Solve M.E.

A Home for Infection-Associated Chronic Conditions and Illnesses (IACCIs) at NIH

A Solve M.E. White Paper

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EXECUTIVE SUMMARY

Infection-Associated Chronic Conditions and Illnesses (IACCIS) are a growing, but under-researched, health and economic burden. These illnesses — such as ME/CFS, Long COVID/PASC, POTS/dysautonomia, fibromyalgia, persistent lyme disease, MCAS, and more — severely impact patients' quality of life and ability to work and can often cause a lifetime of disability. Following COVID, major IACCIs are now estimated to impact up to 73.3 million Americans.Research into IACCIs is severely underfunded[1] relative to disease burden, and is decades behind illnesses with similar levels of severity due to their nature as complex, multi-systemic illnesses that aren't clearly within the domain of any existing medical specialty.

Our paper analyzes the distribution of NIH-funded IACCI research[2] over the past 10 years. We found that major IACCIs — in total — receive an average of $5.2 million in NIH research per year, with ME/CFS and Fibromygalgia being the only IACCIs having any record of NIH funding prior to 2020. This research funding is spread across 21 different NIH institutes with little-to-no central coordination.

Both patients and experts — including at the National Academies[3] and the Federation of American Scientists[4] — have called for more funding and multidisciplinary collaboration for IACCI research, due to extremely high rates of comorbidity between these illnesses and increasing evidence of shared biological underpinnings. The COVID-19 pandemic has further increased the urgency of IACCI research, due to Long COVID affecting up to 56 million Americans[5] (17% of the population) with no established treatments, therapeutics, or research plan.

Our primary call for the 2024 Solve Advocacy Week is to request Congressional Members' support for the **establishment of a dedicated IACCI research entity at NIH**. This entity needs to have 1) the authority to direct research funding and 2) the ability to coordinate multi-disciplinary research and bring in expertise from different parts of NIH. Additional responsibilities include patient engagement and the establishment of clinical trials. We have identified two different forms that this entity could take, depending on the level of funding and commitment provided by Congress and NIH leadership.

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

A second solution would go much further in tackling the problems posed by IACCIs is the establishment of a full office for IACCI research. This would require cooperation and budget commitment from Congress, and would advance research into priority areas — such as diagnostics, therapeutics, and clinical trials. Such an entity would also provide a permanent home for research infrastructure developed by the RECOVER Initiative, reducing poten-

tial waste and duplication of projects and incentivizing more upcoming researchers and clinicians to specialize in a field that currently has very few dedicated specialists.

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

Study Distribution 2014-2022 - ME/CFS + Fibromyalgia + POTS		
Institute	*Number of Studies*	*Percentage of Total*
NINDS (Neurological Disorders and Stroke)	168	25%
NIAID (Allergy & Infectious Disease)	110	16%
NIAMS (Arthritis and Musculoskeletal and Skin Diseases)	100	15%
NHLBI (Heart, Lung, and Blood Institute)	63	9%
NCCIH (Center for Complementary and Integrative Health)	53	8%
NIDA (National Institute on Drug Abuse)	48	7%
Other (15 Institutes)	142	21%
Total	684	

Table 7: Combined total of NIH-funded studies on ME/CFS, Fibromyalgia, and POTS from 2014-2022 by Institute. *NIH funding for these three illnesses is spread across 21 institutes, with the highest contributor being NINDS, at 25% of total studies.*

INTRODUCTION

We are asking Congress to address the critical issues at NIH regarding funding and coordination of research on Infection Associated Chronic Conditions and Illnesses (IACCIs). IACCIs are a group of complex, multi-systemic illnesses predominantly caused by viral, fungal, or bacterial infection; which include myalgic/encephalomyelitis(ME/CFS), Postural Orthostatic Tachycardia Syndrome (POTS) and other forms of dysautonomia, fibromyalgia, persistent Lyme, MCAS, and most recently, Long COVID (a.k.a. Post-Acute Sequela of COVID-19).

