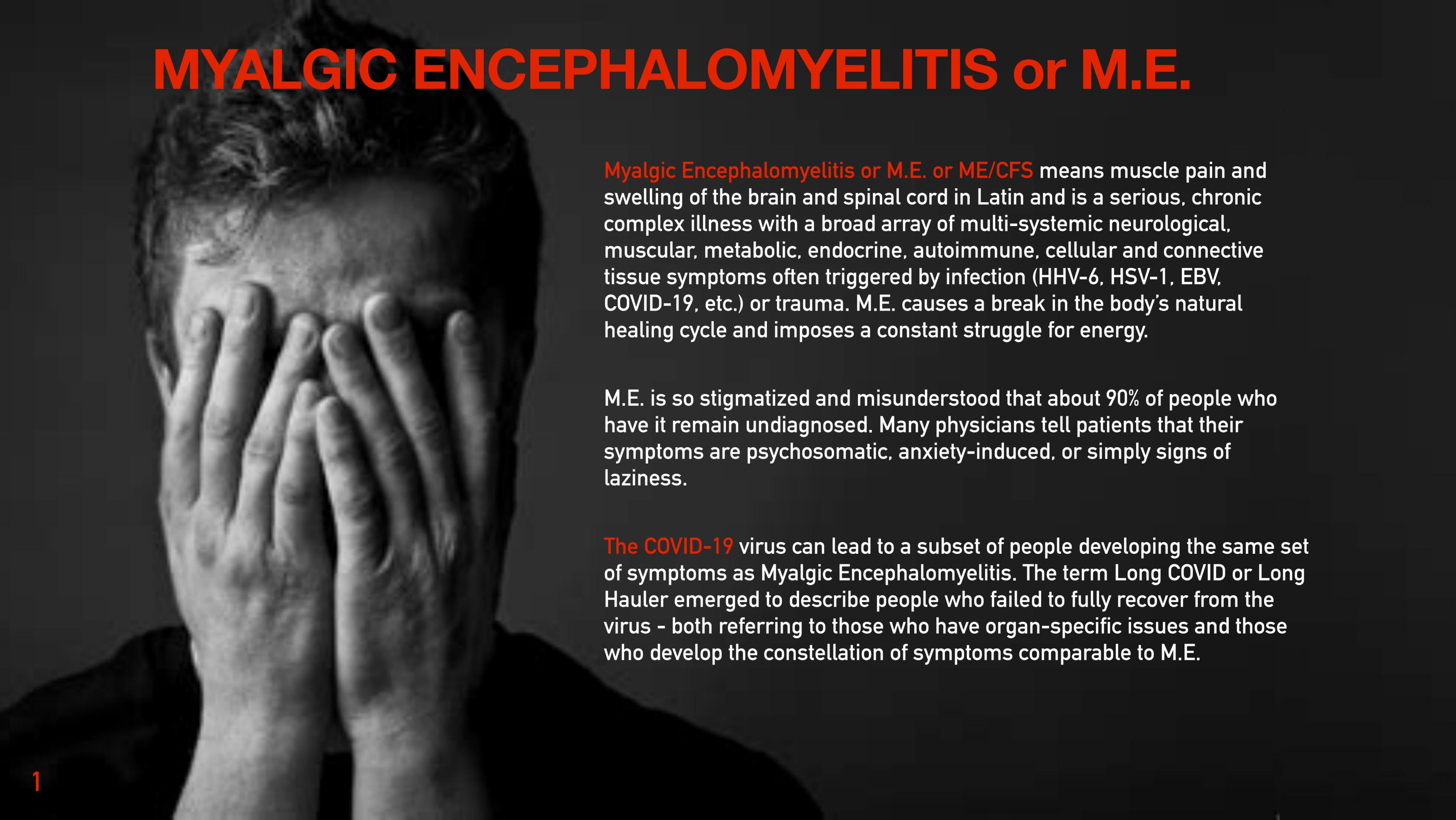


A person is seen from behind, walking away on a paved path. They are wearing a black beret and a green and white patterned coat. The path is bordered by a body of water on the left and a row of trees on the right. The scene is misty or foggy, and the overall atmosphere is quiet and contemplative.

+ DO YOU HAVE M.E.?  
awareness campaign

# MYALGIC ENCEPHALOMYELITIS or M.E.



**Myalgic Encephalomyelitis or M.E. or ME/CFS** means muscle pain and swelling of the brain and spinal cord in Latin and is a serious, chronic complex illness with a broad array of multi-systemic neurological, muscular, metabolic, endocrine, autoimmune, cellular and connective tissue symptoms often triggered by infection (HHV-6, HSV-1, EBV, COVID-19, etc.) or trauma. M.E. causes a break in the body's natural healing cycle and imposes a constant struggle for energy.

M.E. is so stigmatized and misunderstood that about 90% of people who have it remain undiagnosed. Many physicians tell patients that their symptoms are psychosomatic, anxiety-induced, or simply signs of laziness.

**The COVID-19** virus can lead to a subset of people developing the same set of symptoms as Myalgic Encephalomyelitis. The term Long COVID or Long Hauler emerged to describe people who failed to fully recover from the virus - both referring to those who have organ-specific issues and those who develop the constellation of symptoms comparable to M.E.

# AWARENESS CHALLENGES

There was an awareness crisis around post-viral disease before COVID-19, now it is an even more **urgent humanitarian crisis**. In order to care for people and conduct proper research, we need a public awareness campaign.

