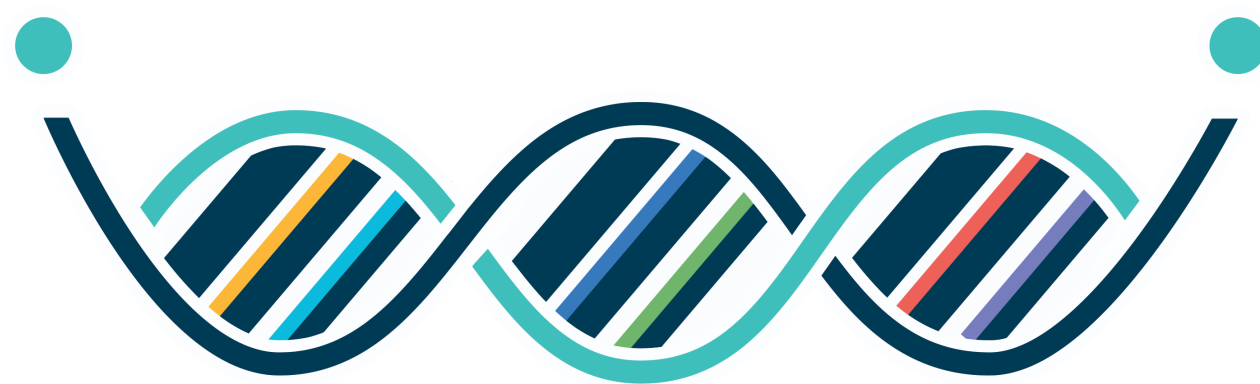


# Community-Developed Resource Guide for Infection-Associated Chronic Conditions



I A C C I

Infection-Associated Chronic Conditions Initiative

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A project of the Long COVID Alliance

[IACCIinitiative.org](https://IACCIinitiative.org)

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## Who Are We

The Infection-Associated Chronic Conditions Initiative (IACCI) was established to address the urgent and growing issue of infection-associated chronic conditions (IACCs). This initiative aims to unify research, patient advocacy, clinical care, and policy under one collaborative effort to better understand the root causes of IACCs and to push for effective treatments, cures, and systemic change within healthcare with a focus on ensuring that healthcare systems, researchers, and policymakers recognize the interconnectedness of these conditions and work toward solutions that will benefit the millions of individuals affected.

The Infection-Associated Chronic Conditions Initiative is a newly launched effort under the [Long COVID Alliance](#) (LCA), which was formed to address the complex challenges of Long COVID and related conditions through research, advocacy, and education. The Long COVID Alliance brings together a diverse group of organizations and individuals to drive forward progress in understanding, treating, and advocating for those affected by chronic conditions that develop following infections. The LCA was founded by the [COVID-19 Longhailer Advocacy Project](#), [Global Pandemic Coalition](#), and [Solve M.E.](#), and joining them on the Long COVID Alliance Executive Committee is [Dysautonomia International](#) and the [Patient-Led Research Collaborative](#), as well as individual advocates Liza Fisher and Michael Sieverts. Together with their broad expertise and lived experiences, they form the backbone of the alliance's leadership and help guide the IACC Initiative.

Learn more about the [Infection-Associated Chronic Conditions Initiative](#) and [Long COVID Alliance](#).

## Why We Created This Guide

Historically, infection-associated chronic conditions have been largely neglected, under-researched, under-funded, under-studied, and under-recognized. As such, upwards of 30 million people in the United States alone have long gone without the needed resources and support. Many IACCs share similar symptoms, impacts to daily living, and barriers to accessing quality medical care. Long COVID has highlighted the prevalence of IACCs and the lack of resources available. It has also highlighted the overlap in IACCs and the need for cross-sector collaboration between patient communities and disease organizations, clinicians and researchers, government, and the private sector. The rise in IACCs due to the pandemic has emphasized the need for education on the potential long-term effects of infections from viruses, bacteria, fungi, or parasites.

Throughout the [CDC Foundation ICUE Project](#), the Long COVID Alliance convened stakeholders in the IACC community to identify common needs and objectives. These needs and objectives were identified as 1) Promoting comprehensive research, 2) Enhancing

patient and caregiver quality of life, 3) Advancing public awareness of IACCs, 4) Modernizing health systems, and 5) Supporting clinician education. Throughout the last year, we have investigated and compiled resources from the IACC community to develop this guide as a first step providing the needed foundation and resources for patients, caregivers, and various other stakeholders to begin to uplift, recognize, and take action to address and respond to IACCs, improving the lives of tens of millions in the U.S. alone. This guide is intended to be a living document which will be added to on a periodic basis. Suggested additions can be made using this [form](#).

## Who Is This Guide For

This guide was created by patients, caregivers, and leaders within the IACC community for use by patients, caregivers, clinicians, researchers, educators, payers, drug industry, clinical societies, public health agencies, federal government, state, tribal, local, and territorial health authorities, international organizations, employers, and beyond.

## Disclaimer

This guide is intended solely for informational purposes. It should not be taken as medical or legal advice. The content is based on patient experiences, available research at the time of publication (1/2025, V1), community engagement, community submissions, and collaborations with various organizations, but it is not a substitute for professional medical or legal consultation. By using this guide, you acknowledge and agree to this disclaimer and release its authors, leadership, contributors, and all involved parties from any liability or claims related to the information provided herein. Additionally, please note that the external links to websites and videos provided in this e-book are for your convenience. We do not have control over the content of these external sites, and they may be updated, moved, or removed without our knowledge.



# Guide to Infection-Associated Chronic Conditions (IACCs)

## What Are IACCs and What Causes Them?

Infection-associated chronic conditions (IACCs) are chronic health conditions that can be triggered by infections, including those caused by viruses, bacteria, fungi, or parasites, affecting an estimated 31 million Americans. Many patients remain ill for years or life following the initial infection with a range of symptoms that can significantly impact quality of life, and the mechanism of the symptoms is unclear. Common infections associated with IACCs include Epstein-Barr virus, influenza, Lyme disease, strep, and, most recently, SARS-CoV-2, the virus responsible for COVID-19.

## History of IACCs, Gaps, and the Impact of Long COVID

The history of IACCs is marked by long standing neglect and stigmatization. Conditions like myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), postural orthostatic tachycardia syndrome (POTS), and persistent Lyme disease have often been dismissed or minimized by the medical community, resulting in insufficient research, limited public awareness, and inadequate treatment options. The COVID-19 pandemic, and the emergence of Long COVID as a prominent IACC, has shed light on these gaps and underscored the urgent need for better preparedness, prevention, and management of such conditions.

Long COVID has highlighted the significant gaps in healthcare and research for IACCs, revealing the need for a more coordinated approach to understanding, treating, and preventing these conditions. It has also underscored the importance of public health measures and the development of robust surveillance systems to prevent the long-term consequences of infections.

## IACC Community Priorities and Needs

The IACC community has identified several key priorities:

1. **Increased Research Funding and Promotion of Comprehensive Research:** There is an urgent need for more research into the etiology, diagnosis, and treatment of IACCs,

with a focus on understanding the underlying mechanisms and developing effective interventions.

2. **Support Clinician Education and Improved Clinical Care:** The development of comprehensive clinical care guidelines, informed by the latest research and patient experiences, is essential to improving patient outcomes.
3. **Public Education and Awareness:** Raising awareness about IACCs among the public, healthcare professionals, and policymakers is crucial to reducing stigma and ensuring that patients receive the support they need.
4. **Improved Public Health Policies:** Advocating for policies that recognize and address the full spectrum of IACCs, including equitable access to healthcare and the inclusion of IACCs in disability policies.
5. **Enhancing Patient and Caregiver Quality of Life:** These illnesses can cause highly debilitating symptoms, resulting in a very low quality of life. Both patients and their family caregivers suffer and need multifaceted types of support.

