

# LONG COVID ALLIANCE

A project from



**Solve M.E.**

# COVID-19 impacted more than 27.7 million Americans... and counting



- **The most frequent symptoms reported after six months were fatigue (77.7%), post-exertional malaise (72.2%), and cognitive dysfunction (55.4%)**

Davis, H. E., Assaf, G. S., McCorkell, L., Wei, H., Low, R. J., Re'em, Y., . . . Akrami, A. (2020, December 24). Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact. medRxiv.

- **An estimated 25-35% of people with COVID-19 experience new, post-viral symptoms after 90 days that may become permanently disabling**

Strazewski, Len. Dr. Fauci Offers 2021 Forecast on COVID-19 Vaccines, Treatments, American Medical Association, 9 Nov. 2020

- **"Over the course of one year, that [increase] would at least double the number of Americans suffering from ME/CFS...a remarkable event in the history of a chronic illness."**

-Dr. Anthony Komaroff, Harvard Medical School  
Will COVID-19 Lead to ME/CFS?, Front. Med., 13 Jan. 2021

**“We do know for absolutely certain that there is a post-COVID syndrome. Anywhere from 25% to 35%—or more—have lingering symptoms.”**

**Dr. Anthony Fauci,  
Director of the National Institute of Allergy and  
Infectious Diseases (NIAID)**



# LONG COVID ALLIANCE

- A network of patient-advocates, scientists, disease experts, and drug developers who have joined together to leverage their collective knowledge and resources to educate policy makers and accelerate research to transform our understanding of post-viral illness
- Helped secure \$1.15 billion for Long COVID research and clinical trials, with an additional \$100 million specifically used for the Rapid Acceleration of Diagnostics





# **WE MUST ENSURE THIS \$1.15 BILLION IS SPENT ON QUALITY RESEARCH THAT WILL TRANSFORM OUR UNDERSTANDING OF POST-VIRAL ILLNESSES**

## **Key Alliance Priorities**

- Ensuring meaningful patient participation
- Confronting systemic bias and racism in the Long COVID response
- Advancing health equity initiatives
- Facilitating data harmonization
- Leveraging existing post-viral disease knowledge and infrastructure
- Expediting public-private partnerships
- Creating a platform for thought leaders
- Connecting policy makers with patients and scientists
- Providing expert guidance and resources to media and policy makers

# OUR GOALS



Ensure Long COVID Research Funding at the NIH



Provide guidance to NIH about Long COVID research informed by Alliance patients, stakeholders, and experts



Leverage public and private sector resources to create post-viral research infrastructure



Ensure continued growth, equity, and sustainability of research infrastructure, beyond pandemic response



Translate research results into diagnostics, treatments, and cures for millions



Address critical needs in medical education, access, and patient outcomes



CDC

- Clinical Care Guidance
- Medical Education
- Public Awareness Campaigns
- Epidemiology Studies
- Natural History Report



AHRQ (Agency for Healthcare Research and Quality)

- Treatment Efficacy recommendation
- Disparity and Health Equity reports
- Medical Education effectiveness analysis
- Morality and comorbidity research



PCORI (Patient-Centered Outcomes Research Institute)

- Comparative Clinical Effectiveness Research
- Patient-led research
- Healthcare Delivery and Disparities Studies
- Recommendations for post-viral research infrastructure



Creation of a Long COVID Federal Advisory Committee



# Our Strategy and Approach

## Collaborative

Long COVID has highlighted many challenges in science, research, and healthcare. We can only face these challenges by working together.

## Connecting the Dots

The Alliance builds inroads among patient communities, industry, scientists, and healthcare providers from multiple fields and disciplines.

## Science Strong

The Alliance relies upon researchers and scientists from public and private sectors. Peer-reviewed, evidence based practices will be core to the Alliance's efforts.

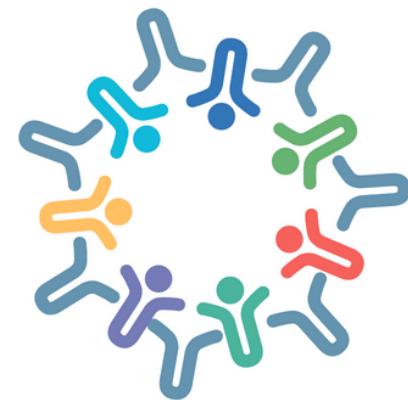
## Patient-Centered

"Nothing about us, without us." The post-viral patient voice and experience is key. The Alliance will strive to include patient-leaders at every stage of its work.

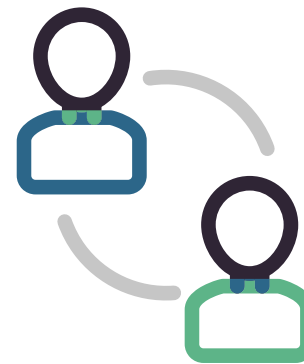
# NEXT STEPS



**Generate Research  
Recommendations**



**Build the  
Alliance**



**Advocacy  
Week and  
Congressional  
Meetings**



**Policy and  
Funding  
Solutions**



**Webinars,  
Education, and  
Media  
Opportunities**





# FOR MORE INFORMATION

Please don't hesitate to contact us

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