



FOR IMMEDIATE RELEASE: February 25, 2021

LONG COVID ADVOCATES JOIN TOGETHER TO FORM ALLIANCE TO MAKE POLICY RECOMMENDATIONS, SECURE RESEARCH FUNDING, AND TRANSFORM UNDERSTANDING OF POST-VIRAL ILLNESSES

Alliance embraces values of collaboration, strong science, patient-centered engagement and inclusion, and applying multidisciplinary approaches to advance comprehensive solutions

LOS ANGELES, Calif. (February 25, 2021) – Today, leaders of 50 organizations and patient groups announced the formation of the Long COVID Alliance. The Alliance includes a network of patient-advocates, scientists, public health and disease experts, and drug developers who have joined together to leverage their collective knowledge and resources to educate policymakers and accelerate research that will address the challenges faced by ‘COVID long haulers’ and related post-viral illnesses.

Their goal is to transform the current understanding of Long COVID and related post-infectious illnesses such as: myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), postural orthostatic tachycardia syndrome (POTS), other forms of dysautonomia, Ehlers-Danlos syndrome (EDS), hypermobility spectrum disorder (HSD) and mast cell activation syndrome (MCAS), autoimmune diseases and other related illnesses.

“The Long COVID Alliance is a critical collaboration based on the current reality that doctors and researchers are reporting that millions of COVID-19 patients continue to experience chronic and often debilitating post-viral symptoms. This state of extended illness is presently labeled Long COVID,” said Oved Amitay, Solve M.E. President and Chief Executive Officer, one of the three Alliance founders. “Even though tests might reveal that no virus remains in the body, COVID-19 ‘long haulers’ continue to struggle, often alone. Our community brings past experiences that are relevant to the current crisis.”

In 2020, this same group came together to successfully call for urgent government investments for Long COVID, and \$1.15 billion for long-term COVID-19 research at the National Institutes of Health shortly followed. The effort laid the foundation for the new Long COVID Alliance, which will prioritize:

- Health equity and confronting systemic bias and racism in the Long COVID response;
- Facilitating data harmonization (i.e., combine data from different sources and provide users with a comparable view of data from different studies);
- Leveraging each member’s expertise to make recommendations to the National Institutes of Health (NIH) regarding the implementation of the recent \$1.15B allocated by Congress for Long-COVID research and clinical trials;
- Deploying financial resources from the NIH to create a public-private post-viral

- research infrastructure and translate research results into treatments and cures for millions;
- Providing expert guidance and resources to media and policymakers;
- Expanding public-private partnerships;

- Leveraging existing post-viral disease knowledge and infrastructure;
- Connecting policymakers with patients and scientists; and
- Ensuring meaningful patient participation.

"So many patients have bonded together as the healthcare community has not understood why some patients are asymptomatic and others are suffering moderate to debilitating issues a year later," said Hunter Howard, chairman of the Global Pandemic Coalition, a founder of the Alliance. "As one of the first infected in Texas, and a healthcare executive, I immediately noticed Doctor friends did not understand my lingering symptoms or the novel coronavirus. We started the Global Pandemic Coalition to bring together private companies to support the public sector pandemic initiatives. If the vaccines continue to drive down mortalities, nothing may be more important now than coming together to drive understanding and fund research for the COVID survivors."

To accompany the Long COVID Alliance's launch, the initial partners from 2020 have drafted key recommendations and guidance for the National Institutes of Health (NIH), which can be found by visiting <https://longcovidalliance.org/wp-content/uploads/2021/02/NIH-Long-COVID-Alliance-NIH-Recommendations-Letter-Final-with-signers.pdf>

Current Long COVID Alliance partners include:

- Action for M.E.
- American Medical Women's Association (AMWA)
- Bateman Horne Center
- Body Politic
- Covid-19 Longhailer Advocacy Project
- Dysautonomia International
- ENIGMA COVID-19 Working Group
- Florida Society of Neurology
- HADASSAH
- Health Rising
- Healthy Women
- Institute for Neuro-Immune Medicine (INIM)
- Kantor Neurology, LLC
- Long COVID Physio
- Massachusetts ME/CFS & FM
- #MEACTION
- ME International
- Medical Partnership 4 MS+
- Minnesota ME/CFS Alliance
- National Association for Nurse Practitioners in Women's Health
- National Health Council
- National Organization for Women (NOW)
- Nurse Practitioners in Women's Health (NPWH)
- Open Medicine Foundation
- PandoraORG
- PolyBio Research Foundation
- Pulmonary Wellness Foundation
- Sex and Gender Health Collaboration
- Simmaron Research
- Solve M.E.
- The American Dysautonomia Institute (ADI)
- The Mast Cell Disease Society, Inc.
- The SHANE Foundation
- Utah COVID-19 Long Hailer
- Whittemore Peterson Institute
- YOU + ME Registry (Solve M.E.)

“Many long haulers are now approaching a full year post-infection. We have lost jobs, lost significant quality of life, and lost pieces of who we once were. It's been a long road with an uncertain future and we've finally found hope,” said Karyn Bishof, Founder of the COVID-19 Longhailer Advocacy Project and of the Long COVID Alliance. “With the help of our partners, we will ensure that Long haulers are not left out in the cold. The Long COVID Alliance will fight with us for awareness, answers, and ensuring that patient voices are included at every step of solving this ‘second wave’ Long COVID health crisis.”

To learn more, join the Long COVID Alliance, or become a signatory to the NIH letter, visit:
www.longcovidalliance.org.

###

About Solve M.E.

The Solve ME/CFS Initiative (Solve M.E.) is the leading, national non-profit organization solely dedicated to solving ME/CFS. We are committed to making ME/CFS understood, diagnosable, and treatable. Solve M.E. is the largest U.S. provider of private competitive research funding exclusively for ME/CFS working to accelerate the discovery of safe and effective treatments; we strive for an aggressive expansion of funding for research that will lead to a cure, and seek to engage the entire ME/CFS community.

Media Inquiries Only

Contact Emily Taylor

Director of Advocacy and Communications

714-296-1661

ETaylor@solvecfs.org

ALL OTHER INQUIRIES, PLEASE CALL THE SOLVE ME/CFS INITIATIVE AT: 704-364-0016 OR EMAIL
Communications@SolveCFS.org