



Details from a long hauler's life; bottom center: PET/MRI brain image of an infected SARS-COV-2 patient.

The Forever Disease: How Covid-19 Became a Chronic Condition

Thousands of people have been suffering a slew of crazy postinfection syndromes for months—and there's no end in sight.

Alexander Zaitchik / February 2, 2021



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Covid-19 is a trickster. Those who have lived with it the longest often describe the disease as if it knows what mischief it's making. Miel Singletary Schultz, a 48-year-old "long hauler" and former sailing crew worker in San Diego, thought she had experienced every possible symptom when in October her skin began exuding tiny yellow crystals all over her body; a fellow long hauler suggested it might be uremic frost, the manifestation of a kidney disease. The skin discharge was not the most debilitating of her dozen-plus symptoms, which included headaches, nerve pain, cognitive dysfunction, hair loss, constipation, and extreme weight loss, but this one seemed especially sinister. It suggested a future defined by an endless parade of bizarre maladies, on top of the baseline fatigue that has kept her out of work since summer.

"This unpredictable disease is so devastating, it's had me on my knees begging God to let me die," said Schultz. "I feel like I'm being tortured, or going through a long and terribly painful transition into something else. I can hardly perform basic tasks, and can't imagine going back to work or stepping on a boat. I'm not sure what I'll do without insurance. The total failure of our institutions makes this experience all-encompassing, almost as bad as the virus itself. Nobody deserves this."

Rather than depicting a simple fork, with one route leading to death and the other to recovery, Covid-19's prognostic map resembles a chaotic intersection. While some roads do lead back to health, others feed into post-viral roundabouts that, as in a bad dream, have no visible exits. Every day, the number of Covid-19 survivors trapped on these roundabouts grows; thousands have been on them since March of last year, and thousands more will certainly join them as caseloads spike across the country. Many of these long haulers had mild to moderate symptoms during infection, were never hospitalized, and suffered no organ damage. As of early January, they were still waiting for science to name their condition.

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By now, most people are familiar with this condition's troika of persistent fatigue, short breath, and the vague cognitive issue known as "brain fog." Like the word "recovered," this too-brief litany—until very recently echoed by the Centers for Disease Control and Prevention—conceals much more than it explains. The stories cataloged on the proliferating number of online long hauler support groups don't describe nagging tiredness or grogginess of the sort to which we can all relate. They describe a debilitating symptomatological clown car that is possibly unique in the annals of human disease. "We used to say TB, sarcoid, and syphilis were the three conditions that could give you just about anything," Trisha Greenhalgh, Oxford professor of primary care, told the *British Medical Journal* podcast in August. "And I think Covid can[, too]. It can give you just about every symptom in the book."

In many cases, these severe fatigue and cognitive issues resemble myalgic encephalomyelitis/chronic fatigue syndrome, or ME/CFS, a little-understood multisymptom syndrome that can, in extreme cases, result in immobility verging on full-body paralysis. Many long haulers also suffer symptoms associated with a general malfunction of the nervous system, known as dysautonomia, that can find expression in every bodily system and organ. The systemwide nature of Long Covid can make it difficult to isolate, or even keep track of; manifestations include muscle, joint, back, and nerve pain, racing pulse, fever, chest pain, chills, insomnia, fibrosis, headaches, blurred vision, tremors, pounding and ringing in the ears, memory loss, kidney problems, gastrointestinal pain and dysfunction, palpitations, high glucose, low oxygen, cough, blood pressure swings, and traveling blood clots. Some long haulers experience unstoppable nose runs of bloody, yellow mucus; all manner of rashes, hives, and discolorations; and

olfactory disorders that make everything taste like “rotten meat and metal,” in the words of one long hauler. (One rare exception appears to be Dr Pepper, which has emerged as a Long Covid folk remedy.) Many develop an inability to stand without dizziness, known as postural orthostatic tachycardia syndrome. Heavy hair loss is common, leading many long haulers to shave their heads.

Research on post-viral illnesses suggests that as many as half or more of those who survive the virus could suffer one or more symptoms for months or years.

