



Solve M.E.

RESEARCHER RESOURCE GUIDE

Key literature, biospecimen repositories, and publicly available datasets for ME/CFS and Long COVID research



PURPOSE

This resource guide is intended to help Solve Grant and Award applicants, especially those new to the field, identify **(1)** foundational literature, **(2)** biospecimen repositories, and **(3)** existing datasets that may support rigorous, feasible studies in ME/CFS and Long Covid

Applicants are not required to use the resources listed here. Rather, this guide highlights selected starting points that may help investigators understand the field, identify existing samples or datasets, and design studies that build on prior ME/CFS, Long COVID, and infection-associated chronic conditions and illnesses (IACCI)s research.

1. FOUNDATIONAL LITERATURE AND FIELD

ME/CFS DEFINITIONS

Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness

National Academy of Medicine / Institute of Medicine Report. (2015)

Link: <https://www.nationalacademies.org/publications/19012>

Overview: A foundational report that reviewed the evidence base, proposed updated diagnostic criteria, and emphasized ME/CFS as a serious, complex, multisystem illness.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management

Bateman, L., Bested, A. C., Bonilla, H. F., Chheda, B. V., Chu, L., Curtin, J. M., Dempsey, T. T., Dimmock, M. E., Dowell, T. G., Felsenstein, D., Kaufman, D. L., Klimas, N. G., Komaroff, A. L., Lapp, C. W., Levine, S. M., Montoya, J. G., Natelson, B. H., Peterson, D. L., Podell, R. N., Rey, I. R., ... Yellman, B. P. (2021)

Link: <https://pubmed.ncbi.nlm.nih.gov/34454716/>

Overview: A practical clinical/research orientation paper authored by many major ME/CFS clinicians and researchers. Useful for understanding core symptoms, diagnosis, management context, and clinical phenotype.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: When Suffering Is Multiplied

Anthony L. Komaroff (2021)

Link: <https://pubmed.ncbi.nlm.nih.gov/34356297/>

Overview: A concise overview from Tony Komaroff summarizing ME/CFS as a biologically grounded illness and highlighting major biological abnormalities identified through newer research technologies.

ME/CFS Research Roadmap Report

NIH NANDS and NINDS ME/CFS working group members (2024)

Link: <https://www.ninds.nih.gov/about-ninds/who-we-are/advisory-council/nandsc-mecfs-research-roadmap-working-group>

Overview: This working group was put in place to identify the research priorities for ME/CFS in order to move the field closer to clinical trials to develop treatments for the disease. The final report from the working group was presented to the NANDS Council for discussion and approval on May 15-16, 2024 (note: image below outlines the 8 sections that the roadmap covered).



ME/CFS BIOLOGY AND MECHANISMS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: the biology of a neglected disease

Arron, H. E., Marsh, B. D., Kell, D. B., Khan, M. A., Jaeger, B. R., & Pretorius, E. (2024).

Link: <https://pubmed.ncbi.nlm.nih.gov/38887284/>

Overview: A recent broad review of ME/CFS biology that integrates immune dysregulation, inflammation, metabolic alterations, gut dysbiosis, genetic susceptibility, and infectious triggers into a multifactorial model of disease.

The viral origin of myalgic encephalomyelitis/chronic fatigue syndrome

Hanson, M. R. (2023).

Link: <https://pubmed.ncbi.nlm.nih.gov/37590180/>

Overview: A concise review of the historical and contemporary evidence linking ME/CFS to infectious, particularly viral, triggers. Provides useful context for investigators studying post-infectious mechanisms and the relationship between ME/CFS and other infection-associated chronic illnesses.

Biomarkers for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): a systematic review

Maksoud, R., Magawa, C., Eaton-Fitch, N., Thapaliya, K., & Marshall-Gradisnik, S. (2023).

Link: <https://pubmed.ncbi.nlm.nih.gov/37226227/>

Overview: A systematic review of 101 studies evaluating potential ME/CFS biomarkers across immunological, genetic and epigenetic, metabolic and mitochondrial, microbiome, vascular, neurological, ion-channel, and physiological domains. A useful overview of the breadth of biological abnormalities studied in ME/CFS and the current limitations of biomarker research.