## Common IACCs and Their Definitions, Codes, Diagnosis Criteria, Specialists, and Symptoms

Here are some of the most common IACCs, along with brief explanations:

### Long COVID (LC)

- **Consensus 2024 NASEM Long COVID Definition:** Long COVID (LC) is an infection-associated chronic condition that occurs after SARS-CoV-2 infection and is present for at least 3 months as a continuous, relapsing and remitting, or progressive disease state that affects one or more organ systems.

LC manifests in multiple ways. A complete enumeration of possible signs, symptoms, and diagnosable conditions of LC would have hundreds of entries. Any organ system can be involved, and LC patients can present with:

- Single or multiple symptoms, such as: shortness of breath, cough, persistent fatigue, post-exertional malaise, difficulty concentrating, memory changes, recurring headache, lightheadedness, fast heart rate, sleep disturbance, problems with taste or smell, bloating, constipation, and diarrhea.
- Single or multiple diagnosable conditions, such as: interstitial lung disease and hypoxemia, cardiovascular disease and arrhythmias, cognitive impairment, mood

disorders, anxiety, migraine, stroke, blood clots, chronic kidney disease, postural orthostatic tachycardia syndrome (POTS) and forms of dysautonomia, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), mast cell activation syndrome (MCAS), fibromyalgia, connective tissue diseases, hyperlipidemia, diabetes, and autoimmune disorders such as lupus, rheumatoid arthritis, and Sjogren's syndrome.

- Important Features of Long COVID:
  1. LC can follow asymptomatic, mild, or severe SARS-CoV-2 infection. Previous infections may have been recognized or unrecognized.
  2. LC can be continuous from the time of acute SARS-CoV-2 infection or can be delayed in onset for weeks or months following what had appeared to be full recovery from acute infection.
  3. LC can affect children and adults, regardless of health, disability, or socioeconomic status, age, sex, gender, sexual orientation, race, ethnicity, or geographic location.
  4. LC can exacerbate pre-existing health conditions or present as new conditions.
  5. LC can range from mild to severe. It can resolve over a period of months or can persist for months or years.
  6. LC can be diagnosed on clinical grounds. No biomarker currently available demonstrates conclusively the presence of LC.
  7. LC can impair individuals' ability to work, attend school, take care of family, and care for themselves. It can have a profound emotional and physical impact on patients and their families and caregivers.
- ICD Code: U09.9 (Post COVID-19 condition, unspecified)
- Diagnosis Criteria: See NASEM definition above.
- Symptoms: There are [over 200 symptoms of Long COVID](#) ranging across all body systems. Some of the more common symptoms include fatigue, cognitive dysfunction, post-exertional malaise, and musculoskeletal pain.
- Specialists: Infectious disease specialists, pulmonologists, neurologists, and rheumatologists.
- Learn more:
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#)

- [Consensus 2024 NASEM Long COVID Definition & Report, Webinar, & HHS Letter to NASEM adopting the 2024 NASEM Long COVID Definition.](#)
- [COVID-19 Longhailer Advocacy Project Website](#)
- [Patient-Led Research Collaborative Website](#)
- Long COVID Justice and The Sick Times' [Long COVID Essentials Resource Sheets](#)

## Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

- **Definition:** A chronic condition characterized by severe, persistent fatigue that is not alleviated by rest.
- **ICD-10 Code:** G93.32 (Myalgic encephalomyelitis/chronic fatigue syndrome)
- **Diagnosis Criteria:** While diagnostic criteria can differ, typically ME/CFS is diagnosed following a substantial reduction in quality of life lasting for 6 months or more for adults (3 months or more for children) resulting from otherwise unexplained, persistent fatigue, along with other symptoms such as unrefreshing sleep and cognitive impairments. Generally, the symptom post-exertional malaise (PEM<sup>1</sup>) must be present for a diagnosis.
- **Symptoms:** Severe fatigue, sleep disturbances, cognitive difficulties, and orthostatic intolerance.
- **Specialists:** Neurologists, rheumatologists, and infectious disease specialists.
- **Learn more:**
  - [Could I have ME/CFS? Take the Quiz by Solve M.E.](#)
  - [Centers for Disease Control and Prevention \(CDC\): ME/CFS Overview](#)
  - [Video: What is ME/CFS by the Bateman Horne Center](#)
  - [ME-pedia.org](#): a project by The MEAction Network that collects and shares information on the history, science, and medicine of ME/CFS and related diseases.
  - [How Do I Know If I Have ME?](#) from The Sleepy Girl Guide to Social Security Disability by Lily Silver

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<sup>1</sup> Post-Exertional Malaise (PEM) is new or worsened symptoms following even a small amount of exertion, including physical, mental, and emotional. PEM is a key feature of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).



## Postural Orthostatic Tachycardia Syndrome (POTS)

- **Definition:** Postural Orthostatic Tachycardia Syndrome (POTS) is a form of autonomic nervous system dysfunction that is characterized by an abnormal increase in heart rate that occurs after moving from a lying to a standing position. POTS is defined as a sustained increase in heart rate of  $\geq 30$  beats per minute (BPM) (or  $\geq 40$  BPM in individuals aged 12–19) within 10 minutes of standing, in the absence of orthostatic hypotension.
- **ICD-10 Code in the US:** G90.A (postural orthostatic tachycardia syndrome). In other countries, there is no specific POTS code, but other codes related to autonomic disorders unspecified, tachycardia, syncope or small fiber neuropathy may be used.
- **Diagnosis Criteria:**  
To diagnose POTS, [all of the following criteria must be met](#):
  1. A sustained HR increment of not less than 30 beats/minute within 10 min of standing or head-up tilt. For individuals who are 12 to 19 years old, the required HR increment is at least 40 beats/minute; and
  2. An absence of orthostatic hypotension (i.e. no sustained systolic blood pressure [BP] drop of 20 mmHg or more); and
  3. Frequent symptoms of orthostatic intolerance during standing, with rapid improvement upon return to a supine position. Symptoms may include lightheadedness, palpitations, tremulousness, generalized weakness, blurred vision, and fatigue; and
  4. Duration of symptoms for at least 3 months; and
  5. Absence of other conditions explaining sinus tachycardia such as anorexia nervosa, primary anxiety disorders, hyperventilation, anemia, fever, pain, infection, dehydration, hyperthyroidism, pheochromocytoma, use of cardioactive drugs (e.g. sympathomimetics, anticholinergics) or severe deconditioning caused by prolonged bed rest.

The heart rate criteria for POTS is based on Tilt Table Testing, which is the most sensitive test to diagnose POTS. When tilt testing is not available, a 10 minute Active Stand Test can be used to diagnose POTS. However, the Active Stand Test is known to miss 20%-60% of POTS cases and has not been validated in pediatric populations. Therefore, anyone with symptoms suggestive of POTS who does not meet the heart rate criteria on the Active Stand Test should be referred for more precise Tilt Table Testing.

