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Neglected Diseases and Patients: The NIH Funding Crisis

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Abstract

The role of the National Institutes of Health (NIH) and its partnership with academic research institutions has come under threat, attributed to meager funding and inequities in research devoted to diseases that primarily affect marginalized groups. This paper aims to probe the shortcomings of the NIH that led to one such event that devastated the U.S. and the world to an unparalleled extent, the COVID-19 pandemic. The paper will then transition to a study of the implications of current NIH funding cuts on medical research, particularly for patients afflicted by traditionally underfunded chronic diseases. I utilize data from a variety of sources, including interviews conducted by myself and others, federal laws, news articles, academic journals, and published numeric data. This compilation of evidence will build toward the thesis that the effects of a now-gutted NIH constitute the final blow of a prolonged attack on disparate health care, and cannot be ascribed to the actions of any singular presidential administration. Academic research institutions are now situated in an exceedingly vulnerable position, and the future of the medical field is uncertain. As a matter of course, Americans have become more prone to lethal diseases.

Dedication

To my loved ones, especially my brother Jacob for his unwavering support.

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Introduction

"If you think about our big – what are the existential threats to the American people right now, it's nuclear proliferation, climate change, and pandemic threats. And I think we're now probably less prepared than ever to deal with the pandemics that will surely arise," Peter Hotez, the founding dean of the National School of Tropical Medicine at the Baylor College of Medicine, testified before Congress on infectious diseases (Hotez 2024, 59-60). Despite his prestigious credentials, he wasn't very accustomed to the spotlight, a consequence of his specialization in a niche field of infectious tropical diseases. His career trajectory drifted into prominence due in large part to his overlapping vaccine research for coronaviruses, namely SARS, MERS, and at present, COVID-19. His projects were funded predominantly but sparingly by the foremost public medical research funder, the National Institutes of Health (NIH). The global, urgent threat of the COVID-19 pandemic lent momentous weight to his expertise and recurrent concern as an infectious disease researcher, which had previously been undermined by wide indifference and inadequate funding. From congressional subpoenas to an appearance on Joe Rogan's podcast and even a nomination for the Nobel Peace Prize (Rogan 2019; Fletcher 2022), his awkward emergence into the mainstream slots into a timeline in which diseases that disproportionately affect traditionally marginalized populations are systematically ignored.

The remiss downplaying of the early strains of human coronaviruses by the scientific community and research funders foreshadowed a historically consequential moment in pandemics, and the world was no more prepared than it should have been for what panned out from 2019 onward. Before elaborating, context is necessary to develop an understanding of the

processes by which academic medical research is facilitated. In the next section, I will explore the extensive legislative history of the NIH with a focus on its roots in the study of the core sciences. Afterward, I will delve into the deficiencies within the federal research funding ecosystem and events leading up to the COVID-19 pandemic. The final section will discuss the present status of the NIH, its outlook, and projected repercussions of institutional research funding cuts for chronically ill patients belonging to disempowered identity groups.

The National Institutes of Health

The Intramural Research Program (IRP) of the NIH spans twenty-seven Institutes and Centers within six campuses mostly concentrated in Bethesda, Maryland. The IRP employs 1,200 principal medical researchers and 4,000 postdoctoral fellows (National Institutes of Health 2022). Though far from insignificant, the intramural program of the NIH is dwarfed by its extramural branch, which 83% of the agency's $48 billion budget was appropriated toward in 2022 (National Institutes of Health 2024). The NIH did not begin at such a scale, tracing its roots to the establishment of a humble Hygienic Laboratory under the Marine Hospital Service (MHS) in 1887. This unsophisticated lab in New York devoted its efforts to the study of bacteria and infectious disease (Harden and Lyons 2018). Albeit limited in function, its establishment served as a symbolic acknowledgment by the federal government for the need to centralize disease research.

