

Contact: Meagan Roderique
Program Manager, Long COVID Alliance
longcovidalliance@solvecfs.org



Solve M.E.



LONGHAULER
ADVOCACY
PROJECT



PATIENT-LED
RESEARCH
COLLABORATIVE

DYSAUTONOMIA INTERNATIONAL



FOR IMMEDIATE RELEASE

Long COVID Alliance Announces Initiative to Strengthen Partnerships Amongst Diverse Disease Communities to Address Infection-Associated Chronic Conditions.

New project will identify common needs and actionable next steps for the infection-associated chronic conditions community.

LOS ANGELES, CA –Today, [Long COVID Alliance](#) proudly announced it will begin establishing a new Infection Associated Chronic Conditions Patient Advocacy Coalition (IACC PAC) using \$77,000 in grant funding through the [CDC Foundation's Infection-Associated Chronic Conditions Understanding and Engagement \(ICUE\) program](#). The project will bring together diverse disease groups and patient organizations to promote collaboration to address those challenges faced by people living with Long COVID and associated conditions, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), postural orthostatic tachycardia syndrome (POTS) and other forms of dysautonomia, mast-cell activation syndrome (MCAS), Ehlers-Danlos syndrome (EDS), Lyme disease and other post-viral or infection-associated conditions.

The global COVID-19 pandemic has created unprecedented awareness of the long-term health implications of viral infection: [Sixty-five million people worldwide](#) are estimated to have Long COVID, many suffering potentially-disabling effects for months or years following initial infection of COVID-19. Cases of Long COVID-associated conditions or other post-infectious conditions, like ME/CFS and dysautonomia, also continue to increase. This uptick in infection-associated chronic conditions severely impacts patient quality of life, stresses healthcare systems, and depletes the labor force, resulting in an estimated economic burden of [nearly \\$4 trillion](#) in the United States. These post-infectious conditions stand to devastate exponentially more patients. Their prevalence is likely much greater than currently available estimates, as they are difficult to identify and can be triggered even when severity of infection is low, or treatments are available.

Through the ICUE Program, the [CDC Foundation](#) is providing more than \$150,000 to two organizations, Long COVID Alliance through [Solve ME/CFS Initiative \(Solve M.E.\)](#) and social impact firm [Commonality, Inc.](#), to help patients with Long COVID and

infection-associated chronic conditions. The effort seeks to strengthen cross-sector partnerships among disease groups, to identify common objectives and actionable steps for this community.

As we work to establish the IACC PAC, Long COVID Alliance will draw upon its experience as a trusted patient-advocate expert. Alliance co-founders Solve M.E. and COVID-19 Longhailer Advocacy Project and longtime partners and executive committee members Patient-Led Research Collaborative and Dysautonomia International will contribute their expertise and lived-experience as key collaborators. COVID-19 Longhailer Advocacy Project founder Karyn Bishof, a first-wave Long COVID patient, said of the initiative: “The COVID-19 pandemic has taught us that cross-community advocacy and leadership is incredibly powerful and too often overlooked at this level. We are very excited to meet and learn from so many other great leaders within the IACC community. I believe together we will pave a path forward.” By leveraging these and other disease groups, like the [over 180 international IACC organizations currently members](#) of the Long COVID Alliance network, the emergent coalition aims to improve patient outcomes, inform clinical education and research, and increase public engagement.

“We are proud to support patient advocacy organizations as they come together to take on this growing health crisis,” said Catherine Zilber, Vice President for infectious Disease Programs at the CDC Foundation. “By pooling their expertise and experience, they will devise new strategies to raise awareness and address the needs of those living with the debilitating and ongoing effects of Long Covid and similar illnesses.”

Together with CDC Foundation, Long COVID Alliance can further amplify the lived-experience of people with infection-associated chronic conditions, elevating their perspectives to guide federal, scientific, and clinical decision making.

“It has become clear that collaboration among various stakeholders – patient organizations, healthcare practitioners, researchers, and government agencies – is necessary to improve care and outcomes across these broader patient populations,” said Oved Amitay, President and CEO of Solve M.E. “We are very excited that the CDC Foundation has selected the Long COVID Alliance to lay the foundation for a broader coalition of organizations to make progress in addressing the needs of the millions living with chronic infection-associated diseases.”

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The Long COVID Alliance is a global network of patient-advocates, clinicians, disease experts, and drug developers leveraging their collective knowledge and resources to educate policy makers, accelerate research, and transform the broader understanding of post-viral illness.

Solve ME/CFS Initiative serves as a catalyst for critical research into diagnostics, treatments, and cures for myalgic encephalomyelitis/chronic fatigue syndrome, Long COVID, and other post-infectious diseases. Its work with the scientific, medical, and pharmaceutical communities, advocacy with government agencies, and alliances with patient groups lays the foundation for breakthroughs to improve the lives of millions with various “long haul” diseases.

COVID-19 Longhailer Advocacy Project, through community outreach, is able to synthesize information and generate educational resources to bridge knowledge gaps between the patient/caregiver community and healthcare providers, researchers, and government agencies.

Patient-Led Research Collaborative is a group of people with Long COVID and other IACCs who has extensive experience in facilitating and conducting patient-led IACC qualitative and quantitative research for application to federal policy recommendations.

Dysautonomia International has over a decade of experience fostering collaborations amongst patients, researchers, fellow nonprofits, and government agencies to advance patient-centric research on autonomic nervous system disorders and their comorbidities, many of which are post-infectious in nature.

Join the IACC-PAC mailing list

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