Neuroinflammation and Cytokines in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): A Critical Review of Research Methods

VanElzakker, M. B., Brumfield, S. A., & Lara Mejia, P. S. (2019).

Link: <https://pubmed.ncbi.nlm.nih.gov/30687207/>

Overview: A critical review of neuroinflammation research in ME/CFS, with particular attention to PET imaging, magnetic resonance spectroscopy, and peripheral and cerebrospinal-fluid cytokine

studies. Especially useful for investigators designing neuroimmune studies because it highlights major methodological and interpretive challenges in the existing literature.

Chronic fatigue syndrome and the immune system: Where are we now?

Mensah, F. K. F., Bansal, A. S., Ford, B., & Cambridge, G. (2017).

Link: <https://pubmed.ncbi.nlm.nih.gov/28410877/>

Overview: A review of immune abnormalities reported in ME/CFS, including natural killer-cell dysfunction and other immunological findings, while emphasizing the inconsistency of results across cohorts and study designs. Helpful background for researchers entering the ME/CFS immunology literature.

Chronic fatigue syndrome: inflammation, immune function, and neuroendocrine interactions

Klimas, N. G., & Koneru, A. O. (2007).

Link: <https://pubmed.ncbi.nlm.nih.gov/18177602/>

Overview: An influential early review examining interactions among inflammation, immune dysfunction, neuroendocrine signaling, genetics, and infectious triggers in ME/CFS. This paper provides helpful historical context for mechanistic hypotheses that continue to shape research in the field.

The Pathobiology of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: The Case for Neuroglial Failure

Renz-Polster, H., Tremblay, M. E., Bienzle, D., & Fischer, J. E. (2022).

Link: <https://pubmed.ncbi.nlm.nih.gov/35614970/>

Overview: Explores neuroglial dysfunction as a potential unifying mechanism connecting immune activation, mitochondrial and metabolic abnormalities, vascular dysfunction, and nervous-system disturbances in ME/CFS. An example of an integrative mechanistic model of the illness.

The Gut Microbiome in Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS)

König, R. S., Albrich, W. C., Kahlert, C. R., Bahr, L. S., Löber, U., Vernazza, P., Scheibenbogen, C., & Forslund, S. K. (2022).

Link: <https://pubmed.ncbi.nlm.nih.gov/35046929/>

Overview: Reviews evidence for alterations in the gut microbiome and their potential relationships with immune, metabolic, neurological, and gastrointestinal abnormalities in ME/CFS. Good resource for investigators interested in host-microbiome interactions and multi-system mechanisms.

ME/CFS, LONG COVID, AND IACCIs

ME/CFS and Long COVID share similar symptoms and biological abnormalities: road map to the literature

Komaroff, A. L., & Lipkin, W. I. (2023).

Link: <https://pubmed.ncbi.nlm.nih.gov/37342500/>

Overview: A particularly useful comparative review of ME/CFS and Long COVID that maps shared abnormalities across the immune, autonomic and central nervous systems, vasculature, microbiome, energy metabolism, and redox biology. An excellent starting point for investigators interested in mechanisms that may span both illnesses.

Unexplained post-acute infection syndromes

Choutka, J., Jansari, V., Hornig, M., & Iwasaki, A. (2022).

Link: <https://pubmed.ncbi.nlm.nih.gov/35585196/>

Overview: A foundational review placing Long COVID and ME/CFS within the broader context of post-acute infection syndromes. It highlights overlapping clinical features across illnesses triggered by different pathogens and argues for investigation of shared biological mechanisms underlying chronic post-infectious disease.

Unravelling shared mechanisms: insights from recent ME/CFS research to illuminate long COVID pathologies

Annesley, S. J., Missailidis, D., Heng, B., Josev, E. K., & Armstrong, C. W. (2024).

Link: <https://pubmed.ncbi.nlm.nih.gov/38443223/>

Overview: A recent review examining biological abnormalities shared between ME/CFS and Long COVID, including immune dysfunction, altered energy metabolism, microbiome changes, and neuroinflammation. Particularly useful for researchers entering Long COVID who may benefit from the longer history of mechanistic ME/CFS research.