IACCIs are among the most neglected illnesses in medical research and practice, and decades of underfunding means that most IACCIs have no known treatments or cures. Better understanding of the biological underpinnings of these illnesses and clinical trials for potential treatments are desperately needed — due to the extremely rapid rise in IACCI cases caused by the COVID-19 pandemic.

Illness	Estimated US Cases
Long COVID/PASC	24,000,000-56,000,000
Myalgic Encephalomyelitis (ME/CFS)*	800,000-2,500,000 (pre-COVID), between 4,000,000 and 9,000,000 (post-COVID)
Fibromyalgia*	4,000,000
Post-Treatment Lyme Disease (PTLD)	1,000,000
POTS/Dysautonomia*	3,000,000 (pre-COVID)
Mast Cell Activation Syndrome (MCAS)*	Unknown, up to 17% pre-disposed[6]
Ehlers-Danlos Syndrome (EDS)	66,000
Gulf War Illness	250,000
Total Major IACCI Estimated Cases	*Between 36,316,000 and 73,316,000*

Table 1: List of IACCIs. *Some of the most prominent IACCIs and related conditions, and their estimated prevalence in the United States. These case estimates are likely to be underestimated, due to low diagnosis rates for nearly all conditions on this list. Illnesses marked with a star (*) have known comorbidity with Long COVID, meaning that their prevalence will be amplified by large numbers of Long COVID cases in the coming decades.*

Tens of millions of Americans are living with IACCIs such as ME/CFS, Persistent Lyme disease, POTS, and Long COVID — and the prevalence of these illnesses is accelerating rapidly. Long COVID alone was found to impact 6.8% of American adults (24 million people) in the CDC's Household Pulse Survey[7] conducted in 2022. A more recent version of this survey, using data collected in early 2024, found that 17.6% of American adults (56 million people) reported having experienced Long COVID.

Significant percentages of people with Long COVID meet the criteria for other IACCIs — 50%[8] of people with Long COVID meet diagnostic criteria for ME/CFS, and prevalence of POTS in Long COVID patients is as high as 80%[9] in some studies. A study of electronic health records found that COVID increased the risk of developing ME/

CFS by a factor of four[10]. In addition to these diagnoses, COVID has been found to trigger over 200 symptoms[11] across nearly every organ system. This means that a massive amount of complex chronic illness resulting from COVID is at risk of becoming a new baseline level of disability and lost productivity[12] at the national level. Long COVID is set to double or triple the prevalence of comorbid IACCIs such as ME/CFS and POTS, in addition to increasing disease burden across nearly all medical specialties.

Long COVID and other IACCIs have a tremendous economic toll. These complex illnesses cause a high level of disability that makes people unable to work, attend school, or even engage with activities of daily living. Economists have been among the fields paying the closest attention to Long COVID's impact on the economy and workforce — one analysis from 2022 estimated that Long COVID has cost the US economy $3.7 trillion[13]. A Brookings Institute analysis[14] estimates that up to four million people in the US may be out of work due to post-COVID disability, a number that could account for 15% of the existing labor shortage.

CURRENT STATE OF IACCI RESEARCH

Despite the high disease burden and level of disability caused by IACCIs, these illnesses are among the most underfunded conditions[15] at NIH. Medical education around IACCIs is similarly poor. For example, only one third[16] of medical school curriculums include ME/CFS, and the average medical practitioner is not trained or prepared to treat IACCI patients. The lack of funding for IACCI research is attributable to two main causes:

1) a lack of known biomarkers and diagnostic tests for IACCIs
2) IACCIs being multi-systemic illnesses that do not clearly fit into a single research domain or medical specialty

Establishing a permanent "home"at NIH to fund IACCI research would directly address both of these problems.

