

Open Medicine Foundation®

HOPE  Leading Research. Delivering Hope.

Open Medicine Foundation

ANNUAL REPORT

2024



OUR VISION

Our vision is to uncover the root causes, enhance diagnostic methods, develop effective treatments, and expand access to knowledgeable clinicians to improve the lives of people suffering from ME/CFS and Long COVID.

OUR MISSION

Our mission is to support and facilitate open, collaborative research aimed at halting the impact of these debilitating conditions, with an unwavering commitment to discovering cures through relentless scientific breakthroughs.

OUR RECOGNITIONS

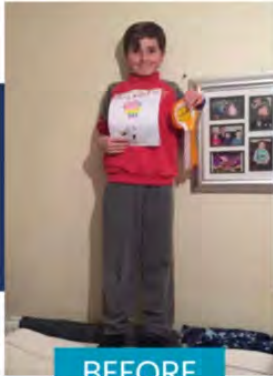


OMF COMMUNITY VOICES

“

ME/CFS robbed me of my dreams and shattered my independence, leaving me bed-bound and reliant on others for even the simplest tasks.

~Sean



BEFORE



AFTER



Me in '97, before I got sick with ME/CFS. Past 15 years, no more photos standing up.

~ Julia



“

When asked by OMF to tell our story, Lucas existed again for a little while. It helps me to keep him alive - the best I can - when he has already largely disappeared from this world. When all that is left is suffering in silence and isolation, I know that I am not alone. With OMF, I know that we are in this fight together.

ANNA



“

I was only fourteen when ME/CFS took over my life. I now join thousands of others in supporting OMF in their research to help improve the lives of millions across the world.

CHARLOTTE



“

I found salvation in the power of my mind. Today, I recognise how this illness has degraded the quality of my life, but in return, it has strengthened my love for life.

~Faten

”

FROM OMF'S PRESIDENT / CEO

As we step into 2025, I reflect on the enduring mission, purpose, and vision of Open Medicine Foundation (OMF) over the past 13 years. Our core principles guide us daily, especially when interacting with individuals affected by these debilitating diseases. Our dedication to "get people better," a phrase our late friend Ron Tompkins so beautifully articulated, remains the driving force behind all our efforts. We accomplish this by raising funds, supporting, and facilitating our projects, including open collaborative research and medical education, with integrity, purpose, and efficiency.

In 2023, we proudly introduced the OMF's StudyME Participant Registry—a global participant registry designed to connect individuals eager to partake in research studies with the researchers conducting them. The enthusiastic response from our community has been inspiring. Over 11,000 participants have signed up and we have already helped 13 researchers at top universities recruit patients to accelerate their research studies.

Our Collaborative Center Directors from Harvard, Stanford, Montreal, Uppsala and Melbourne Universities, continue to engage in monthly teleconferences to discuss research plans and share findings. However, our annual in-person meeting remains a highlight. This past year, we gathered in Cambridge, UK, after a week-long science conference, for an in-depth discussion on research findings from OMF-funded projects, network analysis from our Computational Center, and significant global research discoveries. We will meet this year again in Cambridge, UK in May. These discussions help us refine our focus for the upcoming year and identify potential targets for clinical trials.

We also delved into the laboratory tests crucial for distinguishing between responders and non-responders in our first clinical trial. The "Life Improvement Trial (LIFT)" was launched in September and is a randomized, double-blind, placebo-controlled study examining the effects of Low Dose Naltrexone (LDN) and Mestinon (pyridostigmine), both individually and in combination. This significant trial launches our first as we hope to develop a Clinical Trial Network in search of effective treatments.

Our Medical Education Resource Centre (MERC) partner, the Bateman Horne Center, has trained more than 13,000 healthcare professionals in 46 US states and in 89 countries, to understand, diagnose, and treat ME/CFS and Long COVID through excellent online programs, in-person conferences, and multiple video series.

In our ongoing commitment to advancing groundbreaking open collaborative research at our funded research centers, we have already supported 67 projects, many ongoing, and 37 publications.