Molecular Mechanisms of Neuroinflammation in ME/CFS and Long COVID to Sustain Disease and Promote Relapses

Tate, W., Walker, M., Sweetman, E., Helliwell, A., Peppercorn, K., Edgar, C., Blair, A., & Chatterjee, A. (2022).

Link: <https://pubmed.ncbi.nlm.nih.gov/35693009/>

Overview: Proposes a mechanistic model in which systemic inflammation and immune dysregulation communicate with the central nervous system to sustain neuroinflammation, disrupted homeostasis, and relapse–recovery cycles in ME/CFS and Long COVID. Useful for investigators interested in neuroimmune signaling and disease persistence.

Long COVID: major findings, mechanisms and recommendations

Davis, H. E., McCorkell, L., Vogel, J. M., & Topol, E. J. (2023).

Link: <https://pubmed.ncbi.nlm.nih.gov/36639608/>

Overview: A widely cited review of Long COVID biology that synthesizes evidence for viral persistence, immune dysregulation, autoimmunity, endothelial and microvascular dysfunction, neurological abnormalities, and other candidate mechanisms. Provides useful context for identifying biological pathways that may overlap with ME/CFS and other IACCI.

Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome?

Komaroff, A. L., & Bateman, L. (2021).

Link: <https://pubmed.ncbi.nlm.nih.gov/33537329/>

Overview: An early and accessible bridge between the emerging Long COVID population and the established literature on post-infectious ME/CFS. Particularly useful for investigators entering ME/CFS research through SARS-CoV-2 or post-viral illness research.

Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)—A Systematic Review and Comparison of Clinical Presentation and Symptomatology

Wong, T. L., & Weitzer, D. J. (2021).

Link: <https://pmc.ncbi.nlm.nih.gov/articles/PMC8145228/>

Overview: A systematic comparison of Long COVID and ME/CFS symptom profiles demonstrating

substantial overlap in fatigue, impaired daily activity, cognitive symptoms, sleep disturbance, and post-exertional malaise. Helpful background for comparative phenotyping and cohort design.

Post-exertional malaise among people with Long COVID compared to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)

Vernon, S. D., Hartle, M., Sullivan, K., Bell, J., Abbaszadeh, S., Unutmaz, D., & Bateman, L. (2023).

Link: <https://pubmed.ncbi.nlm.nih.gov/36911963/>

Overview: Directly compares post-exertional malaise in Long COVID and ME/CFS populations. Especially relevant for investigators studying exertion intolerance, PEM phenotyping, patient stratification, or harmonization of outcome measures across the two diseases.

2. BIOSPECIMEN REPOSITORIES AND BIOBANKS

NIH/RTI ME/CFS resource:

searchMECFS

Link: <https://searchmecfs.org/>

An interactive query tool that allows researchers to locate and request ME/CFS biospecimens based on participant clinical and demographic characteristics. NIH describes searchMECFS as a tool for navigating biospecimens available for ME/CFS research, and RTI notes that it currently facilitates access to biospecimens and associated data from the Chronic Fatigue Initiative study and the CDC Multi-Site Clinical Assessment of ME/CFS study.

Brain and tissue resource:

NIH NeuroBioBank

Link: <https://www.neurobiobank.nih.gov/>

A national NIH-funded resource that collects and distributes human post-mortem brain tissue and related biospecimens for research on nervous system conditions. NIH's ME/CFS resources page notes that the NeuroBioBank includes biospecimens from individuals with ME/CFS, and NINDS notes that the NeuroBioBank coordinates researcher requests and distributes brain tissue and related resources, including medical records and clinical data when available.

Other ME/CFS-specific biobanks

UK ME/CFS Biobank / CureME

Link: <https://cureme.lshtm.ac.uk/index.php/biobank/>

One of the major ME/CFS-specific biobank resources. CureME states that academic, non-commercial, and commercial researchers may apply to use samples and/or data if they present a sound scientific rationale, with services provided on a cost-recovery basis.