Illness	Average NIH funding per year 2014-2024
ME/CFS	$12 million
Fibromyalgia	$13 million
Post Treatment Lyme Disease	$3.2 million (2023)[17], $1 million (pre-2023)
POTS	$3.4 million
Ehlers-Danlos Syndrome	$0
MCAS	$0

Table 2: Average NIH funding of IACCIs from 2014-2024. *These figures are taken from the NIH RePORT[18], which provides information on the amount of funding given by disease category, as well as a list of studies receiving this funding. Of the eight IACCIs searched for in RePORT, only four (ME/CFS, Fibromyalgia, Lyme Disease, and POTS) had received some amount of NIH funding. EDS and MCAS had no record of NIH funding. Excluded from this analysis were Long COVID and Gulf War Illness, due to these conditions having government research programs outside of the scope of the RePORT.*

One of the major hurdles to establishing a research base on IACCIs at NIH is that in the absence of a dedicated entity, existing NIH research in IACCIs is spread piecemeal across many different institutes. Analysis of all of the NIH-funded studies on the four IACCIs receiving NIH funding between 2014 and 2022 found that these grants were spread across **21 different NIH Institutes and Centers**. No single NIH entity provided the majority of research funding.

Study Distribution 2014-2022 - ME/CFS		
Institute	*Number of Studies*	*Percentage of Total*
NINDS (Neurological Disorders and Stroke)	117	29%
NIAID (Allergy & Infectious Disease)	106	27%
NHLBI (Heart, Lung, and Blood Institute)	51	13%
NIDA (National Institute on Drug Abuse)	30	8%
Other (12 Institutes)	96	24%
Total	400	

Table 3: NIH-funded studies on ME/CFS by Institute*. NIH funded 400 studies on ME/CFS between 2014 and 2022 across 17 Institutes and Centers. No one institute provided a majority of funding — instead, NINDS and NIAID funded about one quarter of the studies each, with the remaining portion being split between NHLBI, NIDA, and 13 other institutes providing lower levels of funding. Recent focus on ME/CFS has begun to move under NINDS with the release of the NANDS Council Working Group for ME/CFS Research's Roadmap[19].*

Study Distribution 2014-2022 - Fibromyalgia		
Institute	*Number of Studies*	*Percentage of Total*
NIAMS (Arthritis and Musculoskeletal and Skin Diseases)	80	30%
NINDS (Neurological Disorders and Stroke)	49	18%
NCCIH (Center for Complementary and Integrative Health)	47	18%
NIDA (National Institute on Drug Abuse)	18	7%
Other (10 Institutes)	71	27%
Total	*265*	

Table 4: NIH-funded studies on Fibromyalgia by Institute. *NIH funded 236 studies on Fibromyalgia between 2014 and 2022 across 15 Institutes and Centers. Like with ME/CFS, no one institute dominated funding for this condition. NIAMS provided about one-third of total funding, NCCIH and NINDS combined provided a second-third, and the remaining third was split between NIDA and 11 other institutes.*

Study Distribution 2020-2022 - POTS		
Institute	*Number of Studies*	*Percentage of Total*
NHLBI (Heart, Lung, and Blood Institute)	12	63%
NHGRI (Human Genome Research Institute)	2	13%
NIDCD (Deafness and Other Communication Disorders)	2	13%
NINDS (Neurological Disorders and Stroke)	2	13%
NIDDK (Diabetes and Digestive and Kidney Diseases)	1	5%
Total	*19*	

Table 5: NIH-funded studies on POTS by Institute. *NIH first began funding POTS research in 2020, with a total of 19 studies on the condition being funded from 2020-2022. This research was split between 5 NIH Institutes, with NHLBI funding the most studies.*

Study Distribution 2014-2022 - Post-Treatment Lyme Disease			
Institute	*# of Lyme Studies*	*# of PTLD Studies*	*Percentage*
NIAID (Allergy & Infectious Disease)	640	18	3%
NCATS (Center for Advancing Translational Sciences)	12	5	42%
Other	49	0	0%
Total	701	23	

Table 6: NIH-funded studies on Post-Treatment Lyme Disease (PTLD) from 2014-2022. *The vast majority of funding for Lyme Disease research at NIH comes from NIAID's Lyme Disease program. However, this program funds research into all aspects of Lyme Disease, with its main focus being on the acute illness phase and the pathogen that causes it. A comparatively small portion of NIAID's Lyme Disease funding — 3%, an average of $1 million/year — goes to study PTLD. As of 2023, NIAID has pledged an additional $3.2 million[20] to PTLD-focused projects.*