In December 2024, we announced the upcoming launch of a significant biomarker discovery study for ME/CFS, aptly named BioQuest. With an impressive collection of over 1,200 blood plasma samples already collected from patients at Harvard Medical School and Uppsala University Medical Center, our objective is to analyze these samples meticulously. Our goal is to identify biomarker signatures that could pave the way for developing a diagnostic tool, ultimately enhancing our ability to diagnose ME/CFS and differentiate from other related diseases.

This past year has been remarkable, thanks to the concerted efforts of our incredible OMF staff in ensuring the smooth operation of the foundation. We are truly fortunate to have 3 exceptional OMF Foundation Boards (OMF, OMF Canada, and OMF Australia) and a 21-member scientific advisory board that governs and guides our team. Our 7 Directors are deeply committed to our mission of improving lives. We are immensely grateful for their support and enthusiasm.

As we continue to drive transformative research, foster global collaboration, and improve the lives of those affected by these debilitating diseases, I look forward to the upcoming year with optimism and profound hope for what we will achieve together.

With hope for all,



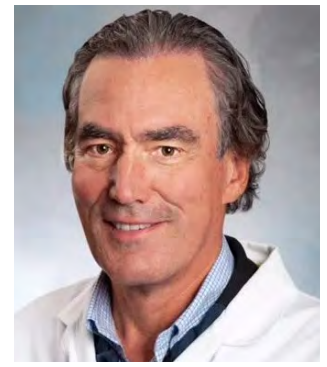
Linda Tannenbaum

CEO/President and Founder, Open Medicine Foundation



The Life Improvement Trial (LIFT) Has Officially Begun

Recruitment and screening started in August 2024, and the first participants were enrolled in September. This milestone represents a major step forward in the search for effective ME/CFS treatments.



What is the LIFT?

The LIFT is a double-blind, placebo-controlled clinical trial investigating the effect of low-dose naltrexone (LDN) and pyridostigmine (Mestinon) on functional capacity, physiological response, and the symptoms of ME/CFS. Placebo-controlled means that the study compares the effect of the drugs to placebo treatments—treatments that look like the drug, but don't have the active ingredients that the drug does. A double-blind trial means that neither the study team nor the participant knows whether the participant is taking the drug or the placebo until after the trial is complete. This helps reduce any biases involved with the data collection.

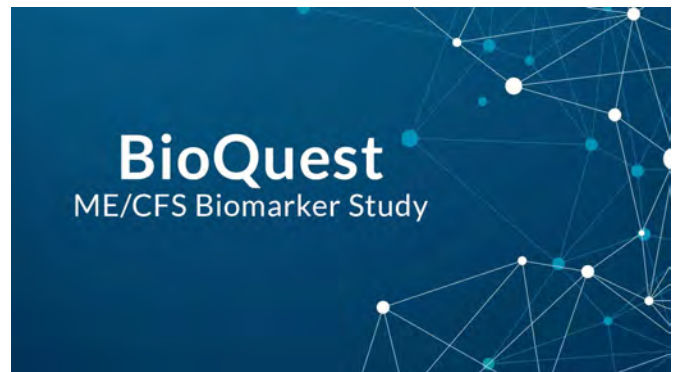
Why conduct this trial?

LDN and Mestinon have both shown promise in relieving patients' symptoms, but there isn't a lot known about why they might help people with ME/CFS or which people they might help. We know that LDN and Mestinon won't help everyone, but importantly, the LIFT is designed so the team can try to identify differences between responders and non-responders.

Ultimately, if the trial indicates that these drugs can help relieve symptoms of ME/CFS, the study will provide scientific evidence that both doctors and patients can use to support decisions about treatment. We also hope that if we can better understand what makes someone respond positively to either drug, then this information can help guide more personalized treatment plans for patients in the future. Want to learn more about the LIFT? Click [here](#).

BioQuest: A New Large-Scale ME/CFS Biomarker Study

The lack of a diagnostic test for ME/CFS is a widely acknowledged problem for both patients and healthcare providers. In December 2024, OMF proudly announced BioQuest, a groundbreaking, large-scale biomarker study for ME/CFS. Symptom-based diagnosis can not only be subjective but overlap with other conditions, ultimately delaying diagnosis and clinical management of the disease.



