



Solve M.E.



LONGHAULER  
ADVOCACY  
PROJECT



PATIENT-LED  
RESEARCH  
COLLABORATIVE



## FOR IMMEDIATE RELEASE

For more information please email [contact@iaccpac.org](mailto:contact@iaccpac.org)

### Webinar Announcement: Unveiling Crucial Community Insights on Infection-Associated Chronic Conditions

WASHINGTON, DC –The [Infection Associated Chronic Conditions Understanding and Engagement \(ICUE\) Project](#) announces an upcoming webinar that promises to shed light on the pressing needs and priorities of the infection associated chronic conditions (IACC) community. We invite you to join us as we unveil the key findings from a report summarizing engagement sessions with participating organizations over the past year.

Date: Tuesday October 24, 2023  
Time: 9:00am PT / 12:00pm ET  
Location: Online  
Webinar Link: <https://bit.ly/IACCPACWebinar>

This webinar will provide a comprehensive overview of the findings of a new report on the top priorities, essential needs, and future goals related to infection associated chronic conditions. The report's findings were gathered through a series of workshops that brought together diverse disease groups and patient organizations. Participants in these focus groups included people living with Long COVID, 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.

Key topics to be covered during the webinar include:

- Community Voices: Hear directly from those living with infection-associated chronic conditions, sharing their experiences and perspectives.
- Priority Areas: Discover the most urgent shared needs and concerns identified by our community.
- Future Goals: Learn about our collective vision for advancing research, awareness, and support for IACCs.
- Action Steps: Find out how you can get involved and make a difference in the lives of those affected by IACCs through our newly forming Infection Associated Chronic Conditions Patient Advocacy Coalition.

We encourage all stakeholders, including healthcare professionals, researchers, patients, caregivers, and advocates, to attend this informative session. Together, we can build a stronger, more resilient IACC community and work toward a healthier future.

Join us on Tuesday October 24 at 9am PT / 12pm ET by clicking the following link to register: <https://bit.ly/IACCPACWebinar>

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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. Contact: [www.longcovidalliance.org](http://www.longcovidalliance.org)

**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. Contact: Emily Taylor, VP of Advocacy and Engagement, [etaylor@solvecfs.org](mailto:etaylor@solvecfs.org)

**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. Contact: Karyn Bishof, Founder, [admin@longhaileradvocacy.org](mailto:admin@longhaileradvocacy.org)

**Patient-Led Research Collaborative** is a group of people with Long COVID and other IACCs that has extensive experience in facilitating and conducting patient-led IACC qualitative and quantitative research for application to federal policy recommendations. Contact: Lisa McCorkell, Co-founder, [lisa@patientledresearch.com](mailto:lisa@patientledresearch.com)

**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. Contact: Lauren Stiles, President and Founder, [lstyles@dysautonomiainternational.org](mailto:lstyles@dysautonomiainternational.org)

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