Examining how IACCI research is funded at NIH reveals that **there is no obvious "home" for these illnesses within NIH's existing structure**. Funding for each illness is spread across NIH, and the largest amounts of NIH funding for each IACCI come from entirely different institutes! Combining the distribution of studies for the three IACCIs that follow this pattern gives the following result:

Study Distribution 2014-2022 - ME/CFS + Fibromyalgia + POTS		
Institute	*Number of Studies*	*Percentage of Total*
NINDS (Neurological Disorders and Stroke)	168	25%
NIAID (Allergy & Infectious Disease)	110	16%
NIAMS (Arthritis and Musculoskeletal and Skin Diseases)	100	15%
NHLBI (Heart, Lung, and Blood Institute)	63	9%
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Missing from this breakdown of IACCI research at NIH is Long COVID, due to the fact that all of NIH's Long COVID research is being done through the RECOVER Initiative. The RECOVER Initiative is set up as a trans-disciplinary research program that is not located within any one NIH Institute, but instead coordinates collaboration between different experts across NIH. This approach to research reflects Long COVID's status as a multi-system disease that touches on many areas of medical expertise, but does not fit cleanly into one. Our hope is that establishing an **NIH office for IACCI research** can make the **cross-cutting research infrastructure established by RECOVER permanent**, as well as **expand to cover a broader range of complex post-infectious illnesses.** The wave of post-infectious illness caused by COVID-19 will impact our health system and broader society for decades to come. Investing in a permanent IACCI research entity at NIH is essential to meeting this long-term challenge.

PROPOSED SOLUTIONS

Congress can improve research outcomes by authorizing the creation of a **permanent entity at NIH dedicated to IACCI research.** The prevalence and toll of IACCIs is massive and will only continue to grow in the coming decades. The National Academies of Science, Engineering and Medicine (NASEM) have called for greater investment and cross-disciplinary coordination in IACCI research both prior to and during the pandemic. A 2015 Institute of Medicine report[21] on ME/CFS identified this illness as a serious, multi-systemic condition that is poorly understood by clinicians, and called for the development of evidence-based diagnostic criteria. A more recent NASEM report[22], released in 2023, identified the need for a common research agenda for IACCIs such as Long COVID, ME/CFS, persistent Lyme, and Multiple Sclerosis (MS) — citing increasing evidence of overlapping symptoms and common underlying mechanisms. Additional NASEM reports evaluating this topic area, especially in regards to NIH structural challenges, would be another helpful mechanism for understanding the current IACCI challenges in research and identifying additional solutions.

The necessary functions of an IACCI research entity at NIH are:

1) Having the authority to **fund IACCI research**
2) Convening experts and researchers across specialties at NIH to facilitate and streamline **multidisciplinary research**
3) Ensuring **patient engagement in research**, through patient outreach and collaboration with entities such as Patent-Led Research Collaborative (and their patient engagement in research scorecard[23])
4) Establishing **clinical trials** for potential IACCI treatments

This entity could take a couple of different forms, depending on the level of funding and commitment provided by Congress and NIH leadership. A less expensive option that could be established with relatively little budget commitment from Congress is a **Common Fund Project** established under the Office of the Director. However, to truly address the scope of the IACCIs in the long-term, a dedicated **Office of IACCI Research** is truly needed. This entity would operate at a higher budget than could be provided by the Common Fund — and would therefore require Congressional funding. However, establishing this office would give IACCI research a permanent home at NIH and directly address the major existing research barriers described earlier in this paper.

Common Fund Project

One option for establishing a dedicated entity for IACCIs at NIH would be for the Office of the Director to establish a **IACCI program**, which would serve as a hub for IACCI research that is currently being conducted at disparate NIH institutes. This type of entity could be operated at relatively low cost with a few dedicated staff members using the NIH's Common Fund, but have the authority to advocate for more recognition and funding of IACCI research at NIH. This program would ideally work in tandem with existing IACCI initiatives at NIH, such as the RECOVER

Initiative and the NANDS Council Working Group for ME/CFS Research[24], with a future goal being to bring these projects all under one umbrella.