- **Symptoms:** rapid heartbeat, brain fog, fatigue, headaches, lightheadedness, heart palpitations, exercise intolerance, nausea, diminished concentration, tremulousness (shaking), syncope (fainting), coldness or pain in the extremities, chest pain and shortness of breath, according to [Dysautonomia International](#). About half of POTS patients develop a reddish purple color in the legs upon standing, believed to be caused by blood pooling or poor circulation.
- **Specialists:** Cardiologists, neurologists, electrophysiologists, and autonomic disorders specialists.
- **Additional Information:** In addition to POTS, there are many other forms of dysautonomia, each with their own distinct diagnostic criteria and treatment approaches. Some of the other forms of dysautonomia that can develop after an infection include:
  1. Orthostatic Intolerance
  2. Orthostatic Hypotension
  3. Neurocardiogenic Syncope (previously called Vasovagal Syncope)
  4. Inappropriate Sinus Tachycardia
  5. Autoimmune Autonomic Ganglionopathy
  6. Hyperhidrosis
- **Learn more:**
  - [Postural Orthostatic Tachycardia Syndrome Summary Page](#)
  - [Dysautonomia International: Autonomic Disorders Video Library](#)
  - [Dysautonomia International Patient Education Resources Quick Links](#)
  - Letter for providers regarding POTS ICD code and treatment guidance resources: [bit.ly/ICDCodeForPOTS](http://bit.ly/ICDCodeForPOTS)

## Persistent or Chronic Lyme Disease (PLD/CLD)

- **Definition:** Patients who remain ill for 6 months or more, following an initial course of antibiotics for Lyme disease, are considered to have PLD. There is considerable impairment of health-related quality of life among patients with this condition.
- **Common ICD Codes include** A69.2 (Lyme disease) and/or D84.90 (immune deficiency), among others

- **Diagnosis Criteria:** Because many patients do not develop the erythema migrans rash (which begins as a reddened area near the tick bite and increases in size) and laboratory tests are insensitive, clinicians often must make a clinical diagnosis, based on characteristic symptoms described below.
- **Symptoms:** Characteristic symptoms of persistent Lyme include musculoskeletal pain, memory and cognitive impairment, fatigue, difficulties sleeping, and symptoms involving the heart and GI tract, among other systems of the body.
- **Specialists:** In surveys, most PLD patients report seeking out clinicians with extensive experience treating PLD. These typically have received training from the International Lyme and Associated Diseases Society (ILADS). Only 10% of PLD patients report being treated by infectious disease specialists.
- **Learn more:**
  - [LymeDisease.org](http://LymeDisease.org)
  - [Bay Area Lyme Foundation](http://BayAreaLymeFoundation.org)

## PANS/PANDAS (Pediatric Acute-onset Neuropsychiatric Syndrome/ Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections)

- **Definition:** Inflammatory brain disorders characterized by the sudden onset of neuropsychiatric symptoms following infections, such as strep throat.
- **ICD Code:** No specific ICD code. Utilized codes include, but are not limited to, D89.89, G04.81, and G04.90.
- **Diagnosis Criteria:** PANS and PANDAS are clinical diagnoses. Guidelines for PANS diagnosis include the abrupt onset of obsessive compulsive disorder (OCD) or severely restricted food intake and the concurrent presence of at least 2 specified neuropsychiatric symptoms. Guidelines for PANDAS diagnosis include the presence of OCD or tics; age of onset between 3 years and puberty; acute onset and relapsing, remitting course; association with Group A Streptococcal infection; and association with neurological abnormalities.
- **Symptoms:** Symptoms may include OCD, tics, anxiety, including severe separation anxiety; depression and emotional lability; joint pain and fatigue; GI symptoms; irritability, aggression or severe oppositional behaviors; behavioral or developmental regression; deterioration in school performance, handwriting, or math skills; sensory abnormalities; and profound sleep disturbance. Some patients also present with POTS.

- **Specialists:** Pediatric neurologists, psychiatrists, rheumatologists, allergists immunologists. Continued care with adult providers may be required as patients age. In addition, cases of onset during young adulthood may occur.
- Learn more:
  - [Alliance for PANS and Immune Related Encephalopathies \(ASPIRE\)](#)
  - [Neuroimmune Foundation](#)

# Guide to Patient & Caregiver Roles and Resources

## Identifying Infection-Associated Chronic Conditions (IACCs)

Identifying an infection-associated chronic condition (IACC) can be challenging due to the complex and often overlapping symptoms these conditions present. Common symptoms include chronic fatigue, cognitive impairment, muscle and joint pain, and autonomic dysfunction. Patients and caregivers should be vigilant in recognizing persistent symptoms that do not improve after an initial infection. Understanding the potential link between a prior infection and ongoing symptoms is crucial. Keeping detailed records of symptoms, any triggers, and how they fluctuate over time can provide valuable information when seeking a diagnosis.

## Preparing for Medical Appointments

Preparation is key to making the most of medical appointments when dealing with IACCs. Patients and caregivers should:

- **Document Symptoms:** Maintain a symptom diary, noting the onset, duration, and severity of each symptom. Include any potential triggers or patterns observed over time.
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapters 2, 3, 5, and Mini Guide's starting on pages 486 (Medical Documentation & Planning Guide for Patients & Caregivers) and 497 Long COVID Clinical Assessment Guide for Clinicians).
  - The Sick Times x Long COVID Justice's [Tracking your symptoms](#)
  - Solve ME: [Symptom Diary](#)
  - National Academy of Medicine's [Person-Centered Chronic Pain Journey Map](#)
- **Gather Medical Records:** Compile relevant medical history, including past infections, treatments, and previous diagnoses.
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapters 2, 3, 5, and Mini Guide's starting on pages 486 (Medical Documentation & Planning Guide for Patients & Caregivers)



- **List Questions and Concerns:** Prepare a list of specific questions to ask the healthcare provider. This can help ensure that all concerns are addressed during the appointment.
  - [Provider Interview Questions](#)
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapters 2, 3, 5, and Mini Guide starting on page 497 (Long COVID Clinical Assessment Guide for Clinicians).
  - The Sick Times x Long COVID Justice's [How to talk to healthcare providers about Long COVID](#)
  - [History of Present Illness template](#) by the Spiral Guide
- **Bring Support:** Having a caregiver or trusted individual accompany you can provide emotional support, help remember information shared by the doctor, and advocate for your needs.
  - [Securing a Personal Support System](#)
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapters 6, 7, and 8)

## Locating IACC Care, Research, and Support

Finding specialized care, research, and support for IACCs can be challenging due to the limited number of healthcare providers, researchers, and organizations familiar with these conditions. Here's how to locate the right care, research, and support:

### Long COVID (LC):

- **Care Providers:** Seek out clinics specializing in post-COVID care or Long COVID clinics. These are often affiliated with major hospitals or research institutions.
  - COVID-19 Long Haulers Advocacy Project's [COVID-Competent Healthcare Providers](#)
  - COVID-19 Longhailer Advocacy Project's [Post COVID Care Centers List](#)
- Biobanks, Registries, and Select Research Studies

- [Visible App](#): provides personalized pacing insights through wearable data and allows people to join research studies in the platform.
- [Long COVID Studies](#): A resource listing all clinical trials in Long COVID
- [University of Florida Long COVID Registry](#)
- [COVID-19 HUB - UK Biobank](#): a large-scale biomedical database and research resource, containing in-depth, de-identified genetic and health information from half a million UK participants.
- [RECOVER Initiative](#): the NIH's main Long COVID study.
- **Support Groups**: Online communities provide peer support and shared resources.
  - Body Politic [List of Community Support for Long COVID](#)
  - COVID-19 Longhailer Advocacy Project has [60 state and community-based chapters](#) on Facebook.

## Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS):

- **Care Providers**: Look for specialists in ME/CFS, often found within neurology or infectious disease departments.
- The ME/CFS Clinician Coalition provides a [directory of knowledgeable clinicians](#) and the American Myalgic Encephalomyelitis and [Chronic Fatigue Syndrome Society \(AAMES\)](#) provides a [Physician and Clinic Database](#).
  - [Solve M.E. Clinical, Research and Patient Leaders](#) Resource Guide
    - ▶ Encourage providers to learn more at the [Resource Page for Medical Providers](#)
  - [#MEAction webpage which includes a handout on diagnosis & management](#): Encourages healthcare providers to learn about ME/CFS diagnosis and management with evidence-based handouts and clinical guidance.
  - Massachusetts ME/CFS Association [Working with Your Healthcare Provider for People with Chronic Illness](#): A guide for patients with chronic illnesses on effectively collaborating with healthcare providers to improve care outcomes.
  - [ME/CFS Clinician Coalition](#): a group of expert clinicians dedicated to improving ME/CFS diagnosis and treatment by providing consensus-based clinical resources.