Whatever the final number, the pandemic’s mortality rate will continue to be dwarfed by the long hauler population. This raises issues that so far have been pushed to the shadows of a pandemic whose symbols are the mask and the ventilator. High among them is how to support and care for a new cohort of chronically ill Americans, possibly numbering in the millions. This effort will be complicated by the sheer range of severe symptoms that do not show up on blood tests, and may not have treatments.

“You’re going to have a massive swath of the workforce applying for permanent disability.”

As we enter the second year of the pandemic, all eyes are turned toward the distribution of vaccines that began this winter. But if and when the pandemic is contained, drastically reducing the risk of getting and dying from acute Covid, we will still have to wrestle with a new chronic condition playing out on a massive scale. This condition will challenge a health care system that is ill-equipped to handle what it cannot diagnose, and test Joe Biden’s administration’s commitment to addressing the full range of pain and dislocation caused by the pandemic. If there is a bright side, it is the potential for research into Long Covid to midwife breakthroughs in our understanding of not only coronaviruses, but also the mystery of why some people don’t recover their health following viral infections, even when the tests all say they have.

Last April, Amy Watson, a 47-year-old Portland schoolteacher who contracted a Covid-19 infection the previous month, coined a term when she founded the

Facebook group “Long Haul Covid Fighters.” At the time, her sequelae included a range of symptoms, such as a stubborn fever. When I spoke to Watson in November, seven months later, the fever had still not cleared. “I haven’t seen 98.6 since March, and suffer fatigue, respiratory issues, and signs of post-viral dysautonomia, which affects the whole nervous system,” she said. “The experience is full of doubts, denial, and gaslighting.”

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When long haulers talk of gaslighting, they could as easily be talking about their doctor as about a virus that makes you feel insane. Watson said her original inspiration to start an online community was her frustration and anger with a medical establishment that often seemed to dismiss her concerns about prolonged symptoms. From the beginning, Watson noticed a gender dynamic that has been reported by many members of the group. While males seem to be at greater risk of acute and fatal Covid-19 infections, the long hauler population appears to skew female, suggesting the condition is related—as some early studies indicate—to autoimmune disorders that affect women at four times the rate of men.

“A common middle-age to older woman thing, especially with older male physicians, is that they doubt you,” said Watson. “People are waiting two months for an appointment, only to be told it’s their fault, that it’s psychosomatic anxiety. When people feel invalidated, it makes dealing with this much worse. A lot of new members come to the group in tears with the same stories.”



Amy Watson says she ran a fever for seven months straight.

COURTESY OF AMY WATSON

This is a familiar phenomenon among patient populations of other “invisible” illnesses that disproportionately affect women, notably ME/CFS. The medical community’s most urgent task is making Covid’s long tail visible, which starts with giving it a name. “We need to know what to call this thing,” said Watson. “We need a name and an accounting of symptoms. Then, people who’ve been sick for months and feeling invalidated can apply for disability or reduced workloads. We may not recover for another six months. It could be two years. It could be never. It’s all very scary.”

Those who live with ME/CFS know full well the consequences of living in a medical no-man’s-land. Like Long Covid, ME/CFS usually has no clear biological markers. There are no on-label treatments. Patients are often undiagnosed, misdiagnosed, or altogether dismissed by doctors. What the ME/CFS community realized early on, before the long hauler community had achieved self-awareness,

was the many similar challenges Long Covid patients would face. “We knew you were coming: We’ve watched patients develop our illness ... after getting sick from a wide variety of viruses and other pathogens,” declared an October *Washington Post* article addressed to long haulers, written by Jennifer Brea, Julie Rehmeyer, and Brian Vastag. “We’ve been fighting for you since before any of us had ever heard of Covid-19.”

ME/CFS advocates have waged this fight against shockingly strong institutional headwinds. Though the disease has upended tens of millions of lives worldwide, only a third of medical school curricula include anything about the condition. ME/CFS research funding, meanwhile, ranks close to the bottom of diseases targeted by tens of billions of dollars in annual U.S. government research grants. In an open letter to National Institutes of Health director Francis Collins, Vastag, a former *Washington Post* science writer with ME/CFS, described the anguish of watching his government spend less on his condition—\$5 million in 2014—than on hay fever.