Since this option could be established by the NIH director with few budgetary commitments from Congress, the primary role for members of Congress for this option is to lend their support to the creation of a dedicated IACCI entity at NIH. Having the support of Congressional members across the political spectrum increases the likelihood of NIH taking action to address this need.

Pros of the Common Fund Project

- **First Step**: Establishing an IACCI program at NIH would give IACCI research a home at NIH and would be a good first step in establishing a cross-disciplinary body to fund research into this family of illnesses. It would also be a major step in official NIH acknowledgement of the reality of IACCIs as serious, biologically-based illnesses.

- **Coordination Between NIH Institutes**: Having a hub for IACCI research at NIH would help address one of the major barriers to researching these illnesses — the lack of a home for these illnesses within NIH's current structure. A coordinating body would also allow for the development of a common research agenda across IACCI illness categories, as recommended by the National Academies' report.

- **Funding Authority**: An IACCI research program would have the authority to direct grant funding towards research projects — the question is how much funding would be available.

- **Congressional Commitment**: Congressional members can support this option with relatively little budget commitment, since NIH leadership has the authority to establish this type of program without Congressional authorization. However, Congress members' support for this type of program is needed to encourage NIH leadership to take action and set aside funding.

Cons of the Common Fund Project

- **Band-Aid Solution:** The current funding level for IACCIs ($5.2 million/year across all illnesses) is too low. An analysis of ME/CFS funding[25], compared to its disease burden, estimated that ME/CFS funding would need to multiplied by 14 times its current amount (12 million x 14 = $168 million) to meet the existing need. This number does not even take into account all of the other illnesses that fall under the IACCI umbrella — including those that have never received NIH funding. This analysis was also done prior to the pandemic, so it does not account for Long COVID's role in multiplying IACCI prevalence rates.

- Although moving the existing level of IACCI funding under a single entity (versus the current piecemeal approach) could make more efficient use of these limited funds, the scope of this program would be severely constrained without additional funding commitments.

- **Integration with Existing Projects**: An ideal approach to IACCIs at NIH would be able to build upon and incorporate existing programs that exist in this space, such as the RECOVER Initiative and the NANDS ME/CFS Working Group. A smaller program with limited budget may not be able to take full advantage of this existing infrastructure.

- **Future Commitments**: This program would require present funding commitments from NIH leadership, as well as future investment from both NIH leadership and Congress to expand to meet the needs posed by widespread prevalence of IACCIs within the population. These future commitments are not guaranteed, and may be even harder to obtain from NIH leadership or Congress if IACCI research is seen as a 'resolved' issue.

- **Vulnerability**: A program set up under the Office of the Director using Common Fund money could easily be defunded or eliminated by a change in administration or NIH leadership.

Office of IACCI Research

The problem of understanding IACCIs as biological illnesses and finding treatments for these devastating illnesses requires a robust, long-term solution to truly meet the scope of what is needed. In order to rise to this challenge, an **Office of IACCI research** needs to be established at NIH. A major goal in establishing this office is to permanently house the multidisciplinary IACCI research infrastructure currently being built by the RECOVER initiative, and to expand this research base to include other infection-associated conditions with similar underlying mechanisms to Long COVID.

RECOVER has been described by some as a "slow-moving glacier[26]", and one of the reasons for the project's slow initial movement is the work that has gone into building an interdisciplinary research base that is capable of tackling the complex, multi-systemic nature of Long COVID. This type of research base, once established, should be extremely valuable for progressing IACCI research into priority areas — such as finding biomarkers, underlying pathophysiology, and establishing clinical trials for potential treatments.

RECOVER is not without its weak points[27] — it has been criticized for its slow progress, and due to not being established as a permanent entity, runs the risk of being defunded and shut down in the future if Congress declines to renew its funding. Establishing a permanent entity for IACCI research would ensure that current investments into RECOVER are not wasted in the event of the initiative being sunsetted, and would allow some of the criticisms about RECOVER to be more substantially addressed and improved upon.

