

FOR IMMEDIATE RELEASE - May 12, 2022

WORLDWIDE LAUNCH OF LONG HAUL VOICES: LIVING WITH LONG COVID AND ME/CFS RELEASED TODAY IN HONOR OF WORLD ME DAY 2022

New and timely series will amplify the experiences of individuals with Long Covid and myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS) to improve care and increase understanding

LOS ANGELES, CA - Today, in honor of <u>World ME Day</u>, Solve M.E. released the first episode of a three-part series: <u>Long Haul Voices</u>: <u>Living with Long Covid and ME/CFS</u>. <u>Long Haul Voices</u> seeks to amplify globally the experiences of individuals with Long Covid and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), the experts devoted to improving their care, and the challenges surrounding these largely invisible, poorly-understood diseases that affect a rapidly growing population. Access the series <u>here</u>.

"Long Haul Voices highlights how people with ME/CFS and Long Covid can share their journey to improve the management and understanding of these diseases across the world," said Oved Amitay, president and CEO, Solve M.E. "By focusing on our community's stories throughout this series, Solve M.E. honors the core theme of this year's World ME Day: 'What Can the World #LearnFromME?'"

"There is nothing more powerful than sharing authentic stories of individuals who are suffering from these often-debilitating diseases," added Amitay. We must continue to shine a light on the difficulties of living with complex, chronic conditions that have no FDA-approved treatments or cures."

The mini-series, created in partnership with Unfixed Media Productions, is directed by award-winning filmmaker Kimberly Warner and edited by Emmy award winner Michael Wolcott, both of whom live with chronic disease. Each featured member of the *Long Haul Voices* cast shares a connection to ME/CFS and/or Long Covid. Cast members include:

- Cynthia Adinig Patient Advocate & Equity Policy Advisor (Long Covid, POTS, MCAS)
- Paul Burnside Retired Banker & Organist (Long Covid, Vestibular Neuritis)
- Dr. Anthony Komaroff Professor of Medicine Harvard Medical School
- Soh-Yeon Lee Senior Program Analyst (ME/CFS)
- Lili Lim Actor, Comedian (ME/CFS)
- Dr. Nina Muirhead Dermatology Surgeon (ME/CFS)
- Dr. Amy Proal Microbiologist & Viral Science Advisor
- Bilal Qizibash CEO (Long Covid, Autism)
- Sarah Ramey Author/Musician (ME/CFS, CRPS, POTS)
- Emily Taylor VP Advocacy & Engagement at Solve M.E. (ME/CFS Patient Caregiver)

Complete episode guide here.

Before the pandemic, experts estimated there were up to 1 to 2.5 million cases of ME/CFS. Now, after two years of COVID-19, those same experts <u>estimate</u> between 5 and 9 million cases of ME/CFS. And a similar explosion of cases is happening with other post-viral conditions. Long Covid is estimated to affect 22 million U.S. adults – close to 7% of the population. Last month Solve M.E. <u>released a whitepaper</u> that provided a startling, in-depth look at the prevalence of Long Covid in the United States.

World ME Day falls in the middle of Solve M.E. 's annual <u>Advocacy Month</u>, a nationwide advocacy effort empowering people with ME/CFS, Long Covid, and other chronic illnesses; scientists; clinicians, and caregivers to share their unique stories with Congress.

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About Solve ME/CFS Initiative (Solve M.E.)

The Solve ME/CFS Initiative (Solve M.E.) is a non-profit organization that serves as a catalyst for critical research into diagnostics, treatments, and cures for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), Long Covid, and other post-infection diseases. Our work with the scientific, medical, and pharmaceutical communities, advocacy with government agencies, and alliances with patient groups around the world are laying the foundation for breakthroughs that can improve the lives of millions who suffer from various "long haul" diseases.

About Unfixed Media

Unfixed is a media production company that shares and elevates stories of humans living with chronic illness and disability. The **Unfixed** portfolio of projects demonstrates that living well is not about eradicating our wounds and weaknesses but understanding how they complete our identities and equip us to help others. Current productions include the Unfixed docu-series, Unfixed Focus, Life Rebalanced Chronicles, MS Confidential, Long Haul Voices, the Unfixed podcast, and a feature documentary film Why We Matter.

To learn more about the Solve ME/CFS Initiative, visit www.solvmeecfs.org. Follow Solve M.E. on <u>Facebook</u>, <u>Instagram</u>, or <u>Twitter</u>.

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