- 90% of people with M.E. are undiagnosed.
- There is no FDA approved diagnostic test or treatment.
- On average, it takes 5 years for a patient to receive a diagnosis.
- Clinical guidance used by medical providers in practice includes treatments that are outdated, inappropriate, and potentially harmful.
- It is estimated that there are fewer than two dozen nationally recognized M.E. specialists in the entire country.
- Less than one-third of medical schools include M.E. in their core curricula.
- Patients struggle to find doctors willing and able to care for them.
- There is a higher rate of suicide in the patient population than the general public.
- There has never been a proper epidemiological study which is the cornerstone for research.



# MISSION

Partner with government, corporate, NGO and individuals on the DO YOU HAVE M.E.? Awareness Campaign to raise awareness about how to obtain a diagnosis of M.E., sign-up on a global registry, become a subject at regional research centers and more.

# OBJECTIVES

The DO YOU HAVE M.E. Awareness Campaign strives to build Public Awareness around M.E. along with ways to identify the warning signs and symptoms, in order to:

- Increase diagnosis.
- Diagnose earlier.
- Increase physician access to nation-wide informational resources.
- Increase public access to state-wide specialists.
- Encourage enrollment to in state research studies.
- Increase awareness of the related disability.
- Increase supportive workplaces.
- Decrease suicide.



# AWARENESS CAMPAIGN

The awareness campaign slogan is, “Knowing is the beginning”. For many people, the lingering dysfunction across metabolic, endocrine, autonomic and immune systems after acute viral infections, is worsened when confronting the unknown alone. As with any chronic illness, taking caring steps in the early phase can dramatically decrease symptom severity and increase the likelihood of recovery. These are two stark realities that the awareness campaign will address.

The awareness campaign is informationally bi-directional where we both provide and receive information to and from the public. On the DoYouHaveME website, visitors may discover how to obtain a diagnosis, locate clinician specialists, become study subjects at regional academic research centers, download a free long-term symptom tracking app, sign-up for a global registry and find local support groups. Importantly, this will all be done in full collaboration and partnership with other non-profits, universities, research centers, physicians, government and other public health institutions.

Sponsored by:



# CAMPAIGN OBJECTIVES

- Encourage the public to self-diagnose or find a regional clinician with expertise in diagnosis. The sooner that someone is diagnosed, the better chance they have for recovery.
- Advertise the global Solve M.E. registry where people may register as having the illness and track symptoms. This can become a part of a larger epidemiological study.
- Provide informational resources to the public, like what regional research centers are recruiting subjects for studies.
- Inform the public that Post-Exertional Malaise (PEM) should not be pushed past physically. That this can lead to a worsening of symptoms and even trigger M.E.
- Provide educational materials about how to cultivate a supportive organizational culture for employees with M.E. and caregivers to better navigate their illness more successfully.
- Provide a Physician starter kit of educational materials for clinicians.

A coordinated public awareness campaign for M.E. requires both broad and targeted distribution starting with a pilot program.

Distribution includes:

- Print
- Billboards
- Radio
- Social
- TV
- Promotional

# PARTNERS

These are a few of our strategic NGO partners: Open Medicine Foundation, Solve M.E. and ME Action.



Linda Tannenbaum



Oved Amitay



Laurie Jones



# REACHING DIVERSE AUDIENCE

As an Awareness Campaign around public health, it is our priority to equitably disseminate these critical messages to communities. This means placing the diversity of languages, cultures and priorities at the forefront while maintaining alignment with the core message.

The campaign will accomplish this by:

- Messaging and testing research.
- Collaborative involvement with diverse communities from development through testing and distribution.
- Develop content for each linguistic audience and thoughtfully reflect the priority perspective for each community.
- Cultivate strategic partnerships while keeping all communities in mind.
- Work with community leaders and influencers to share message with their audience.
- Distribute through variety of communication channels for all demographics.
- Address communications barriers including for the blind, deaf and disabled.

# IMPACT METRICS

Developing a chain of impact measurement strategy from the outset allows us to work in the direction of clear and unbiased objectives. To determine the success of the objectives, we have identified these metrics:



- **Visibility Metrics:** Objective measurement of how many people directly saw or heard campaign.
- **Quantitative Metrics:** Quantitative metrics include measurement of key objective markers, such as numbers of: diagnoses by pilot area medical providers, registrations on Solve ME app, sign-ups for research studies at pilot academic centers and more.
- **Open Feedback:** There are different ways to collect and assemble sets of useful feedback; setting up interviews, general surveys, open questions, and inquiries on personal experiences in relation to the project. This can be given to residents, physicians, partners and other groups involved as overall storytelling about impact and case studies.
- **Outreach Metrics:** Social media and website metrics to obtain outreach data.
- **Inclusion & Diversity Metrics:** Surveys with individual questions about power dynamics, representation, and inclusion.
- **Additional Support:** In the form of partnerships, donations and sponsorships, additional support can be an effective measure of the pilot campaign's broader impact and expansion potential. This may include potential partners like the Ad Council and expanding the campaign past the pilot program.

# CONTACT

The DO YOU HAVE M.E. Awareness Campaign is bringing together collaborators of all kinds - governmental, corporate, foundational, and individual - in a combined effort to raise public awareness.

We encourage everyone who reads this packet to get involved right away.

Chesley Heymsfield  
Executive Director  
Louisiana International Film Festival

Cell: (917) 622-8800

Email: [chesleyproducer@gmail.com](mailto:chesleyproducer@gmail.com)



**movie about M.E.**