Another NIH entity that can function as a blueprint for an Office of IACCI research is the Office of Autoimmune Disease Research (OADR)[28]. Congress authorized the creation of OADR in 2022, and the reasons behind this office's establishment are extremely similar to the issues currently being faced with IACCIs. OADR's establishment was based on a NASEM report[29] advising the creation of a dedicated research entity for autoimmune disease

research due to **research on these conditions being spread across NIH institutes and centers with no coordinated research agenda**. OADR was created to facilitate cross-NIH multidisciplinary research on autoimmune disorders and develop a coordinated research plan for these conditions. IACCIs currently face the same research challenges as autoimmune diseases prior to the establishment of OADR. As an additional parallel to NASEM's report on the need for OADR, a call for a common IACCI research agenda[30] to be established at NIH was released by NASEM earlier this year.

Pros of an Office of IACCI Research

- **Establishing a Permanent Home at NIH:** An Office of IACCI Research would come with all of the positive aspects of the earlier IACCI program proposal — only more so! With a higher level of investment, this entity would be much better equipped to achieve its goals; which include coordinating multidisciplinary research, engaging patient advocates in research, and most importantly, conducting clinical trials for potential treatments and therapeutics.

- **Level of Funding**: Funding IACCI research at a level comparable to the significant burden of the diseases would be a vast improvement over the small amount of funding that these illnesses currently receive. More research funding would allow this field to progress beyond basic research, and into priority areas such as biomarkers, diagnostics, and therapeutics.

- **Utilizing Existing Infrastructure**: The RECOVER Initiative is already establishing multi-disciplinary research infrastructure for Long COVID that could advance IACCI research more broadly. However, RECOVER is not set up as a permanent entity, and the investments that have been made into the initiative could be lost if its funding is not periodically renewed. Integrating RECOVER and other existing IACCI projects at NIH under an office would give these initiatives a permanent home and progress research into priority areas, such as pathophysiology and clinical trials.

- **Existing Precedent**: The challenges currently faced by IACCI research at NIH parallel those faced by autoimmune diseases — which had their own dedicated office (OADR) established by Congress in 2022. The National Academies have issued reports calling for coordinated research agendas at NIH for both of these disease families.

- **Incentivizing IACCI Research**: Underinvestment in IACCI research is a vicious cycle that translates into clinical practice — despite the large and growing numbers of people suffering from these conditions, there are painfully few clinicians who specialize in them. In both research and clinical practice, IACCIs exist on the margins of many different specialties without clearly belonging anywhere within this framework. Currently at NIH, IACCI research must compete for funding at large institutes such as NINDS or NIAID — despite not being a major focus area for these institutes. Dedicated IACCI funding at NIH would remove this barrier to research.

Establishing a funded research base for IACCIs at NIH would also incentivize more upcoming researchers and clinicians to specialize in this area. Having more specialists and clinicians trained in IACCIs, along with the improvements in evidence-based diagnostics and treatments that more research funding could provide, will revolutionize clinical practice for the millions of Americans that have and will continue to develop post-infectious conditions over the coming decades.

Cons of an Office of IACCI Research

- **Congressional Buy-In**: As a fully-fledged office, the amount of funding needed to establish this entity and provide grant funding exceeds what the Common Fund can provide. Therefore, establishing this office requires Congressional authorization and a funding commitment. This may prove to be a hurdle due to the extremely close voting margins in both chambers, as well as whatever changes occur after the 2024 election. Possible remedies for this are buy-in from members of both parties, or the inclusion of this new entity in an omnibus spending bill.

CONCLUSION

Establishing an Office of IACCI Research is the solution that is currently needed to address the situation with IACCI research at NIH. Future investment could expand this entity into a Center or Institute, if the need and scope of research is sufficient to justify this. The need for a permanent entity at NIH to fund and coordinate IACCI research is becoming increasingly clear and urgent. However, we need Congressional support to make this office a reality. We hope that Congressional offices across the political spectrum will lend their support to this important effort.

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