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Dear Dr. Walensky, Dr. Arias, Ms. Hamilton, and Dr. Fraser:

The undersigned organizations and individuals, comprising health care providers, scientists, patients, public health, and the pharmaceutical and diagnostics industries, urge the Centers for Disease Control & Prevention (CDC), the Council for State and Territorial Epidemiologists (CSTE) and the Association of State and Territorial Health Officials (ASTHO) designate *Clostridioides difficile* (also known as *C. diff*) as a Nationally Notifiable Disease. We believe this designation will end the fragmented federal and state reporting structures, better inform the public about this dangerous and, too often deadly, infection, and, ultimately, save lives.

## Background

When *C. difficile* was first identified in 1978 as a significant cause of antibiotic associated diarrhea, it was mostly considered a “nuisance” disease that additional doses of antibiotics would cure. Despite ongoing research to better understand and treat *C. diff*, this was the consensus of the medical community through the 1990s. The new millennium would change all that. In 1999, there were less than 800 deaths attributed to *C. diff* infections. Over the next seven years, that number would increase eight-fold with more than 6,225 *C. diff*-related deaths in 2006. Starting in 2003, a new strain of *C. diff* identified as NAP1/027 or the “Quebec” strain began causing outbreaks with high death rates in Canada, Europe and the United States. In October 2006, 49 people died at hospitals in Leicester, England.

Despite this surge of increasingly deadly *C. diff* outbreaks across the world, the disease never captured the attention of the media and, therefore, the public as MRSA had and Ebola and Zika would later. So unbeknownst to us, from 2000 to 2014 hospital-onset *C. diff* cases alone more than doubled – increasing 217% - among Americans under 65. More specifically, *C. diff* infections increase 111% in children, 180% in ages 18-44 and 253% in ages 45-64. While people at the CDC and numerous doctors and scientists took note of this rise, there was no call

to action for the public. Worse, despite the tireless efforts of patient advocates who worked to pass state laws mandating the public reporting healthcare-associated infections, many states have since moved to report through the federal system, eliminating local regulations and delaying information reaching the public.

## An Inflection Point

This spring represented an inflection point in the battle against *C. difficile* infections. Shortly after COVID-19 pandemic overwhelmed our healthcare system and our media, a study was published in the New England Journal of Medicine noted that the number of overall *C. diff* cases in the US declined by 24% between 2011 and 2017<sup>i</sup>. This was largely driven by a 36% decrease in hospital-acquired CDI, with community-acquired remaining unchanged. The authors noted that making CDI prevention a national priority led healthcare facilities to improve infection prevention, antibiotic and diagnostic stewardship. Unfortunately, no similar progress has been made in the community. In fact, a study in the Journal of the American Medical Association published six months ahead of the NEJM study, demonstrated an increasing rate of community-acquired CDI between 2013 and 2017. We're faced with a disease that once mostly impacted elderly hospital patients now increasingly harming and even killing middle-aged and even young adults in the community.

With all due respect to the incredible work of CDC's Emerging Infections Program and National Healthcare Safety Network, reporting gaps for community-acquired CDI remain. Given that *C. diff* spores are found in nearly every healthcare and nursing facility as well as in non-clinical settings, including households and businesses, colonization is happening in the community. For mild and moderate cases of community-onset CDI, patients are treated on an outpatient basis with no mechanism to detect an outbreak.

This lack of surveillance is contrary to the CDC's noting that *C. difficile* is one of the US' Top 5 Urgent Antimicrobial Threats. Putting aside treatment-resistant gonorrhea, which is estimated to afflict 500,000 people annually but is rarely fatal, CDI causes more infections and fatalities than the three urgent threats (Carbapenem-resistant *Acinetobacter*, *C. Auris* and Carbapenem-resistant Enterobacteriaceae) combined. Of the top 5 threats, *C. diff* is the only one not currently designated as Nationally Notifiable.

We argue that the lack of designation has contributed to the low public awareness of CDI as a growing threat. A simple Google News search demonstrates that while other countries hard hit by *C. diff* infections like Canada and England have had extensive media coverage of outbreaks, there is virtually no reporting on *C. diff* outbreaks in the U.S. Public awareness of the threat contributed to both Canada and England moving swiftly to reduce *C. diff* infections by significant percentages. Conversely, the state and facility data made available to the US public is released annually and is often 12-18 months old.

## A Way Forward

The SARS COV 2 pandemic has laid bare what many of us have known for a long time: the US public health infrastructure is woefully underfunded and in disrepair following decades of under-investment. This has been particularly glaring when it comes to data on infectious diseases. That is why many of us supported the successful “Data | Elemental to Health” campaign to secure \$1 billion over ten years to modernize our public health data infrastructure. We recognized the vital importance of having a state-of-the-art National Notifiable Disease Surveillance System, leveraging Electronic Case Reporting, Vital Records, Laboratory Information Systems and, the workforce necessary to implement and maintain a 21<sup>st</sup> Century system.

We believe that, given the high burden and mortality of CDI as well as the excess healthcare costs associated with it, C. difficile infections must be designated as Nationally Notifiable. Progress has been made on antibiotic stewardship to prevent CDIs; new therapeutics are available with many more in the pipeline; and we have a growing national movement of CDI survivors, family members, physicians, scientists, nurses and other healthcare workers determined to make C. diff infections rare, treatable and, most important, survivable. But to fully tackle this urgent public health threat, we need to ensure we are capturing the full scope of the problem and engaging the public in our solutions.

Therefore, we urge CDC, CSTE and ASTHO to move quickly to designate C. diff as a Nationally Notifiable Disease.

Signed,

*Organizations*

Peggy Lillis Foundation

Individuals

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<sup>i</sup> <https://www.nejm.org/doi/full/10.1056/NEJMoa1910215>