Preliminary forms of federal agencies missioned to promote public health appeared during the late eighteenth and nineteenth centuries as measures against endemic yellow fever. The MHS, the first federal department of its kind, was established in 1798 by "An Act for the

relief of sick and disabled seamen" to medically tend to merchant sailors ravaged by an "alarming and destructive pestilence" (Adams 1798; U.S. Congress 1798, 605). In response to another catastrophic yellow fever epidemic nearly a century later in 1879, Congress legislated "An Act to Prevent the Introduction of Infectious or Contagious Disease into the United States and Establish a National Board of Health," which instituted a National Board of Health (NBH) granting federal funds to states and municipalities to implement maritime quarantines (Michael 2011, 124; U.S. Congress 1879, 484). The NBH was short-lived, however, and discontinued operations in 1883 due to a lack of congressional consensus regarding its existence (Michael 2011, 128).

In 1902, Congress passed two distinct federal statutes which extended and focused the authority of the MHS. "An Act To increase the efficiency and change the name of the United States Marine-Hospital Service" added a prefix to the MHS, becoming the Public Health and Marine Hospital Service (PHMHS). The act also broadened the scope of the agency to promote study in the fields of chemistry, zoology, and pharmacology at the Hygienic Laboratory, which had been relocated to Washington, D.C. in 1891 (Morens et al. 2012; U.S. Congress 1902, 712). The second statute, "An Act To regulate the sale of viruses, serums, toxins, and analogous products," authorized the agency's regulation of vaccines, which were referred to as "therapeutic serum" at the time (U.S. Congress 1902, 728). The PHMHS title was demonstrably convoluted and eventually shortened to the contemporary Public Health Service (PHS) in 1912 by "An Act To change the name of the Public Health and Marine-Hospital Service," which also formalized the agency's role in all matters of national public health (U.S. Congress 1912, 309).

The Hygienic Laboratory experienced a similar period of modernization in 1930 under "An Act To establish and operate a National Institute of Health," colloquially known as the

Ransdell Act in honor of its pioneer, Senator Joseph E. Ransdell of Louisiana (Journal of the American Medical Association 1930, 1180; U.S. Congress 1930, 379-380). This act enabled further expansion of the laboratory's facilities and revised its name to the National Institute of Health. When the NIH began to experience spatial limitations barring additional construction projects, it was seen necessary that the institute relocate to its final, present-day location in Bethesda, Maryland in 1938 (Harden and Lyons 2018, 11). The NIH had emerged from a gradual shift in public attitudes toward the federal government's role in public health. Though early predecessors of the agency were swiftly dismantled due to fears of federal overreach (Michael 2011, 128), the medical field expressed a growing need for public sector research over the years. A commentary from *The New York Times* in 1926 concerning the drafts of Ransdell's legislation read, "Research service in the conservation of the health of the nation should not be left entirely to the private interest… Particularly it is desirable that chemistry should be brought back, in its highest development as a science, to the aid of the physician" (Science 1926, 66). This excerpt reflects the public reception of the changing environment of medical research, as it soon became evident that the private sector was leading in medical innovations. Honing in on application-based, for-profit research in the years leading up to the Ransdell Act, dominant commercial interests left the fundamental sciences neglected.

The legislative capstone of the modern NIH, officially titled, "An Act To Consolidate and revise the laws relating to the Public Health Service" or the Public Health Service Act of 1944 was enacted by a growing concern for soldiers infected by unknown diseases in the World War II effort abroad (Willcox 1944, 17). More notably, broader portions of the act consolidated the NIH to closely resemble its current form, establishing a grants program distributing research funds to universities and medical institutions across the country (U.S. Congress 1944, 692). Ever since,

these institutions have worked intimately with the NIH to secure such grants, pursuing the common aim to advance scientific knowledge that builds the foundation for applications in medicine. On a related note, the fifth Surgeon General Hugh S. Cumming of the PHS was reported to have commented on the scientific work of chemist Claude Hudson circa 1930, “I do not know of any possible connection Professor Hudson’s work on sugars will have to public health. Yet, you never can tell” (Harden 1986, 168). The visionary resilience at its inception has allowed the NIH to persist longer than any of its prototypes, filling a gap in basic research which had been left vacant by industry. On the contrary, recent history suggests that the NIH has faltered in this founding principle, sparsely investing in crucial areas deemed futile or irrelevant to the public health needs of Americans. Such disregard for neglected sectors of science has proven to have devastating repercussions for society at large.