Advocates often draw a connection between medicine’s lack of interest in the disease and the hangover of its official categorization, until 1955, as a form of “hysteria”—one of several psychosomatic conditions specific to women. Into the 1990s, media reports sometimes called ME/CFS “the yuppie flu,” based on faulty CDC estimates that only 20,000 or so cases existed nationwide, mostly affecting middle- to upper-class white women. Neither was true. Using community-based sampling, current estimates put the U.S. patient population at between one million and two million, spanning all racial and income groups. The gender difference, however, is stark in the developing literature: Women are estimated to account for between 60 and 80 percent of cases.

Their growing ranks may include Sharon Dow, who contracted Covid in July and has been sick ever since. Unable to return to her job as a teacher’s assistant at a school for autistic children in Walpole, Massachusetts, she spends most of her time in bed managing chronic symptoms that include a tightness in her chest and neck, pounding headaches, and extreme fatigue. “My struggles to walk across a supermarket without needing to sit down suggest ME,” she said. “The first time it

happened, a doctor said my chest was clear and shrugged, ‘We know very little about this virus.’”



Sharon Dow says she has trouble walking across a supermarket without having to sit down.

COURTESY OF SHARON DOW

Long haulers bring new advocacy muscle to ME/CFS, a disease whose secrets may lie close to those of Long Covid. “Long Covid could be the key to better understand ME and other complex illnesses that our system hasn’t studied enough or dealt with very well,” said Leonard Jason, an expert in the epidemiology of ME/CFS who directs the Center for Community Research at DePaul University in Chicago. “Covid-19 is an opportunity to track the factors that may lead to postinfectious fatigue. Really going into the mysteries of unexplained illnesses has the potential to transform medicine.”

Jason is concerned by early signs that the medical community is repeating some familiar mistakes. “Our health care system has not done well with invisible illnesses like ME, and my fear is that long haulers are in for similar trouble,” he said. “General practitioners see a lot of people with fatigue and pain. When the tests look good, they assume it must be lifestyle-related, or psychiatric. They want to help, so they often prescribe exercise or antidepressants, but these strategies are not effective for those with ME.”

In September, after using her accrued vacation days and time off, Dow applied for disability from her private insurer, and listed “Covid-related illness” as the cause. She was approved for short-term benefits in October, but didn’t receive the payment until December, after three months of follow-up calls to the insurance company.

Many long haulers have similar stories. One member of Dow’s online group hired a lawyer to investigate the delays at numerous insurers, and the lawyer reported back that the industry has adopted a stalling strategy on the expectation that people will either die or give up. The stress of her worsening economic situation, said Dow, does not help her symptoms.

“People tell me to just buck up, go back to work, but the last time I tried that, I collapsed with low oxygen and had to be hospitalized,” she said. “I called the insurance company once a week, telling them, ‘I have no income. I started a GoFundMe. My car was repo’d. My phone is going to get shut off. Do you think I’m joking?’ People who think everybody who’s not limping can go back to work don’t understand this illness and have no idea what’s coming. You’re going to have a massive swath of the workforce applying for permanent disability.” Ineligible for long-term disability benefits herself, Dow has since filed for unemployment. She has yet to see any payments.

Long haulers unable to return to work will face more obstacles than they anticipated. Some may find temporary relief under the Family and Medical Leave Act and state-level benefit programs; most will likely turn to their earned Social Security Disability Insurance benefits, which average \$1,260.57 per month.

The eligibility determination for disability benefits is notoriously stringent. The initial application typically takes three to five months. Long haulers with proven anatomical damage will often have the objective medical evidence helpful for speedier approval—but those with chronic Covid symptoms that are more difficult to verify through diagnostic tests can expect challenges similar to those of patients with other poorly understood chronic illnesses, like ME/CFS. Though it's estimated that 75 percent of Americans with the condition are unable to work even part-time, as of 2017, the U.S. Social Security Administration reported that only about 13,000 individuals were receiving Social Security disability for a diagnosis of ME/CFS.