- [Bateman Horne Center Testing Recs ME/CFS](#): Offers detailed recommendations on appropriate testing for ME/CFS diagnosis and management, tailored for clinicians and patients.
- [WorkWell Foundation](#): Focuses on assessing and managing post-exertional malaise (PEM) in ME/CFS patients through cardiopulmonary exercise testing (CPET) and functional capacity evaluations.
- #MEAction's [ME-friendly Practitioners](#): Crowd-sourced directory of healthcare practitioners knowledgeable about ME/CFS to help patients find appropriate and compassionate care.
- Biobanks, Registries, and Select Research Studies:
  - [SearchME/CFS at RTI](#)
  - [SolveME Solve Together Registry](#): Solve Together is a patient-centered platform that accelerates treatment discovery by integrating data on post-infectious diseases and making it accessible to researchers, while also allowing patients to track their health and create reports for doctors. Any U.S. adult can join for free, whether they have ME/CFS, Long COVID, other post-viral illnesses, or none, with the option to opt out at any time.
  - [CureME UK Biobank](#)
  - [Netherlands ME/CFS Cohort and Biobank consortium \(NMCB\)](#)
  - [OMF's StudyME](#)
  - [Simmaron Research Biobank](#) (under Dr. Daniel L. Peterson)
  - [AusME Registry & Biobank](#)
  - [Visible App](#)
- **Support Groups**: Organizations like the Solve ME/CFS Initiative offer [resources and connections](#) to support networks.
  - [Bateman Horne Center Crisis Support](#)
  - [#MEAction Support Groups](#)
  - [Center for Chronic Illness](#)
  - [CFSPhoneSupport](#)
  - [Mass ME/CFS group](#)

## POTS/Dysautonomia:

- **Care Providers:** Cardiologists, electrophysiologists, neurologists and board certified autonomic disorders specialists are often involved in the care of people living with POTS or other forms of dysautonomia. Dysautonomia International offers a provider directory on their website and each of their free online support groups offers a regional list of providers recommended by local patients.
- **Biobanks, Registries, and Select Research Studies:**
  - Dysautonomia International, Vanderbilt University and University of Calgary maintain the “Big POTS Survey,” the largest international research registry of POTS patients, which has been enrolling for nearly a decade. If you have been diagnosed with POTS by a medical professional, you can learn more or enroll at [bit.ly/BIG-POTS](http://bit.ly/BIG-POTS)
- **Support Groups:** Dysautonomia International and similar organizations host [forums and support groups](#) for patients and caregivers.

## Persistent Lyme Disease:

- **Care Providers:** Seek out Lyme-literate medical doctors (LLMDs) who specialize in diagnosing and treating Lyme disease and its chronic manifestations.
  - [LymeDisease.org Lyme Disease Physician Referral](#)
  - [ILADS Provider Search](#)
- **Biobanks, Registries, and Select Research Studies:**
  - [MyLymeData](#) is a patient-driven registry and research platform that has enrolled over 18,000 patients and published 8 peer-reviewed studies in collaboration with academic researchers.
  - [The Lyme Disease Biobank](#) serves as a repository for biological samples such as blood, urine, and tissue from individuals with Lyme disease and other tick-borne illnesses. The goal is to provide researchers with the necessary materials to study these diseases, develop better diagnostics, and find new treatments.
  - [The Lyme Clinical Trials Network \(CTN\)](#) seeks to identify more effective treatments for Lyme and other tick-borne diseases. The network brings together leading researchers and institutions, including Columbia University, Johns Hopkins University, University of California San Francisco, and Children's National Hospital, to conduct large-scale clinical trials and pilot studies.

- **Support Groups:** LymeDisease.org provides educational resources, including Lyme Basics, a symptom checklist, a weekly email newsletter, a doctor referral service and an online patient support group.

- Generation Lyme offers weekly zoom support meetings geared towards different groups, including patients, family and friends. <https://www.genlyme.org/meetups>

## PANS/PANDAS:

- **Care Providers:** Treatment requires a multidisciplinary team, which may involve neurology, rheumatology, allergy/immunology, gastroenterology, psychiatry, and psychology. Identifying PANS and PANDAS specialists or physicians willing to learn more about the condition and consult with experts is crucial for proper management.
  - Contact the [Neuroimmune Foundation](#) for recommended providers in your area or consult the [PANDAS Physician Network \(PPN\) Directory](#).
  - [Stanford PANS Clinic and Research Program](#) - The Stanford Immune Behavioral Health Clinic is the first multidisciplinary PANS clinic. The program conducts research and provides care to patients. Access to the clinic is limited to the surrounding area.
  - [Dartmouth Neuroimmune Psychiatric Disorders Clinic \(NIPD\)](#) - Access to the clinic may depend on geographical location.
  - [Neuroimmune Foundation Expert Consultation Panel](#) is available to physicians for face-to-face virtual consults with leading experts in neuroimmunology and immunopsychiatry concerning patients.
  - The Louisa Adelynn Johnson Fund for Complex Disease publishes an online series, [HARD TRUTHS: How the Health Care System Treats Complex, Chronically Ill Children](#), which highlights the extreme obstacles often facing patients and families and is intended to raise awareness amongst health care providers.
  - The Alex Manfull Fund podcast [Untangling PANS and PANDAS](#) interviews experts in the field.
- **Biobanks, Registries, and Select Research Studies:**
  - [Georgetown POND Brain Bank](#) - The PANDAS/PANS and Other Neuroimmune Disorders Brain Bank is an integrated educational, clinical, and experimental resource that provides detailed neuropathological evaluations and manages the



procurement, storage, and distribution of tissue and biofluids to researchers worldwide.

- The [Stanford PANS Program](#) maintains a clinical database and collects patient blood specimens in various disease states. The program also distributes blood and cerebrospinal fluid specimens to collaborating institutions.
- **Support Groups:** The [Neuroimmune Foundation](#) hosts an on-line support group. [ASPIRE](#) holds regional Chit Chat meetings and has an on-line support group.

## IACC Overall

- Care Providers
  - [Email to educate your clinician about IACCs](#): an email template to educate clinicians about what IACCs are
- Biobanks, Registries, and Select Research Studies:
  - NIH All of Us Research Program: <https://www.joinallofus.org - part of the NIH, a research project dedicated to advancing precision medicine>
  - [RECLAIM](#) at UMassChan, a research study investigating the role of oxidative stress and how it contributes to chronic diseases and illnesses
- Additional Resource Guides
  - [Spooniverse](#): a directory made by patients for patients of clinical trials, patient communities, research opportunities, financial aid, and more
  - [DiseaseMaps.org](#): connects people who have different conditions to help them find community and advice.
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#)

## Self-Advocacy: Coping, Accommodations, Disability, and Support Services

Self-advocacy is a crucial skill for individuals living with infection-associated chronic conditions (IACCs). Navigating the complexities of chronic illness requires an understanding of your rights, available accommodations, and the support services that can enhance your quality of life.