COVID-19: A Spotlight on an Unusual Celebrity

“Some diseases have Bono or Angelina Jolie as their champions. But hookworm has only Peter Hotez,” Hotez boasts of his work on hookworm during his early research career (Shore, 2010). Parasitic worms like hookworm are infectious diseases which fall under Neglected Tropical Diseases (NTDs). The World Health Organization (WHO) defines NTDs as “a diverse set of 20 diseases and disease groups that disproportionately affect populations living in poverty, predominantly in tropical and subtropical areas” (WHO Director-General 2020a, 2). These diseases often fly under the radar of the world health agenda, and research and intervention efforts are thus relatively sparse. Case in point, Hotez’ final dissertation on a hookworm vaccine he had helped devise in the late eighties entered phase II clinical trials in 2023 (Hotez 2023, 1).

“For neglected tropical diseases, there’s no obvious path. The classical model is, you make a discovery, you license it to a pharma company, and then they run with it to make it into a usable technology. For something like a hookworm vaccine, there is no pharma company interest given the lack of a lucrative US-based market,” he said in a 2023 interview (Hotez 2023, 2).

In addition to parasitic diseases, Hotez conducted research on the first identified human strains of coronavirus, known as SARS-CoV-1 (SARS) and MERS-CoV (MERS). SARS, dubbed the “first pandemic of the twenty-first century,” was a newly identified strain of human coronavirus originating from Guangdong Province, China in 2002. At its peak, 8422 SARS cases were reported across 29 countries, of which 916 died (Cherry and Krogstad 2004, 1). By the time Hotez and his team at Baylor College had invented a prototype SARS vaccine, they hit a brick wall. MERS cropped up in the Middle East in 2012, forcing the vaccine into oblivion and gearing the team up for the development of another to address the more urgent disease (Hotez 2024, 24). WHO’s response to MERS was again, unsurprisingly lukewarm, stating the outbreak did not amount to a “public health emergency of international concern” (Kupferschmidt 2013). A frustrated Hotez countered their assessment, stressing that waiting for the situation to deteriorate before initiating vaccine research would be a recipe for disaster (Hotez et al. 2014, 530). “This isn’t going to be the last one,” Hotez recalls telling his lab colleague, Maria Elena Bottazzi, in 2013. “We’ve had two now. You know, there’s a message here. We’re going to have a third one and probably it’s going to come out of China” (Hotez 2021).

“Today our nation has achieved a medical miracle. We have delivered a safe and effective vaccine in just nine months. This is one of the greatest scientific accomplishments in history. It will save millions of lives and soon end the pandemic once and for all,” President Trump addressed a wounded nation watching with anticipatory relief in late 2020 (Trump 2020). It was

undeniably a miracle, like something out of a Christopher Nolan movie; scientists had innovated a safe and functional COVID-19 vaccine in less than a year, circumventing tedious protocol to fast-track its development and distribution. Even so, the victory was not claimed without sacrifices. The development of the COVID-19 vaccine is a story about a longstanding partnership between the private and public medical research sectors derailed, with timely questions about the current and future state of public health.

In 2016, when MERS was winding down and no longer posed a significant health threat, Hotez pushed again to initiate clinical trials for his SARS vaccine, which was sitting handsomely in the freezer (Hixenbaugh 2020). The problem was, by this time, interest in a SARS vaccine had also largely evaporated. Hotez testified before Congress during the height of the COVID-19 pandemic on March 5, 2020, "There was no transmission of SARS anywhere and we could not attract further public and private investments to carry this through clinical trials and licensure" (Hotez 2020). Earlier that year, a cross-analysis between SARS and COVID-19 determined that they "were about 80% similar and the two viruses bound to the same human receptor in the lungs," which gave his team a considerable head start when it commenced development of a COVID-19 vaccine (Hotez 2020). Regardless, it was evidently too little, too late; the virus was already taking its toll at this point. "It's a fight with one hand tied behind our back," he lamented (Hotez 2020). Much could have been done in preparation for an event of this scale. Research expenditures on coronaviruses, along with Zika, Ebola, and Dengue comprised only a small fraction of the total epidemiological NIH budget from 2000 to 2014, even in the respective years of the SARS and MERS outbreaks. HIV research, on the other hand, enjoyed a fourfold funding increase from the NIH in the same period (Kiszewski et al. 2021, 2461, 2464).