Therefore, the goal of BioQuest is to identify a biochemical signature for ME/CFS that can be conveniently evaluated through a blood test and would differentiate ME/CFS from other similar conditions. Open Medicine Foundation is uniquely poised to conduct this study, with access to up to 1,200 patient and contrast control samples—including multiple sclerosis, fibromyalgia, and autoimmune disorders—already collected from patients at Harvard Medical School and Uppsala University Medical Center and stored.

In this study, the team will measure over 10,000 proteins and metabolites in these blood samples. Then, using bioinformatic and artificial intelligence techniques, they will aim to identify a 5-20 protein/metabolite biomarker that is unique to ME/CFS. With the initial funding we received, the study team can proceed with finalizing the study design and obtaining the necessary approvals (the first stage of the research process) to begin testing a portion of the already collected samples.

THE END ME/CFS & Long COVID PROJECT

2024 Research Portfolio

OMF made remarkable strides in 2024, driving innovation and discovery across ME/CFS and Long COVID research. OMF supported over 35 active research projects across our collaborative research centers, each holding the potential to make a significant impact in advancing our understanding of ME/CFS and Long COVID.

OMF funded research which led to six scientific publications and three preprints in 2024, further expanding the global body of knowledge about ME/CFS and Long COVID. Click on each study to learn more.

2024 Publications

Melbourne ME/CFS Collaboration

In vitro B cell experiments explore the role of CD24, CD38, and energy metabolism in ME/CFS

Collaborative Center at Uppsala

Analysis of tryptophan metabolites and related compounds in human and murine tissue: development and validation of a quantitative and semi-quantitative method using high resolution mass spectrometry

Collaborative Center at Uppsala

Untargeted Metabolomics and Quantitative Analysis of Tryptophan Metabolites in Myalgic Encephalomyelitis Patients and Healthy Volunteers: A Comparative Study Using High-Resolution Mass Spectrometry

Collaborative Center at Stanford

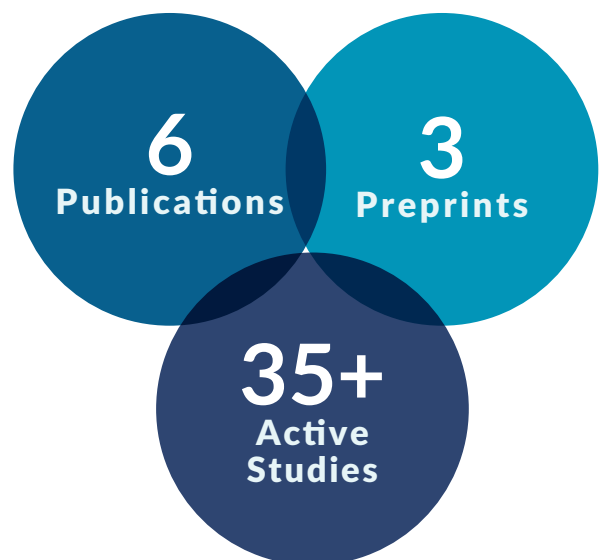
Longitudinal Cytokine and Multi-modal Health Data of an Extremely Severe ME/CFS Patient with HSD Reveals Insights into Immunopathology, and Disease Severity

Melbourne ME/CFS Collaboration

Unravelling Shared Mechanisms: Insights from Recent ME/CFS Research to Illuminate Long COVID Pathologies

Melbourne ME/CFS Collaboration

Discriminating ME/CFS and Comorbid Conditions Using NMR Metabolomics in UK Biobank



2024 Preprints

Computational Research Center

Systems Modeling Reveals Shared Metabolic Dysregulation and Novel Therapeutic Treatments in ME/CFS and Long COVID

Computational Research Center & Collaborative Center at Stanford

A Network Medicine Approach to Investigating ME/CFS Pathogenesis in Severely Ill Patients: A Pilot Study

Computational Research Center

Patient-Reported Treatment Outcomes in ME/CFS and Long COVID



Empowering Research Breakthroughs: StudyME's Collaborative Journey

In April 2023, Open Medicine Foundation proudly launched StudyME, a participant registry powered by Studypages. This innovative recruitment tool is designed to bridge the gap between individuals living with ME/CFS, Long COVID and related diseases, and the researchers dedicated to understanding and finding effective treatments for them.