“The more we talk to the long haulers, the more we see our experience reflected in theirs, beginning with doctors who don't understand or know how to treat their debilitating symptoms,” said Therese Russo, a 33-year-old with ME/CFS and advocate with the group #MEAAction. “We are very sick, and yet most of us have seen multiple doctors that say, ‘We can't figure out what's wrong with you, and we don't know how to help you.’ This is a major problem, given how important a supportive, ME-knowledgeable physician can be to the disability application process. Even with a good doctor, because there is no standard diagnostic test that ‘proves’ you both have and are debilitated by ME/CFS, getting approved for benefits can be really challenging.”



Therese Russo, a 33-year-old with ME/CFS, has been rejected for disability benefits twice.

COURTESY OF THERESE RUSSO

Russo knows this firsthand. Worsening symptoms forced her to step down from her job with NYC Health + Hospitals in June 2018. Since then, she says, despite having an official ME diagnosis and medical documentation of her condition, her Social Security disability application has twice been rejected. In January, she presented her case before an administrative law judge, backed by legal representation and a medical team that included specialists in ME/CFS and dysautonomia.

“It’s taken a physical, mental, and emotional toll on me, and I’m one of the lucky ones,” said Russo. “Only about 10 percent of people with ME even have a diagnosis. There are only about 15 ME specialists in the entire country. Most people don’t have access to ME-knowledgeable specialists or the medical tests that can improve

your chances of disability approval. My specialist has advised me to get a two-day cardiopulmonary exercise test, which objectively measures a symptom called post-exertional malaise in ME/CFS and that has been key for other people in the community who have won their cases. Only a few places in the whole country are familiar with CPET testing in the context of ME/CFS. It costs \$2,500 out of pocket. How many people can clear this bar?”

Long haulers who are approved for disability benefits will automatically qualify for Medicare, regardless of age, but both benefits come with a hitch. The first SSDI check arrives five months after approval, followed by a statutory two-year waiting period for Medicare enrollment. “The mounting number of long haulers makes eliminating both waiting periods even more important,” said Nancy Altman, president of Social Security Works, a D.C.-based advocacy group. “In the meantime, some people found medically eligible may end up on SSI [Supplemental Security Income] and Medicaid, but that requires having virtually no income at all.”

Long haulers are already running out of savings, and in the coming months will begin turning in greater numbers to disability benefits. This will make the politics of expanding Social Security an early challenge for Joe Biden’s administration.

The first long hauler online communities were international affairs, a refuge for Covid survivors from across the Anglosphere. It wasn’t long before each nationality realized that they needed their own group. The health care systems of Canada, the United States, and Britain were too different to maintain a coherent conversation. Those early days provided memorable educations in comparative health care systems. This was especially true for Americans, who got their first glimpse of life in countries with nationalized medicine.

“It was obvious at the beginning that the U.K. was worlds ahead of what the U.S. government offers its people and what the medical community understands,” said Dow, the long hauler in Massachusetts. “I’ve never felt like America was so far behind.”

One of the advantages of a national health care system is the ability to send information through the entire medical community quickly. By summer, the U.K.'s National Institute for Health Research had initiated an analysis of Long Covid and begun formulating an interagency response. It has since produced a comprehensive report summarizing the state of knowledge and proposing frameworks for diagnoses and treatments, and the NHS has outlined a new clinical care model that covers the medical, social, and psychological dimensions of Long Covid.

Elaine Maxwell, who wrote the October NIHR report, describes Long Covid as a systemwide illness requiring a systemwide state response, beginning with frontline general practitioners who are fully informed about the symptoms. "After we realized that Long Covid is real, followed by an appreciation of its scope, there was a growing recognition that the condition requires a new service model in primary care," she said. "Patients will also need caseworkers with a holistic view, who can look at different systems and work through it."

As early as May, a pilot project was set up at University College Hospital in London. The National Health Service is now developing Long Covid clinics around the country, staffed by multidisciplinary teams including general practitioners and specialists.