After years of oversight, coronaviruses peaked in health salience with COVID-19's formal pandemic status in mid-March of 2020 (WHO Director-General 2020b). The NIH reactively awarded a total of 1108 grants toward COVID-19 research summing to $2.2 billion by the year's end (Balaguru 2020, 2). On the private sector side, the Food and Drug Administration (FDA) gave a hasty green light to pharmaceutical companies Pfizer and Moderna to distribute their first COVID-19 vaccines via emergency use authorization in December 2020, accelerating the vaccine development process which otherwise takes 10.71 years on average and has a 6% success rate (FDA 2020a; FDA 2020b; Pronker et al. 2013, 1). Moderna, Pfizer, and other pharmaceutical companies would go on to work closely with the NIH for further development of COVID-19 vaccines, incorporating an mRNA spike protein mechanism discovered by a collaboration between researchers at the Scripps Research Institute and Dartmouth College from years prior (Morten 2023, 14). This smooth cooperation between the private and public health sectors embodied their historic relationship. Publicly-funded research progressed scientific knowledge despite limited foresight of its applications, and private enterprise concocted a practical use case for said knowledge, innovating functional vaccines for mass distribution.

The honeymoon ended quickly, however, as Moderna disputed the property rights of its vaccine in 2021. The company excluded the names of NIH scientists it had worked with, claiming that "these individuals did not co-invent" the technology used in the vaccine (Stolberg and Robbins 2021). Its proposal to increase the price of its vaccine within a range of $110 to $130 per dose adds insult to injury in its audacious offensive against its government benefactors, who had already paid for 66 million doses at $26.36 per dose upfront to the firm (Hopkins 2023; Kates et al. 2023). While it clearly devalued the support and input of the public sector, Moderna eventually came to its senses; this was a fight it was never going to win. Moderna acknowledged

and agreed to pay for the contributions of the NIH and the institutions that had pioneered the technology in 2023 (Mueller 2023). The price hikes, on the other hand, are live at $141.80 per adult dose and $129 per child dose (Centers for Disease Control and Prevention 2025).

Reducing vaccine affordability expectedly harms low-income people without health insurance by discouraging vaccine uptake (Community Preventive Services Task Force 2016). Outside the U.S., the consequences are even more severe. In addition to affordability, developing countries are denied access by wealthy countries who commercially patent and hoard the vaccine, impeding adoption of domestic production (Altindis 2022, 427; Fidler 2020, 749). Countries with low Human Development Index scores significantly lagged behind in vaccination rates relative to the rest of the world from 2020 to 2022, with African countries faring the worst (Ning et al. 2022, 7). Yet again, the very populations systematically weakened by low visibility in global public health matters and scant research are the ones who chiefly bear the burden of neglected diseases. Although the NIH played a central role during the pandemic by funding research that ultimately led to the innovation of working COVID-19 vaccines, we clearly have not yet fully learned from our mistakes as diseases and populations continue to be marginalized by the mainstream global health agenda. This pervasive attitude that seeps into our medical research ecosystem is what led us into this predicament in the first place.

