, carry out innovative research, and provide public outreach. These Centers will support satellite clinics to serve rural areas and disadvantaged populations and will engage in tele-medicine and tele-mentoring.

**California, with its six UC medical campuses, has the finest public university health care system in the country, as well as several world renown private institutions.** California is uniquely qualified for this undertaking. **With more and more long-haulers being diagnosed every day, many of whom on their way to experiencing post-COVID ME/CFS, there is no time to waste.**

Linda Tannenbaum  
Founder and CEO/President  
Open Medicine Foundation  
Mobile: 818-231-6994  
Email: ltannenbaum@omf.ngo



# Solve M.E.

February 22, 2022

**Gavin C Newsom**, Governor  
**Dr. Richard Pan**, Chair, Senate Committee on Health  
**Jim Wood**, Chair, Assembly Committee on Health

Dear Sirs:

I am writing to express the unqualified support of [Solve M.E.](#) for the State of California to establish Centers of Excellence in Post-Acute Sequelae of SARS-CoV-2 (Long COVID) along with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). The proposal by [#MEAAction](#) and the [Patient-Led Research Collaborative](#) for the University of California to manage such a program is a well-thought-out approach to address the clinical care crisis facing the vast number of Californians who have failed to recover from COVID.

[Long COVID](#) is the common terminology used to refer to the plethora of [symptoms](#) people have experienced several months after infection with acute COVID-19. The American Academy of Physical Medicine and Rehabilitation estimates that [30%](#) of COVID survivors develop Long COVID, which translates to a California incidence exceeding 2.6 million.

[Studies](#) have shown that many COVID long-haulers experience primary symptoms of myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS), a highly debilitating disease that (pre-pandemic) affected nearly 200,000 Californians and cost the California economy roughly \$5 billion annually in medical expenses and lost [income](#). Experts predict that [10%](#) of COVID survivors will develop ME/CFS, which will more than quintuple the California ME/CFS caseload and increase yearly costs to over \$25 billion.

Solve M.E., a non-profit organization based in Glendale, California has been relying on private donations to catalyze critical research **into diagnostics, treatments, and cures for ME/CFS, Long Covid and other post-infection diseases. We co-founded the Long COVID Alliance, consisting of hundreds of organizations, companies and individuals to educate policymakers and accelerate research into Long COVID and other post-viral diseases. We have decades of experience helping chronically ill patients who have nobody to turn to.**

We are quite pleased that the federal government has launched the [PASC initiative](#) for Long COVID research. However, that does not address the extreme shortage of clinical care faced by COVID long-haulers. There are currently [fewer than two dozen](#) Long COVID treatment centers in

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**Oved Amitay, RPh, MSc**  
*President & CEO, Solve M.E.*



California. And with the historic federal underfunding of post-viral conditions, the number of properly trained medical providers is wanting. With only half a dozen specialist clinicians in California, the same can be said of ME/CFS. With a sizable fraction of COVID long-haulers experiencing ME/CFS, we have a true crisis in clinical care.

The clinical care shortage, along with limited and fast-evolving understanding of Long COVID, calls for Centers of Excellence, which in addition to treating patients and performing synergetic cutting-edge research, would train physicians and engage in public outreach. The proposal by MEAction and Patient-Led Research Collaborative specifically calls for Centers to have satellite clinics and engage in tele-medicine to enable servicing of rural areas and disadvantaged populations. Centers would also serve health care providers throughout the State of California through organized training programs and tele-mentoring.

And who could do this better than UC with its first-rate medical campuses. A beauty of the proposal at hand is that California's leading institutions would receive funding as well. California has a golden opportunity to not only serve a huge population of citizens in dire need of proper medical care, but also set an example for the nation that other states could follow.

This is an opportunity that cannot be passed up.

Sincerely,

Oved Amitay

President and CEO  
Solve M.E.

March 6, 2022  
Salt Lake City, UT

Gavin C. Newsom, Governor  
Richard Pan, MD, Chair, Senate Committee on Health  
Jim Wood, Chair, Assembly Committee on Health

Dear Sirs:

We are writing to express our enthusiastic and strong support for the proposal from **#MEAction** and the **Patient-Led Research Collaborative** to establish California Centers of Excellence, urgently needed to address the growing public health crisis surrounding post-viral conditions. Most visible, of course, are the Post-Acute Sequelae of SARS-CoV-2 (Long COVID), but most relevant and helpful will be to study Long COVID alongside the illness complex our non-profit organization has long been committed to serving, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Bateman Horne Center is a non-profit clinic, research and education center of excellence devoted to improving the lives of people with ME/CFS, post-viral, and related conditions. Before the COVID pandemic we focused on improving access to care, advancing research, and providing high quality educational resources to patients and their medical providers. Dr. Bateman has served on the CFS Advisory Committee to the Secretary of DHHS, and the Institute of Medicine (IOM) Committee that reviewed the literature and published evidencebased clinical diagnostic criteria for ME/CFS in 2015. BHC has partnered with the CDC for the 5-year Multi-Site Clinical Assessment and the 5 years of NIH-funded ME/CFS Collaborative Centers' research.

