



Solve M.E.

Policy Advocacy Statement

This Solve ME/CFS Initiative policy statement will drive the organization's efforts to create significant change and improvement for patients. This organization's actions are dependent on resources and board approval to execute an appropriate implementation plan.

Whereas ME/CFS, also known as Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS), is a complex and debilitating post-viral chronic disease with a serious impact on one's quality of life and can be caused by SARS-CoV-2 infection,

Whereas Long Covid, also known as Post Acute Sequelae of COVID-19 (PASC), is a collection of lingering symptoms following SARS-CoV-2 infection,

Whereas the most frequent prolonged Long Covid symptoms- crippling fatigue, post-exertional malaise and cognitive dysfunction- mirror those of ME/CFS and *nearly half* of PASC patients have been found to meet the criteria for ME/CFS,

Whereas "Post-viral" or "Post-infectious" diseases and syndromes are generally precipitated by an acute infection, like COVID-19, and can impact patients regardless of the severity of the initial illness,

Whereas ME/CFS devastates the lives of an estimated 20 million patients worldwide and costs the United States economy an estimated \$51 billion annually,

Whereas ME/CFS patients have the lowest median quality of life scores of any disease tested, including lung cancer, rheumatoid arthritis, and brain stroke,

Whereas ME/CFS patients have experienced over 35 years of neglect and inaction from the federal government, private research, and medical sectors with grossly inadequate funding levels for research, patient care and support,

Whereas the low number and size of request for applications (RFAs) published and funded by the National Institutes of Health (NIH) regarding ME/CFS is insufficient to attract researchers who have historically avoided the field because of a lack of funding,

Whereas intense stigma and misrepresentation regarding ME/CFS exists in the medical community and general population resulting in the discrimination, dismissal, and harm to post-infection disease patients,

It is the Solve ME/CFS Initiative (Solve M.E.) advocacy policy to support federal, state, local, private, and public initiatives that provide desperately needed funding, support, awareness, and education in the areas of ME/CFS, Long Covid, and post-infection research, diagnosis, treatment, and patient care to 1) make post-infection diseases medically understood, diagnosable, and treatable and 2) to support efforts to raise awareness and improve understanding of ME/CFS, Long Covid, and post-infection diseases in the general public.

Solve M.E. advocates for ME/CFS, Long Covid, and post-infection diseases as immediate priorities for government action and scientific research and supports a coordinated, intensive, cross-sector effort to unravel the mysteries of these diseases and improve the lives of patients. Solve M.E. envisions four key areas of progress towards this goal.

1) Expand and Accelerate Research Investment

- Solve M.E. calls upon government, academia, the pharmaceutical industry, and other private entities to increase funding for research efforts commensurate with the burden of the disease to better understand the pathobiology and epidemiology of ME/CFS, Long Covid, and post-infection diseases, to identify biomarkers, to conduct clinical trials, develop, FDA approved treatments, and establish robust prevention strategies
- Solve M.E. calls for an investment in the ecosystem of academic researchers and pharmaceutical companies and calls upon the NIH to immediately prioritize and fund a substantial increase in the size and number RFAs for ME/CFS in addition to stronger financial and strategic commitment to investigator-initiated research regarding ME/CFS, Long Covid, and post-infection diseases.
- Solve M.E. calls for increased research coordination, interdisciplinary collaboration, and investment by all members of the research community and expanded opportunities to bring new researchers, clinicians, and scientists into the field of post-infection disease to accelerate progress and improve the quality of clinical care for patients.

2) Expedite Government Response to the ME/CFS and Long Covid Public Health Crises

- Solve M.E. calls for immediate government acknowledgement of the public health crises that Long Covid and ME/CFS present and for the urgent prioritization and effective action to combat these conditions.
- Solve M.E. supports government investments, initiatives, policies, public/private partnerships, and programs that will improve the lives and ease the suffering of millions of ME/CFS, Long Covid, and post-infection patients.
- Solve M.E. also calls for governments to effectively engage the stakeholders of the ME/CFS, Long Covid, and post-infection communities in planning and executing policies and programs.

3) Increase the Quality and Accessibility of Clinical Care and Patient Support

- Solve M.E. supports programs (such as centers of excellence) and policies by the government, the medical community, and other entities that will dramatically increase the availability of knowledgeable post-infection disease experts and care specialists and improves the quality, accessibility, and affordability of clinical care and patient support for patients.
- Solve M.E. calls for the development and aggressive distribution of medically accurate and expert-reviewed education materials and curriculum by governmental, academic, medical associations, other institutions, and other advocacy groups for the purpose of improving the understanding and outcomes, providing patient and caretaker support, and combating the stigma of ME/CFS, Long Covid, and post-infection diseases.
- Solve M.E. supports programs that will improve cross clinician collaboration in clinical care

and research, providing an enhanced medical infrastructure to exploit emerging research, drive dramatic improvement in clinical standards of practice, and ensure clinicians across the United States are informed of the latest research findings and diagnostic and treatment protocols.

4) Raise awareness and Improve Understanding of ME/CFS in the General Public

- Solve M.E. calls for dramatically expanded efforts to inform government agencies, employers, schools, and the public that ME/CFS and Long Covid are disabling conditions entitled to all governmental protections and benefits available to disabled persons under federal, state, and local laws and is specifically covered by the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and all other civil rights laws protecting disabled persons.
- Solve M.E. calls for accurate information about ME/CFS, Long Covid, and post-infection diseases to be effectively communicated through multiple methods (e.g. CDC, NIH, SSA, and Patient support and advocacy groups) to combat stigma, change the disease narrative, and foster positive interactions with clinicians, employers, potential donors, and government support agencies.