### Coping Strategies:

- **Education:** Understanding your condition is the first step in self-advocacy. Educate yourself about your specific IACC, including symptoms, treatment options, and potential triggers.
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) Chapter 3 goes over many Long COVID Associated Conditions which include many IACCs and resources for each.
  - [ME-pedia.org](#): a project by The MEAction Network that collects and shares information on the history, science, and medicine of ME/CFS and related diseases.
- **Mental Health:** Coping with a chronic illness can be emotionally challenging. Engaging in mental health services, such as counseling or support groups, can help manage stress, anxiety, and depression.
  - Solve M.E. [Mental Health and Chronic Disease](#)
  - [988 Suicide and Crisis Hotline](#) (or call and text 988)
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapter 8 and Mini Guide starting on page 464 (Advice from the Long COVID Community))
- **Pacing and Energy Management:** Learn to manage your energy through pacing techniques, which involve balancing activity with rest to avoid exacerbating symptoms. This is particularly important for conditions like ME/CFS and Long COVID.
  - Solve M.E. [Post-Exertional Malaise \(PEM\) Guide](#)
  - #MEAction and Patient-Led Research Collaborative [Pacing and Management Guide](#)
  - Stanford Medicine [4-Step Toolkit to Avoid PEM](#)
  - Emerge Australia [PEM Toolkit Video Workshop](#)
  - Solve M.E. [Using a Heart Rate Monitor to Prevent PEM](#)

- Workwell Foundation: [Open Letter to Healthcare Providers: GET can Cause Harm](#)
- Long Covid Physio [Pacing Resources](#)
- #MEAction PEM and Pacing for the Pediatric Patient [[video](#)]
- #MEAction PEM and Pacing: Mental Health [[video](#)]
- #MEAction Implementing Pacing to Prevent PEM [[video](#)]
- #MEAction Understanding Post-Exertional Malaise (PEM) [[video](#)]

### Accommodations:

- **Workplace Accommodations:** If your condition impacts your ability to work, you are entitled to [reasonable accommodations](#) under the Americans with Disabilities Act (ADA). These might include flexible work hours, remote work options, ergonomic adjustments, or additional breaks.
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapter 9)
  - Job Accommodations Network: [Long COVID](#) and [ME/CFS](#) Accommodation and ADA Compliance
- **Educational Accommodations:** For students, accommodations might include extended time for assignments, modified classroom environments, or the provision of assistive technologies.
  - Solve M.E. [School and Work Guide](#)
  - [OMF's collection of Children's School Resources](#)
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapter 9)
  - [Council of Parent Attorneys and Advocates \(COPAA\)](#) is a nonprofit network of attorneys, advocates, parents and related professionals to protect the legal and civil rights of students with disabilities.
  - [Wright's Law](#) offers information about special education law, education law, and advocacy for children with disabilities. More information at [www.wrightslaw.com](http://www.wrightslaw.com)
  - [ASPIRE](#)'s resources for educators, schools, parents, and patients on the impact of PANS and PANDAS at school and accommodations.

- **Navigating the ADA:** Understanding your rights under the ADA is critical. This law protects individuals with disabilities from discrimination and ensures access to necessary accommodations in various settings.
  - Severe ME/CFS: [Care, Rights and Research Webinar Playlist](#)
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapter 9)

## Disability and Support Services:

- **Applying for Disability Benefits:** If your condition significantly impairs your ability to work, you may qualify for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). Yet navigating disability benefits with an IACC requires careful documentation and persistence. Start by gathering comprehensive medical records, including detailed notes from healthcare providers that highlight the severity and impact of your symptoms on daily activities. It's important to keep a symptom diary and obtain statements from doctors that clearly explain how your IACC limits your ability to work. When applying for benefits, be thorough in completing the application and consider seeking assistance from a disability lawyer or advocate familiar with your IACC. If your initial claim is denied, don't be discouraged—many applications are approved after an appeal. Stay organized, keep copies of all correspondence, and be prepared for a potentially lengthy process. The application process can be complex, so consider seeking help from a legal professional or disability advocate.
  - [HowToGetOn Guide](#): a self-advocacy guide for anyone who is homebound or bedbound in the US, covering applying for disability, home aids, accommodations, and more.
  - Solve M.E. [Disability Guide](#)
  - Solve M.E. [Financial Guide](#)
  - Kantor & Kantor, LLP [COVID-19 Insurance Denial Guidebook](#)
  - HHS [Long COVID Disability Resources](#)
  - Job Accommodations Network: [Long COVID](#) and [ME/CFS Accommodation](#) and ADA Compliance
  - [Massachusetts ME/CFS & FM Disability Handbook](#)
  - Open Medicine Foundation [“The Nuts and Bolts of Applying for Disability Benefits in the US if you have ME/CFS or Long COVID” Webinar](#)

- Pandemic Patients [COVID-19 and Disability Benefits](#) and their [Legal Assistance](#)
- Social Security Administration (SSA) [Ruling on ME/CFS 2016](#)
- [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapter 9)
- **Support Services:** Various organizations provide services tailored to individuals with IACCs. These services may include case management, transportation assistance, and access to medical equipment. [The Patient Advocate Foundation](#) provides case management services and financial aid to Americans with chronic, life threatening and debilitating illnesses.

## Caregiver Roles and Support

Caregivers play a pivotal role in the lives of individuals with IACCs, often providing both practical and emotional support. Understanding the demands of caregiving and accessing the right resources is essential for both the caregiver's well-being and the care recipient's quality of life.

### Roles of Caregivers:

- **Daily Care:** Caregivers often assist with daily activities such as bathing, dressing, meal preparation, and medication management. Depending on the severity of the condition, the level of care required can vary significantly.
  - [Guide for Caregivers and Loved Ones](#)
  - General Caregiver Info: [CaringInfo.org](#)
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapters 5 and 6 as well as 2, 3, 4)
- **Medical Advocacy:** Caregivers frequently serve as advocates in medical settings, helping to communicate with healthcare providers, manage appointments, and ensure that the care recipient's needs are met.
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapters 5 and 6 as well as 2, 3, 4)



- **Emotional Support:** Providing emotional support is a key aspect of caregiving. Caregivers help their loved ones cope with the psychological impacts of living with a chronic condition, offering comfort, understanding, and companionship.
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapters 5 and 6 as well as 2, 3, 4)

## Caregiver Support:

- **Respite Care:** It's important for caregivers to take breaks to avoid burnout. Respite care services provide temporary relief, allowing caregivers time to rest and recharge.
  - [ARCH National Respite Network](#) helps families locate respite and crisis care services in their communities.
- **Support Groups:** Joining a caregiver support group can provide a sense of community and shared experience. These groups offer a space to discuss challenges, exchange advice, and receive emotional support from others in similar situations.
  - [Caregiver Wisdom](#)
  - [#MEAction's Caregivers' Support Group on Facebook](#)
  - [#MEAction's monthly caregiver support group calls](#)
  - COVID-19 Longhailer Advocacy Project: [Long COVID Caretakers, Partners, & Support Circles](#), [Long COVID Pediatrics, Pregnancy, and Family Planning](#)
- **Resources for Caregivers:** Many organizations offer resources specifically for caregivers, including educational materials, counseling services, and financial assistance programs. Utilizing these resources can help caregivers manage their responsibilities more effectively and maintain their own well-being.
  - Cleveland Clinic: [Caregiver Burnout](#)
  - CDC: [Caring for Yourself When Caring for Another](#)
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#)
  - #MEAction Network [Caregiver Resources](#)
  - [Caregiver Wisdom](#) offers content, community, and coaching for chronic illness caregivers

# Guide to Stakeholder Roles and Resources in the IACC Space

## Who are Stakeholders in the IACC Space?

Stakeholders in the Infection-Associated Chronic Conditions (IACC) space encompass a wide range of individuals and groups who play crucial roles in advancing the understanding, treatment, and support of these conditions. Stakeholders include clinicians, researchers, government agencies, advocacy groups, patients, caregivers, the drug industry, employers, educators, and various public health organizations. Each of these stakeholders has a distinct role in shaping the landscape of care and research for IACCs such as Long COVID, ME/CFS, persistent Lyme disease, POTS, and PANS/PANDAS.