Chronic Diseases and The Current State

Back on the home front, the impact of NIH underinvestment in key areas of research stemming from the pre-COVID-19 era diffuse into ongoing medical research, especially research pertaining to chronic diseases for which there is no known cure. Patients battling uncommon

diseases such as rare forms of cancer are uniquely out of luck, as work toward therapeutics and cures is funded primarily by the federal government. The effects of the current Trump administration's actions gutting the NIH will have profound effects on progress for under-the-radar diseases, but this is certainly not a new phenomenon. Marginalized diseases have always struggled to garner attention from the government, and even more so from big pharma players who are more interested in diseases with high domestic prevalence and straightforward pharmacological treatments. As demonstrated by the COVID-19 pandemic, pharmaceutical companies are deterred from taking on financial risk investing in such niche diseases, regardless of their future trajectory. Once more, this points to the NIH to assume this role.

John Prensner, a physician-scientist at the University of Michigan who specializes in biological chemistry and pediatric cancer, expresses concern over the fraught ramifications of rescinded medical research funds. "The University of Michigan, similar to other universities, has publicly announced that they have reduced the size of their incoming PhD class for the upcoming year due to financial uncertainty," said Prensner when inquired about the status of his personal laboratory. "Competition to recruit graduate students is pretty stiff, and there are many labs and fewer graduate students every year. The competition will become even more intense recruiting graduate students next year. For my lab particularly, this complicates the birth of new projects, especially those that one might want to birth and grow with a new graduate student" (Prensner 2025). Clinical trials necessitate lab staff for implementation, and the reduced number of graduate students consequently restricts operations leading to slowed innovation of treatments for patients. "A number of clinical trials which are often pursued for patients with rare diseases or relapse diseases—a number of clinical trials are supported by the federal government, and

changes to federal support may indeed have an impact on shutting down some of these trials," Prensner added (Prensner 2025).

Pediatric cancer has traditionally ranked quite low on the list of diseases by levels of funding. An analysis conducted by the National Cancer Institute (NCI) of the NIH found that total funds dedicated to pediatric cancer comprised just 4% of the NCI's total budget for the fiscal year 2012 (NCI 2013, 12). Patients witnessed a glimmer of hope in the ensuing decade as the allotted NIH funds for pediatric cancer doubled from 2008 to 2021, an estimated 3.5 percentage point increase in share of the NIH's total budget (Gitterman et al. 2022, 798). Optimism sparked by this growing trend wavered in December of 2024, before President Trump's second inauguration. The Biden administration passed a spending bill which omitted critical funds for pediatric cancer; just one of the four original measures devoted to the cause, a renewal of the "Gabriella Miller Kids First Research Act," survived to be included in the final legislation (Kim 2024; U.S. Congress 2025).

The subsequent Trump administration stressed the importance of progress for pediatric cancer at the beginning of the president's nonconsecutive second term. On March 4, 2025, President Trump pledged to Congress, "since 1975, rates of child cancer have increased by more than 40 percent. Reversing this trend is one of the top priorities for our new presidential commission to Make America Healthy Again" (Kekatos and Kochat 2025). A promise to tackle the deeply-ingrained deficiencies that plague our research systems and boost visibility of underrepresented and underfunded diseases is not to be made lightly. Predictably, the administration has proven that such a task is easier said than done.

A month prior, on February 7, the NIH proposed a change to its research grants policy issuing a 15% indirect cost rate, down from roughly 28% annually between 2009 and 2021 (NIH Office of the Director 2025; NIH Office of Budget, 87). Indirect costs, which fall under "Facilities" or "Administration," include costs of capital and personnel (HHS, 2014). In other words, they comprise the staff and equipment that pediatric cancer patients rely upon. "Institutions onboard new clinical trials based upon their projection on reimbursement of federal loans, and that's because the support given by the National Cancer Institute and the NIH is typically given as reimbursement for expenditures that they incurred," Prensner explains. "In an atmosphere of uncertainty around federal funding, that makes universities potentially less enthusiastic about onboarding new clinical trials because there's greater uncertainty about getting reimbursed for those on the backend" (Prensner 2025). Deviating from its role "derisking" fundamental research for the private sector to then adopt and turn into application, academia has become vulnerable to the threat of incurring losses which initially deterred industry from making these investments. When compared to the private sector, the NIH tends to sponsor proportionally more clinical trials related to terminal pediatric diseases, based on trends from 2015 to 2020 (Goyal et al. 2025, 4). With nowhere left to turn, children with cancer are essentially deserted, with limited prospects of new clinical trials and treatment plans.