In the fall of 2020, after the first 6-7 months of the COVID-19 pandemic, it became clear that many people were not recovering normally from acute COVID-19. Indeed, these people developed chronic symptoms very familiar to those of us who care for patients with ME/CFS. We began sounding the alert and haven't slowed down since. Since early 2021 we have been evaluating Long COVID patients and engaging them in NIH-funded research alongside patients with ME/CFS and related comorbid conditions. We are spearheading or promoting every possible effort to get ahead of this chronic illness tsunami.

Every month there is emerging science regarding the pathophysiology of Long COVID. Many of the presenting symptoms, as well as those of ME/CFS and related conditions,

can be unfamiliar to clinicians, leading to under diagnosis, poor care, advancing illness and unnecessary costs to society. This must come to an end. We know these patients have multi-system illness involving the central and peripheral nervous system, chronic inflammation, auto-immune responses, viral reactivation and altered cellular metabolism. We have existing tools for diagnosis and supportive care. We need rapid establishment of Centers of Excellence throughout the country, centers that can provide clinical care, conduct research, and pass the knowledge on to medical providers and the public. We need centers that can rapidly implement findings from the NIH funded \$1.15 billion RECOVER initiative ([www.recovercovid.org](http://www.recovercovid.org)).

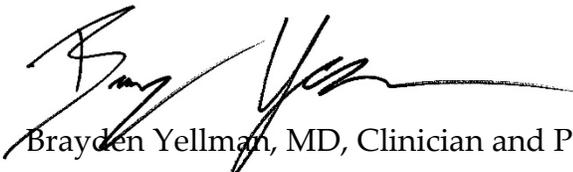
We heartily agree with the visionary proposal and with other letters of support that have been submitted.

Please empower California to take the lead.

Sincerely,



Lucinda Bateman, MD, Medical Director



Brayden Yellman, MD, Clinician and Principle Investigator



Suzanne D. Vernon, PhD, Research Director



Tahlia Ruschioni, Education Director



Rob Ence, Executive Director

February 22, 2022

Gavin C Newsom, Governor

Dr. Richard Pan, Chair, Senate Committee on Health

Jim Wood, Chair, Assembly Committee on Health

Dear Sirs:

I am writing to express my very strong support for the State of California to establish Centers of Excellence in Post-Acute Sequelae of SARS-CoV-2 (Long COVID) along with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). The proposal by [#MEAction](#) and the [Patient-Led Research Collaborative](#), which would have the University of California executing and managing a statewide Centers of Excellence program, represents an important and necessary step to bring about proper treatment for the vast number of Californians whose post-COVID symptoms continue to persist.

[Long COVID](#) commonly refers to the plethora of [symptoms](#) people experience at least a month after infection with acute COVID-19. The American Academy of Physical Medicine and Rehabilitation estimates that [30%](#) of COVID survivors develop Long COVID, which would mean 2.6 million Californians having been afflicted.

[Studies](#) have shown that many COVID long-haulers experience primary symptoms of myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS), a highly debilitating disease that (pre-pandemic) affected nearly 200,000 Californians and cost the California economy roughly \$5 billion annually in medical expenses and lost [income](#). Experts predict that [10%](#) of COVID survivors will develop ME/CFS, which will more than quintuple the California ME/CFS caseload and increase yearly costs to over \$25 billion.

I began my medical career decades ago at the height of the HIV/AIDS epidemic and at one point was Medical Director for one of the largest HIV centers in New York State. This piqued my interest in diagnosing and treating hard-to-manage conditions, such as fibromyalgia, ME/CFS and chronic lyme disease. In 2017, I founded the Center for Complex Diseases in Mountain View. I recently formulated the Continuing Medical Education course *Post Viral Syndrome and Myalgic Encephalomyelitis: What Every Clinician Needs to Know*. Our Center now has a long waiting list of Long COVID patients in need of treatment.

Throughout my career I have seen hundreds upon hundreds of chronically ill patients who have not known where to turn. With the COVID pandemic upon us and the huge number of chronically ill patients who have not recovered, we are facing a crisis of unseen proportions. There are currently [fewer than two dozen](#) Long COVID treatment centers in California. And with the historic federal underfunding of post-viral conditions, the number of properly trained medical providers is only a small fraction of what is needed. With only half a dozen specialist clinicians in California, the same can be said of ME/CFS. With a sizable fraction of COVID long-haulers expected to develop ME/CFS, the shortage of clinical care is unprecedented.

Centers of Excellence will address this acute clinical care shortage and perform synergetic cutting-edge research, while in addition training physicians and engaging in public outreach. As proposed, Centers would service rural communities and disadvantaged populations through satellite clinics and tele-medicine. Centers would also sponsor training programs and engage in tele-mentoring, thereby serving health care providers throughout the State.

Our own University of California, with its six medical campuses spanning the State, is the perfect institution to manage and execute a Centers of Excellence program. California cannot pass up this opportunity to not only serve its large population of chronically ill people with Long COVID, ME/CFS and related conditions, but also set an example that other states could follow.

Please let me know if there is any way I can help move this critically important proposal forward. Thank you for your consideration.

Sincerely,

A handwritten signature in black ink, appearing to read 'D. Kaufman', with a stylized flourish at the end.

David Kaufman, MD