## Clinician Roles in IACC Care

Clinicians are at the forefront of diagnosing and managing IACCs. Their responsibilities include:

- **Diagnosis and Treatment:** Clinicians are responsible for recognizing symptoms of IACCs, using diagnostic criteria, and developing treatment plans tailored to individual patient needs. Given the complex nature of these conditions, which often present with overlapping symptoms, clinicians must stay informed about the latest research and treatment protocols.
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapters 2, 3, 5, 6, 13, 14, and Mini Guides starting on page 497 Long COVID Clinical Assessment and Guide for Clinicians)
- **Patient Education:** Educating patients about their condition, potential triggers, and management strategies is a key role for clinicians. This includes providing guidance on lifestyle modifications, medication management, and navigating the healthcare system.
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#)

- **Advocacy and Support:** Clinicians often serve as advocates for their patients, helping them access necessary services and accommodations. This may involve coordinating care across multiple specialists, assisting with disability claims, or connecting patients with support groups.
  - [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapters 13, 14)

## Researcher Roles in IACC Research

Researchers play a pivotal role in advancing the understanding of IACCs. Their contributions include:

- **Basic and Clinical Research:** Researchers investigate the underlying mechanisms of IACCs, including genetic, immunological, and environmental factors. Clinical research focuses on developing and testing new diagnostic tools and treatment options.
- **Collaboration and Partnership with the Impacted Patient Community:** Researchers should meaningfully engage patients throughout the research process, from hypothesis generation through study design, analysis, and writing. This will help ensure that the research being conducted is of priority to the patient community and is designed in a way that accounts for the condition. [The Patient-Led Research Scorecards](#) can help researchers and patient groups evaluate meaningful engagement in a project.
- **Interdisciplinary Collaboration:** Given the multifactorial nature of IACCs, researchers should collaborate across disciplines, including immunology, neurology, infectious disease, and psychology, to develop a more comprehensive understanding of these conditions.
- **Data Sharing and Standardization:** Researchers contribute to building and maintaining databases and biobanks, which are crucial for standardizing research efforts and facilitating large-scale studies on IACCs.

Resource: [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapter 13)

## Government Roles in IACCs

Government agencies at the local, state, and federal levels play a critical role in shaping public health policies, funding research, and ensuring access to care for individuals with IACCs. Key responsibilities include:

- **Policy Development and Implementation:** Governments develop and implement public health policies that address the needs of individuals with IACCs. This includes funding research, supporting public health campaigns, and integrating IACCs into broader healthcare initiatives.
- **Funding and Grants:** Government agencies like the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC) provide essential funding for research into IACCs. These funds support clinical trials, epidemiological studies, and the development of new treatments.
- **Public Health Initiatives:** Governments lead public health initiatives aimed at raising awareness about IACCs, promoting preventive measures, and ensuring that healthcare providers are equipped to manage these conditions effectively.

Resource: [COVID-19 Longhailer Advocacy Project Comprehensive Guide to Long COVID](#) (Chapter 15)

# General Resources

## Webinars

### IACC Overall

- [NASEM Workshop on Infection-Associated Chronic Illnesses](#)
- [CDC ICUE National Webinar 1](#)
- [CDC ICUE National Webinar 2](#)

### Long COVID

- [World Health Organization Global Long COVID ECHO Webinar Series](#)
- [Project ECHO Long COVID and Fatiguing Illness Recover Program](#)
- [COVID-19 Longhailer Advocacy Project - YouTube](#)
- [Patient-Led Research Collaborative - YouTube](#)
- [Long Covid Physio](#)

### ME/CFS

- Film: [Unrest - YouTube](#)
- [Solve ME - YouTube](#)
- [Open Medicine Foundation - Youtube](#)
- [Bateman Horne Center - YouTube](#)
- [#ME Action - YouTube](#)
- [MassME - YouTube](#)



## Persistent Lyme

- [Johns Hopkins Rheumatology YouTube](#)
- [Columbia University Lyme and Tick-Borne Diseases Research Center](#)
- [LymeCME](#)

## POTS

- [Dysautonomia International YouTube](#)

## PANS/PANDAS

- [Neuroimmune Foundation webinars for families.](#)
- [Neuroimmune Foundation CME videos](#)

## Reports

### IACC Overall

- [NASEM Report on Infection-Associated Chronic Illnesses](#)

### Long COVID

- Long COVID Government Websites
  - HHS Office for Long COVID Research and Practice [The Office of Long COVID Research and Practice \(OLC\) | HHS.gov](#)
  - AHRQ [AHRQ Long COVID Care Network | Agency for Healthcare Research and Quality](#)
  - CDC [Long COVID or Post-COVID Conditions | CDC](#)
  - NIH [Long COVID | NHLBI, NIH](#)
  - WHO [Post COVID-19 condition \(Long COVID\) \(who.int\)](#)
  - SSD [Long COVID: A Guide for Health Professionals on Providing Medical Evidence for Social Security Disability Claims \(ssa.gov\)](#)

- [ACL Resources for People with Long COVID | ACL Administration for Community Living](#)
- **2024 Reports & Actions**
  - [A Long COVID Definition: A Chronic, Systemic Disease State with Profound Consequences](#) (2024 NASEM Long COVID Definition) and [formal HHS letter of adoption](#).
  - [Long COVID: Examining Long-Term Health Effects of COVID-19 and Implications for the Social Security Administration: Proceedings of a Workshop](#)
  - [Long-Term Health Effects of COVID-19: Disability and Function Following SARS-CoV-2 Infection \(2024\)](#)
  - [Toward a Common Research Agenda in Infection-Associated Chronic Illnesses: Proceedings of a Workshop \(2024\)](#)
  - AHRQ's Unique Effort to Advance Care for People Living with Long COVID, a blog on our AHRQ Long COVID Network initiative to advance care for people living with Long COVID. <https://www.ahrq.gov/news/blog/ahrqviews/long-covid-care-network.html>
  - HHS Office of Long COVID published the Implementation of the Government-Wide Response to Long COVID - An Update from the Office of Long COVID Research and Practice. <https://www.hhs.gov/sites/default/files/long-covid-update-2024.pdf>
  - The Office of Disability Employment Policy published ODEP News Brief – International Long COVID Awareness Day Special Edition | U.S. Department of Labor <https://www.dol.gov/agencies/odep/publications/news-brief/20240314>
  - Health+ Long COVID Healthathon [Health+ Long COVID Healthathon: How might we design and implement innovative solutions to improve the lives of those with Long COVID today? \(crowdicity.com\)](#)
- **2023 Reports & Actions**
  - [Examining the Working Definition for Long COVID - Workshop | National Academies](#)
  - [AHRQ Report on Long COVID Models of Care](#)
  - SSA Guide on Providing Medical Evidence for SSD claims [Long COVID: A Guide for Health Professionals on Providing Medical Evidence for Social Security Disability Claims \(ssa.gov\)](#)