NIH funding disparities exist in other areas of disease research, especially among diseases that disproportionately affect marginalized groups. Take, for example, sickle cell disease, a genetic disorder most prevalent in Black populations. On average, the disease received $76.3 million in NIH funding annually from 2008-2017. Conversely, cystic fibrosis, a similar class genetic disorder most prevalent in White populations received $84.2 million annually during the same period. These reported amounts are beside the fact that there were 90,000 total patients in

the U.S. battling sickle cell and only 30,000 for cystic fibrosis (Farooq et al. 2020, 3). There is much to be said about the health inequities within our systems and institutions which place racial minorities at higher risk of disease (Gee and Ford 2011, 116). In the context of health research, people of color (POC) get the brunt end of the stick.

Health equity tourism is defined as the phenomenon in which unqualified medical researchers pivot into the field of health equity without the necessary background or tools to effectively serve POC communities (Lett et al. 2022, 2). Researchers and medical care providers who do not align with the identities of clinical trial subjects or health care patients are less likely to be knowledgeable on culturally specific concerns related to health and lifestyle. In 2020, 65.2% of NIH-sponsored researchers identified as White, 22.1% as Asian, 4.8% as Hispanic, and 1.8% as Black (Nguyen et al. 2023, 3). Black researchers were also the least likely of the racial groups to receive multiple grants simultaneously (Nguyen et al. 2023, 6). Regrettably, Diversity, Equity, and Inclusion (DEI) may have been demoted to buzzword status within certain cohorts, but its underlying motivations for increasing representation of disempowered groups hold drastic implications for medical research. Neglected, rare, and underfunded diseases such as sickle cell disease and NTDs need to be higher up on the list of NIH funding priorities, and the consolidation of various racial, ethnic, and cultural perspectives may help boost their visibility. We have witnessed with high-priced clarity what could happen otherwise.

The inequities perpetuated by the NIH funding environment do not pertain solely to racial groups, but genders as well. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is one chronic and debilitating disease that is two to four times more likely to afflict women than men (Office of the Assistant Secretary for Health 2021). ME/CFS has an estimated disease

burden[1] equivalent to "double that of HIV/AIDS" and is "the most underfunded disease relative to disease burden" among any disease funded by the NIH (Mirin et al. 2020, 279). The overwhelming majority of underfunded diseases in 2019 were found to be female-dominant, diseases for which at least 60% of those affected identified as female (Mirin et al. 2021, 958-959). The fact that highlighted deficiencies within the NIH funding environment minimize diseases of which half the U.S. population is vulnerable to corroborates the notion that the NIH does not fund diseases based on prevalence or disease burden, but privilege. On the researcher side, men nearly doubled women in 2020. When comparing researchers awarded multiple NIH grants, men nearly tripled women. Groups that have been perpetually marginalized are most exposed to neglected diseases, and without funds or representative medical researchers making strides for new treatments, patients are left unable to fend for themselves.

That is all to say, the current Trump administration is not necessarily to blame for these shortcomings. The uprooting of the NIH and neglect of millions of helpless patients were a long time coming. Diseases have been marginalized for decades, and so have their patients. Still, this does not imply that the NIH should be completely disparaged. COVID-19 vaccines were propelled by a vaccine technology adopted by private vaccine manufacturers for widespread distribution in the span of just nine months. Pediatric cancer patients have relied on NIH funds to pursue innovative treatment plans. But there is a need to reexamine the underlying systems that determine which diseases get funded, and which patients are left in the dust. The COVID-19 pandemic has mostly demonstrated that the public and private health sectors can work together to fight disease speedily and effectively. It seems, however, that the NIH has forgotten where it has

[1] Disease burden is measured in disability-adjusted life years (DALYs), or years of life lost due to disease.

come from, an agency which nurtures the fearless pursuit of knowledge and disease research is conducted to the utmost scientific and impartial regard.

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