In the United States, the state response has not been so swift or robust. There are a handful of Covid clinics around the country, notably at Mount Sinai and University of California, San Francisco. But the country's famously segmented health system is largely at the starting line in its response to Long Covid, with strained resources focused on patients suffering from acute infections. Even when the pressure on hospitals and ICUs lets up, it is unlikely that many American long haulers will find doctors as informed as their NHS counterparts.

"Unfortunately, our system still adheres to a widget-based, fee-for-service medical model unsuited to Long Covid," said Rebekah Gee, who served as Louisiana's secretary of health between 2016 and 2020 and drew national attention for her work on Medicaid expansion. "As a wealthy country, the U.S. is uniquely challenged because we have not invested in comprehensive social services like

other countries.”

One of the U.S. system’s most glaring gaps and biggest potential stress points, said Gee, is mental health. Studies of post-viral illness caused by previous epidemics and pandemics, including SARS, show widespread mental health repercussions. This is already a problem with Long Covid, substantiated by surveys conducted on long-hauler forums, and by support group members who have written about experiencing depression and suicidal thoughts. Amy Watson, the long hauler in Portland, believes a basic support network will be key for long haulers struggling with stigma and isolation as well as symptoms. “In Portland, students doing their clinicals at Oregon Health & Science University volunteered to check in on us and help plug us into support systems. But it would be better coming from the government,” she said.

In November, Britain’s NIHR announced a major research initiative to develop and build out mental health supports on the scale the government believes will be needed. Gee said the United States will likewise have to get serious about providing long haulers with mental health resources.

“There’s no way we’re going to be able to create enough mental health professionals to deal with the challenge,” said Gee, who provided counseling to victims and their families in the days following the 9/11 attacks in New York. “We need to start training a new generation of primary care nurses, doctor’s assistants, and counselors to be part of the mental care continuum. Community health workers can be an additional arm of the system to wrap around those dealing with isolation, loneliness, and illness. We’re already seeing increased overdoses in places hit hard by Covid. There’s a fraying of mental health happening unlike anything we’ve witnessed in our lifetimes.”

When Sonia Navas-Martin began researching coronaviruses at the University of Pennsylvania School of Medicine in 1999, the field was a virological backwater. The marquee viruses were HIV and avian influenzas, one of which, H5N1, had jumped the species barrier in Hong Kong in 1997. Only two coronaviruses,

meanwhile, were known to infect humans, and they caused the sniffles. The riposte to the old saw, “We put a man on the moon, but can’t cure the common cold,” is that nobody cared about curing the common cold. Funding and glory lay elsewhere.

“There’s a fraying of mental health happening unlike anything we’ve witnessed in our lifetimes.”

Coronaviruses were so far off the radar that they didn’t even make the suspect list when reports broke, in early 2003, of an “atypical pneumonia” causing deaths in southern China. Chinese experts initially suggested it was airborne chlamydia; other researchers were confident another bird flu had crossed over. It wasn’t until April of that year, a month after the mystery disease was named severe acute respiratory syndrome, that the Sri Lankan virologist Malik Peiris and his research team in Hong Kong identified the culprit as a relative of the common cold, just as contagious but with a mortality rate as a percentage of afflicted populations in the teens. Navas-Martin, who had been doing research on mouse coronavirus, was well-positioned to investigate SARS, and began to advocate for federal funding to support an influx of young coronavirus researchers into the field.

That influx stopped when quarantines in Hong Kong, Singapore, and Toronto suppressed the spread and averted a pandemic. Scientific interest and funding streams soon dried up. A similar script played out in 2012, when MERS, a coronavirus first reported in Saudi Arabia with a higher case fatality rate than SARS, seemingly made the jump from camels to humans. When the MERS threat passed, so did the corresponding spike of interest in coronaviruses. “Too many people saw SARS and MERS as ‘exotic’ events, rather than the clear warnings they were,” said Navas-Martin. “Abandoning coronavirus vaccine research was a big mistake. As a result, we’re still at the beginning of our poor understanding of the molecular mechanisms of SARS-CoV-2 and its sequelae.”