- SAMHSA Developing SSDI Applications for Individuals with Long COVID [Developing SSI/SSDI Applications for Individuals with Long COVID | SOAR Works! \(samhsa.gov\)](#)
- ACL Resources for People with Long COVID [Resources for People with Long COVID | ACL Administration for Community Living](#)
- HHS Announces the Formation of the Office for Long COVID Research and Practice [HHS Announces the Formation of the Office of Long COVID Research and Practice and Launch of Long COVID Clinical Trials Through the RECOVER Initiative | HHS.gov](#)
- HHS establishes a Long COVID Advisory Committee [HHS Establishes Secretary's Advisory Committee on Long COVID | HHS.gov](#)
- NIH Launches Clinical Trials for Long COVID Treatment [NIH Launches Clinical Trials for Long COVID Treatments | NIH COVID-19 Research](#)
- NASEM [Emerging Stronger from COVID-19: Priorities for Health System Transformation](#)
- **2022 Reports & Actions**
  - HHS Health+ Long COVID Human-Centered Design Report [Health+ Long COVID Human-Centered Design Report \(hhs.gov\)](#)
  - HHS Report on Services & Supports for Longer-Term Impacts of COVID-19. <https://www.covid.gov/assets/files/Services-and-Supports-for-Longer-Term-Impacts-of-COVID-19-08012022.pdf>
  - HHS Report on the National Research Action Plan on Long COVID. <https://www.covid.gov/assets/files/National-Research-Action-Plan-on-Long-COVID-08012022.pdf>
  - President Biden Issues Memorandum to Address the Long-Term Impacts of COVID-19. <https://www.whitehouse.gov/briefing-room/presidential-actions/2022/04/05/memorandum-on-addressing-the-long-term-effects-of-covid-19>
- **2021 Reports & Actions**
  - NIH Launches the RECOVER Initiative [NIH makes first infrastructure awards to support research on post COVID conditions | National Institutes of Health \(NIH\)](#)
  - Biden-Harris Admin Marks ADA Anniversary & Announces Support to Individuals with Long COVID [FACT SHEET: Biden-Harris Administration Marks Anniversary of Americans with Disabilities Act and Announces Resources to Support Individuals with Long COVID | The White House](#)

- HHS/ OCR release guidance on Long COVID as a Disability [Guidance on “Long COVID” as a Disability Under the ADA, Section | HHS.gov](#)
- HHS/ OCR Long COVID Under Section 504 [ocr-factsheet-504-20210726.pdf \(ed.gov\)](#)

- 2020 Reports & Actions

N/A

## ME/CFS

- ME/CFS Government Websites

- AHRQ [Diagnosis and Treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Report](#)
- CDC [Clinical Overview of ME/CFS](#)
- NIH [Advancing ME/CFS Research](#)
- WHO [What is Chronic Fatigue Syndrome?](#)
- SSD [Providing Medical Evidence for Individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome \(ME/CFS\)](#)

- Other Important Reports & Actions

- NIH NANDSC [ME/CFS Research Roadmap Working Group](#)
- NASEM [Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness](#)
- Mirin, Dimmock, and Jason: [\\$149-362 ME/CFS economic impact Updated ME/CFS prevalence estimates reflecting post-COVID increases and associated economic costs and funding implications](#)
- [2021 NICE Guideline for ME/CFS diagnosis and management](#)
- [Grach et al \(2023\), Diagnosis and Management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome \(Mayo Clinic Proceedings\)](#)
- Bateman et al (2021), [Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management \(Mayo Clinic Proceedings\)](#)
- [Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis /Chronic Fatigue Syndrome \(ME/CFS\) \(PLOS One\)](#)

- [Women's health research lacks funding – these charts show how](#) (Nature)

## Persistent Lyme

- [NASEM: The Evidence Base for Lyme Infection-Associated Chronic Illnesses Treatment](#)
- Gender disparities in Lyme disease: Women face higher risk of severe and prolonged illness <https://doi.org/10.2147/IJGM.S406466>
- [Access to Care in Lyme Disease: Clinician Barriers to Providing Care](#) [doi.org/10.3390/healthcare10101882](https://doi.org/10.3390/healthcare10101882)
- Tick-Borne Disease Working Group 2018 Report to Congress <https://www.hhs.gov/sites/default/files/tbdwg-report-to-congress-2018.pdf>
- Tick-Borne Disease Working Group 2020 Report to Congress [https://www.hhs.gov/sites/default/files/tbdwg-2020-report\\_to-ongress-final.pdf](https://www.hhs.gov/sites/default/files/tbdwg-2020-report_to-ongress-final.pdf)
- Tick-Borne Disease Working Group 2022 Report to Congress <https://www.hhs.gov/sites/default/files/tbdwg-2022-report-to-congress.pdf>

## POTS

- [Postural orthostatic tachycardia syndrome \(POTS\): State of the science and clinical care from a 2019 National Institutes of Health Expert Consensus Meeting - Part 1](#)
- [Postural orthostatic tachycardia syndrome \(POTS\): Priorities for POTS care and research from a 2019 National Institutes of Health Expert Consensus Meeting - Part 2](#)
- [Autonomic Neuroscience Special Issue on POTS](#) - this special journal issue includes guidance on the POTS workup, non-pharmacological and pharmacological treatment approaches from the leading experts

## PANS/PANDAS

- [PANS Research Consortium Treatment Guidelines](#) published in a 2017 Special Issue of the Journal of Child and Adolescent Psychopharmacology. The guidelines address the use of psychiatric and behavioral interventions, the use of immunomodulatory therapies, and the treatment and prevention of infections.



# Organizations

## Long COVID

- [BIPOC Equity Agency](#) - Founded and led by Long COVID patients, specializing in equity in healthcare and research of BIPOC and other marginalized communities in the IACC space and beyond.
- [Black COVID-19 Survivors Alliance](#) - a grassroots self-help and patient advocacy alliance made up of Black and African-American SARS-CoV-2 patients, caregivers, and family members.
- [COVID-19 Longhailer Advocacy Project](#) - a grassroots, patient-led, volunteer 501(c)(3) nonprofit advancing the understanding of Long COVID and expediting assistance and solutions for Longhailers and their families through advocacy, education, research, resource development. C19LAP works across sectors and patient communities to foster collaboration and partnerships to advance public health and education initiatives, further advancing meaningful solutions and patient outcomes.
- [Long COVID Alliance](#) - a network of patient-advocates, scientists, disease experts, and drug developers who have joined together to leverage their knowledge and resources to educate policy makers and accelerate research.
- [Long Covid Campaign](#) - an organization advocating for equitable, accessible, and affordable treatment for all as well as accelerated research and expanded programs to support people living with and impacted by Long COVID
- [Long COVID Families](#) - an organization focused on accelerated pediatric research and ensuring safe and appropriate access to education and essential medical care.
- [Long COVID Justice](#) - links patient-led support groups and information sharing, groundbreaking research, grassroots community organizing and mobilization, communications, and policy analysis and advocacy for local, state, federal and international policies on the COVID-19/Long COVID pandemic.
- [Long Covid Moonshot](#) - a grassroots, patient-led collective of patients that has mobilized around the crucial need for Long Covid research funding and other issues important to the community.
- [Pandemic Patients](#) - an organization that connects people affected by COVID-19 to a network of attorneys who can provide pro bono legal assistance.

- [Patient-Led Research Collaborative](#) - patient-led group that conducts research into Long COVID and associated conditions, and advocates for policies that enable patients, particularly the most marginalized, to access care and live with dignity.