Long COVID / cross-IACCI resources

RECOVER data and biospecimens

Link: <https://www.nih.gov/news-events/news-releases/nih-recover-makes-long-covid-data-easier-access>

Link 2: <https://recovercovid.org/news/over-14-million-biosamples-available-recovers-biorepository-support-long-covid-research>

RECOVER makes Long COVID data available to researchers through NHLBI BioData Catalyst, with controlled access to de-identified participant-level datasets through dbGaP-managed processes. RECOVER also describes ancillary studies as a pathway for researchers to study RECOVER data and biospecimens from people with and without Long COVID.

3. REGISTRIES, DATA PORTALS, AND ACCESSIBLE DATASETS

NIH / RTI ME/CFS resources:

mapMECFS

Link: <https://mapmecfs.org/>

An interactive data portal developed through the NIH-funded ME/CFS Research Network Data Management and Coordinating Center. It allows investigators to search research results across biological disciplines from ME/CFS studies and supports data sharing and discovery.

ME/CFS and IACCI registries:

Brain Inflammation Center: Solve Together / unhide®

Link: <https://unhidenow.org/>

Solve Together is now connected with the Brain Inflammation Collaborative's unhide® platform. unhide® is described as a patient-centered online health platform, available by web or app, designed to bring patients, healthcare providers, and researchers together and to support research on ME/CFS, Long COVID, and other chronic conditions associated with brain inflammation. While participant enrollment is currently limited to individuals based in the United States, researchers from any institution or country can collaborate with unhide® to use the platform for study data collection and endpoint measurement, providing a standardized, user-friendly approach that can be applied across studies.

N3C Long COVID Tenant

Link: <https://ncats.nih.gov/research/research-activities/n3c/long-covid-tenant/overview>

The N3C Long COVID Tenant provides access to clinical data intended to improve knowledge and potential treatment strategies for Long COVID. NCATS describes N3C access through the Clinical Enclave, with data access requirements including institutional and human-subjects training steps.

German Multicenter Registry for ME/CFS, MECFS-R

Link: <https://pubmed.ncbi.nlm.nih.gov/38892879/>

A multicenter registry designed to collect comprehensive, longitudinal clinical, epidemiological, and laboratory data from adults, adolescents, and children with ME/CFS. The published registry description states that stored data may be used for future research projects approved by the relevant ethics committee.

Genetic datasets:

Genome-wide association study of long COVID

Lammi, V., Nakanishi, T., Jones, S. E., et al. (2025).

Link: <https://pubmed.ncbi.nlm.nih.gov/40399555/>

Overview: A large international GWAS of Long COVID including up to 6,450 cases and more than one million population controls. Provides a major resource for investigators studying genetic susceptibility to persistent post-infectious illness and for comparisons with emerging ME/CFS genetic findings.

Initial findings from the DecodeME genome-wide association study of myalgic encephalomyelitis/chronic fatigue syndrome

DecodeME Genetics Delivery Team, Boutin, T., Bretherick, A. D., et al. (2025). [Preprint]

Link: <https://www.medrxiv.org/content/10.1101/2025.08.06.25333109v1>

Overview: The first large-scale DecodeME genetic analysis, using up to 15,579 ME/CFS cases and identifying eight genome-wide significant signals, including loci with potential roles in immune and neurological biology and response to infection. Particularly valuable as a resource for comparative genetic studies across ME/CFS and Long COVID; findings should currently be interpreted as preprint results pending peer review.

All of Us Researcher Workbench

Link: <https://www.researchallofus.org/data-tools/workbench/>

A broad NIH data resource rather than ME/CFS-specific, but potentially useful for comparator, EHR, genomics, wearable, comorbidity, and population-health analyses. All of Us describes its Researcher Workbench as a secure cloud platform containing survey, EHR, genomic, physical measurement, and wearable data, with access through a formal registration and training process.

Note to applicants:

This guide is not exhaustive, and inclusion of a resource does not imply endorsement or guarantee access. Applicants should contact repositories, registries, and data platforms early to confirm availability, eligibility, timelines, costs, data-use requirements, and IRB or ethics considerations. Applicants may also propose appropriate resources not listed here. If you know of a resource that should be included, please share it with us at research@solvecfs.org