What research exists on SARS and MERS aligns with our developing understanding of SARS-CoV-2, the virus that causes Covid-19. Three years ago, a team at the Beijing Institute of Biotechnology identified an N protein in the

sequences of SARS and MERS that deploys an “unknown mechanism” to monkey wrench the body’s production of type-I interferons. These are the cellular emergency workers the body generates to stimulate the creation of proteins that block viral replication and defend healthy cells. Research suggests the virus’s impact on the interferon system, and the immune system more broadly, is the cause of the “long SARS” symptoms found in so many survivors of the 2003 outbreaks in Hong Kong and Canada. A review of the SARS recovery literature in *Canadian Psychology* found that as many as half of survivors reported long-term bodily pain and a general deterioration in overall physical and mental health.

In September, a team of scientists at Rockefeller University led by Jean-Laurent Casanova located evidence of interferon dysfunction in patients suffering severe Covid-19. In two papers published in *Science*, the team identified two variants of faulty interferon production. In one, rare genetic mutations impaired the body’s production of interferon; in the second, the immune response resulted in something potentially far worse: autoimmune antibodies that attack interferons and other cells. How, exactly, these interact to result in Long Covid, nobody can say. But by studying the general immune system inflammation associated with other viral infections, researchers may be starting to unravel how and why SARS-CoV-2 infection can leave an enduring impact on cells, the central nervous system, and every bodily organ long after the virus and its subsequent antibodies clear without a trace.

“It is still too early to understand what is going on with the long haulers,” said Qian Zhang, a research associate in Casanova’s lab. “However, I will not be surprised if some of them have dysregulated interferon responses, which might lead to syndromes that are associated with uncontrolled inflammation. Long-lasting type-I interferon response is very harmful to the body.”

Since not everyone infected with SARS-CoV-2 develops Covid-19 symptoms, acute or chronic, many researchers suspect the answers will be found in genetics research.

“Why does the virus refract the way it does through a genetically variant population?” asked Navas-Martin. “Something is going on in human genetics that

affects the disease. So far, the best answers are faulty interferon creation and a process called molecular mimicry, where the host's immune response recognizes some of its own proteins as a foreign one after the virus has left. Understanding why this happens in some people requires a sophisticated approach to the genetic interplay driving the disease. Research is underway into the many unknowns. We'll have a lot more data in the spring."

Chronic fatigue is Long Covid's unifying symptom. Whatever other ailments they have, long haulers almost always begin the litany here: with the struggle to summon the energy or maintain the stamina needed for the most basic tasks.

This is consistent with the post-viral literature. High rates of persistent and often debilitating fatigue are well documented among survivors of SARS, Ebola, Epstein-Barr (the "mono" virus), numerous influenzas, and multiple mosquito- and tick-borne viruses. It is estimated that one-fifth of survivors from the 1918 Spanish flu pandemic never fully recovered, but suffered reduced health with a baseline of chronic fatigue.

Patients experience post-viral fatigue on a spectrum. Some cases are considered "manageable," while others leave people completely bedridden and in frequent pain. This deeper end of the chronic fatigue pool is often home to ME/CFS. The hallmark symptom of ME/CFS is post-exertional malaise (PEM), which is a flare of symptoms that can be triggered after the most minor activities. In addition to severe fatigue and PEM, core symptoms of ME/CFS include sleep dysfunction, pain, problems with thinking and memory, and difficulty maintaining blood pressure and other systems while standing, a condition known as orthostatic intolerance. Studies show that, on average, ME lowers quality of life more than heart disease, lung disease, diabetes, some types of cancer, and rheumatoid arthritis. After many years spent lying in bed, patients may suffer fatal organ failure. Some choose not to wait that process out. According to some studies, suicide is one of the leading causes of death among ME/CFS patients.

It's unclear how many Covid survivors have already developed, or will go on to develop, ME/CFS. The data from other epidemics, however, offers clues. In one study of 233 SARS survivors in Hong Kong, more than a quarter met the criteria for

an ME/CFS diagnosis after two to four years. Among those who contracted West Nile virus, studies show 20 percent developed the range of symptoms consistent with ME/CFS. As many as nine out of 10 people who “recovered” from Ebola virus outbreaks remain waylaid by symptoms overlapping with ME/CFS. Based on similar literature, Anthony Komaroff, a professor of medicine at Harvard Medical School, has warned that Long Covid could double the number of Americans with ME/CFS in the next two years. Of these, some will recover over the course of years; many will remain ill until treatments are discovered.