## ME/CFS

- [American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society](#): The American ME and CFS Society is a 501(c)(3) nonprofit, dedicated to serving the needs of patients and caregivers through support, advocacy, and education.
- [Bateman Horne Center](#): A nonprofit clinic and research center specializing in the diagnosis, treatment, and management of ME/CFS, fibromyalgia, and related conditions, providing comprehensive care and supporting research efforts.
- [Health Rising](#): Founder Cort Johnson's website is dedicated to providing timely, accurate information to people with chronic fatigue syndrome (ME/CFS) and fibromyalgia, as well as Long COVID.
- [IACFS/ME](#): The International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis is dedicated to the care and research of people affected by Myalgic Encephalomyelitis/Chronic Fatigue Syndrome and related disorders. Its website includes numerous resources for [clinicians](#), including information on diagnosis, disability documentation, and treatment/management.
- [Massachusetts ME/CFS & FM Association](#): MassME exists to meet the needs of patients with ME/CFS, their families and loved ones. The organization provides patient support such as physician referral, as well as information, advocacy, and support groups.
- [#MEAction](#): A global, grassroots network of patients, advocates, and allies working to raise awareness, advocate for better research and healthcare policies, improve medical education, and empower the ME/CFS community to fight for their rights and well-being. #MEAction hosts the [#ME-Pedia](#), which is a crowd-sourced knowledge base on the history, science, and medicine of ME/CFS and related illnesses. It also hosts several [support groups](#) for people with ME/CFS and for ME/CFS caregivers.
- [Minnesota ME/CFS Alliance](#): The Minnesota ME/CFS Alliance is dedicated to serving Myalgic Encephalomyelitis/Chronic Fatigue Syndrome patient and caregiver needs through support, advocacy, and generating enhanced medical care options.
- [Open Medicine Foundation \(OMF\)](#): A leading research organization focused on accelerating the discovery of effective treatments and a cure for ME/CFS and related chronic complex diseases through collaborative, multidisciplinary research.

- [Solve ME/CFS Initiative \(Solve\)](#): A nonprofit organization dedicated to funding research, advocating for patients, and providing education to improve the diagnosis, treatment, and understanding of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Long COVID, and other IACCI's.
- [Simmaron Research](#) - Driving treatment discovery for ME/CFS and Long-Covid
- [US ME/CFS Clinician Coalition](#) - a group of American ME/CFS expert clinicians who have collectively spent hundreds of years treating many thousands of ME/CFS patients

## POTS/Dysautonomia

- [Dysautonomia International](#): The leading nonprofit that funds research, educates medical professionals, and empowers patients with comprehensive information on POTS and other forms of dysautonomia, including diagnosis, treatment, and patient resources.
- [POTS UK](#): A UK-based charity offering information, support, and resources specifically for UK POTS patients.
- [POTS Facebook group](#) - a international patient-led support group for people diagnosed with POTS.
- [Stanford Health Care - POTS Overview](#): Offers a detailed overview of POTS, including symptoms, causes, and treatment options.
- [Johns Hopkins Medicine - POTS Overview](#): Detailed information about POTS
- [POTS General Information Brochure by Dr. Peter Rowe](#): An overview of orthostatic intolerance and its treatment

## Persistent Lyme Disease

- [Bay Area Lyme Foundation](#): A national, 501(c)(3) nonprofit organization based in Silicon Valley. They collaborate with world-class scientists and institutions to accelerate medical breakthroughs for Lyme and tick-borne diseases. The Foundation also hosts the [Lyme Disease Biobank](#).
- [Center for Lyme Action](#): A 501(c)(4) organization dedicated to growing federal funding for Lyme disease in an effort to find a cure — especially for Lyme patients with persistent, debilitating symptoms.

- [LymeDisease.org](https://www.lymedisease.org): Works to educate the patient community, the public, researchers and legislators. . They function as a hub for Lyme-related news, via its website, email newsletters, an online journal, and social media. They represent patients with policy makers and operate the MyLymeData patient registry, which has resulted in 8 peer-reviewed journal articles.
- [Partnership for Tick-Borne Diseases Education](https://www.tickborne.org): Provides online and in-person educational content and materials on tick-borne diseases that can be acquired in the United States.

## PANS/PANDAS

- [ASPIRE](https://www.aspirefoundation.org): Works to improve the lives of children and families impacted by PANS and PANDAS by closing the gap between symptom onset and access to treatment and support.
- [LOOK Foundation](https://www.lookfoundation.org): Supports children and young adults impacted by infection triggered neuroinflammatory disorders PANS and PANDAS through personal support, community-wide education, professional training, advocacy, and grants.
- [National Alliance for PANS/PANDAS Action \(NAPPA\)](https://www.nappa.org): A steering committee assembled to lead federal PANS and PANDAS legislative efforts.
- [Neuroimmune Foundation](https://www.neuroimmune.org): Dedicated to improving outcomes for individuals with PANS and PANDAS, as well as infectious, post-infectious, and autoimmune encephalitis through the sponsorship of high quality medical education, fundraising for research, and directly supporting families.
- [The Alex Manfull Fund](https://www.alexmanfullfund.org): Supports research, education, and treatment of PANS/PANDAS with an emphasis on adolescents and young adults.
- [The Louisa Adelynn Johnson Fund for Complex Disease](https://www.louisaadelynnjohnsonfund.org): Provides funding to researchers investigating PANS, PANDAS and comorbid conditions, engages with policymakers and other key stakeholders on behalf of the community, and provides provider recommendations and resources for those dealing with severe PANS and comorbid conditions.

## Sjögren's Disease

- [Sjögren's Foundation](https://www.sjogrens.org): A national nonprofit focused on conquering Sjögren's disease, focused on research, education, and awareness of this disease.

## Mast Cell Activation Syndrome

- [Mast Cell Action](#): A UK-based charity supporting people affected by Mast Cell Disease.
- [Super T's Mast Cell Foundation](#): Works to increase awareness of MCAS through resources, education, and support for the mast cell diseases community, while also providing financial assistance to patients.
- [The Mast Cell Disease Society](#): Dedicated to providing multi-faceted support to patients, families, and medical professionals and to leading the advancement of knowledge and research in mast cell diseases through education, advocacy, and collaboration.

## IACC Overall

- [The Sick Times](#): An independent news site reporting on Long COVID, COVID-19, and infection-associated illnesses.
- [Caregiver Wisdom](#): An online venture supporting caregivers who take care of loved ones with chronic debilitating illnesses.
- [Invisible International](#): An online resource library and educational initiative focused on vector-borne and environmental illness.
- [Infection-Associated Chronic Conditions Initiative](#): The IACC Initiative was established to address the urgent and growing issue of infection-associated chronic conditions. This initiative aims to unify research, patient advocacy, clinical care, and policy under one collaborative effort to better understand the root causes of IACCs and to push for effective treatments, cures, and systemic change within healthcare with a focus on ensuring that healthcare systems, researchers, and policymakers recognize the interconnectedness of these conditions and work toward solutions that will benefit the millions of individuals affected.
- [Caregiver Action Network \(CAN\)](#): The nation's leading family caregiver organization with resources, education, and peer support.
- [PolyBio Research Foundation](#): A 501(c)(3) transforming how complex chronic conditions like Long COVID, ME/CFS & Persistent Lyme Disease are studied, diagnosed, and treated.



# Acknowledgments

We are grateful to the CDC Foundation for their support of the Infection-Associated Chronic Conditions Initiative and to Commonality for their collaboration on this project. We are also so grateful to the valued reviewers of this guide for their time and expertise and to all of the workshop participants who provided the resources in this guide.

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- Ability 1st Utah
- Bay Area Lyme Foundation
- BIPOC Equity Agency
- Caregiver Wisdom
- Center for Lyme Action
- COVID-19 Longhailer Advocacy Project
- Dysautonomia International
- HHV-6 Foundation
- The Louisa Adelynn Johnson Fund for Complex Disease
- Lyme Disease Biobank
- LymeDisease.org
- Massachusetts ME/CFS & FM Association
- #MEAction
- Minnesota ME/CFS Alliance
- National Academies of Sciences, Engineering, and Medicine



- National Multiple Sclerosis Society
- The National Alliance for PANS/PANDAS Action (NAPPA)
- Neuroimmune Foundation
- NMUNDA
- Open Medicine Foundation
- Partnership for Tick-Borne Diseases Education
- Patient-Led Research Collaborative
- Simmaron Research
- Sjogren's Advocate
- Sjogren's Foundation
- Solve M.E.
- Steven & Alexandra Cohen Foundation
- Super T's Mast Cell Foundation

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