Solving the mysteries of Long Covid involves stakes bigger than the current pandemic. Biomedical research is a honeycomb of highly specialized fields and subfields, most within a few degrees of separation. A breakthrough in one area will often spill over into others, causing a cascade of scientific progress. During the global response to the HIV pandemic, the research efforts that produced the first effective antiretroviral therapies also advanced the state of knowledge around everything from the common flu to hepatitis C, which is now curable. It makes sense to expect similar spillover to result from any sustained investigation into Long Covid triggers, symptoms, and treatments.

“It’s possible that any new molecular mechanisms we find in Covid-19 will underlie other viral infections,” said Zhang, the Rockefeller University scientist. “We already know that inborn errors in type-I interferon pathways underlies not just Covid-19, but life-threatening influenza and herpes simplex encephalitis.”

That’s why sufferers and researchers alike advocate for greatly expanding research into ME/CFS. Breakthroughs in understanding Long Covid could help treat ME/CFS, as well as address a broader national crisis in fatigue. At any given time, a quarter of the U.S. population struggles with serious fatigue; 4 percent report chronic fatigue lasting six months or longer. Leonard Jason, the ME/CFS researcher at DePaul University, said unlocking the dynamics of Long Covid may hold the key to explaining the fatigue spectrum as well as other mystery illnesses—including dysautonomia—where the state of knowledge remains primitive.

“Our approach to these illnesses is almost comparable to phrenologists who were measuring skulls in 1850,” he said. “Understanding the neuroimmunological underpinnings of these illnesses will cause a dramatic change, as occurred with the discovery of neurons. In 100 years, doctors will be diagnosing them using an enormous amount of patient data involving the billions of connections in the brain. They’ll look back and wonder how we used such crude instruments to diagnose people with these puzzling unexplained illnesses during 10-minute doctor visits.”

It’s also possible these breakthroughs won’t lead to futuristic diagnostics like full-brain mapping, but reveal how to read old tests in new ways. Sonia Navas-Martin, the coronavirus researcher working on Covid-19 antivirals, said immunogenetic research could result in “basic” but effective tests to locate, prevent, and treat currently unexplainable illnesses. “There are a lot of answers in our blood,” she said. “When we have a better sense of what is happening with these conditions, a blood sample could identify potential markers circulating at the cellular level. We’re not there yet, but it’s doable. Unlike SARS, the Covid-19 population is large enough to start studying it with controls. It should be done.”

Getting it done will require resources and political will. Support at the highest levels of the NIH—which in early December organized a two-day workshop focused on Long Covid, its first such event—will be central to this project. But history suggests it won’t be enough. The lesson of SARS and MERS is that bullets dodged—or in the case of post-pandemic SARS-CoV-2, bullets removed—are bullets quickly forgotten. Developing treatments and cures for Long Covid and other neglected mystery conditions is predicated upon breaking the tradition of replacing terror with amnesia.

When asked if she thought history would repeat itself yet again, Navas-Martin sighed and paused before expressing a case for cautious optimism.

“Given the scope of this pandemic, I think the lesson has been learned,” she said. “Not just by governments, but by scientists. We have to be more involved in explaining why research into the long-term impacts of Covid-19 and other viruses is critical, and justifies investments that continue after the development of

vaccines.”

This research can provide hope and, perhaps, new health to long haulers for whom vaccines will arrive too late, as well as to members of the neighboring ME/CFS community. Pouring research into how these viruses ravage the body, and how to stop or undo that damage, is more than just humane and medically important. In the last two decades, three coronaviruses with pandemic potential have jumped the species barrier. It seems prudent and wise to continue researching them inside and out, and to put that research on a permanent war footing, with a fourth novel coronavirus in mind. For all we know, it’s already here.

Opening images, clockwise from bottom center: Courtesy of David S. Younger, M.D., DRPH; courtesy of Amy Watson (x5)

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John Ganz

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