Amplifying Participant Voices

The goal of StudyME is to elevate the voices of those with lived experience of these debilitating conditions. It is our firm belief that the path to groundbreaking discoveries and meaningful advancements in treatment lies in ensuring that these individuals are not only heard but are also active participants in the research that shapes their care. StudyME represents a significant step forward in making this a reality.

Accelerating Research

Recruiting participants for research studies is often one of the most time-consuming stages in the process, creating lengthy delays that can hinder progress. StudyME addresses this challenge head-on by facilitating a direct and efficient link between potential participants and research teams. This not only accelerates the pace of research but enhances its quality and relevance, promising sooner breakthroughs that can transform lives.

Demonstrating the platform's remarkable efficacy, the TreatME survey, bolstered by participants from StudyME, garnered an overwhelming response of over 1,000 participants within just 30 hours of its release. This unprecedented level of engagement underscores the community's readiness to contribute to our research efforts and highlights StudyME's pivotal role in driving forward our mission to find effective treatments.

Key Insights About StudyME

- OMF's StudyME was launched in 2023 and has registered more than 11,600 participants across 61 countries, highlighting the global urgency for research in this field.
- The demographic data – unsurprisingly - reveals a pronounced gender disparity with a notable 5:1 ratio of female to male participants, primarily aged 25 - 55.
- Preliminary insights from the registry highlight the profound impacts of these conditions on everyday life. Participants have indicated that they are interested in research on the following areas:
 - Impairment in carrying out everyday activities (87%)
 - Post-exertional malaise (86%)
 - Cognitive impairment or brain fog (81%)
 - Unrefreshing sleep (78%)
 - Exercise intolerance (77%).

OMF-Supported Medical Education Resource Center Made Significant Strides

In 2024, the OMF-supported Medical Education Resource Center (MERC) at Bateman Horne Center (BHC) experienced unprecedented growth and impact, solidifying its position as a global leader in ME/CFS and Long COVID education.

Through comprehensive, evidence-informed training programs and strong partnerships with leading health organizations, MERC has empowered healthcare professionals across the U.S. and internationally to enhance the diagnosis and treatment of these complex conditions. Our outreach has directly contributed to improved patient care and strengthened the clinical community's understanding of ME/CFS and Long COVID.

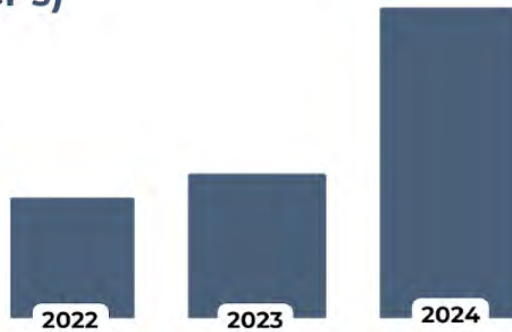
2024 MERC Report

Growth & Performance

Healthcare Professionals (HCPs) Reached

Total HCPs Reached: **13,424**

- 2022: 2,810 HCPs
- 2023: 3,370 HCPs
- 2024: **7,244 HCPs**



Open Medicine Foundation®
Leading Research. Delivering Hope.

Bateman Horne Center
RESEARCH | CLINICAL CARE | EDUCATION



46 States 89 Countries

HOW YOU CAN HELP

Subscribe to our newsletter

Stay up to date on our latest research news at www.omf.ngo or by subscribing to our newsletter.

Make a donation

Every contribution helps us in our mission to end ME/CFS and Long COVID. All donations are tax-deductible to the extent allowed by law.

Give monthly

Join the Hope Builders community, the foundation of OMF's support. Your monthly gifts provide the critical funding needed to advance our research efforts.

Donate crypto

Maximize your impact by donating Bitcoin, Ethereum, or other cryptocurrencies directly to OMF instead of selling and donating the after-tax proceeds.

Leave a bequest

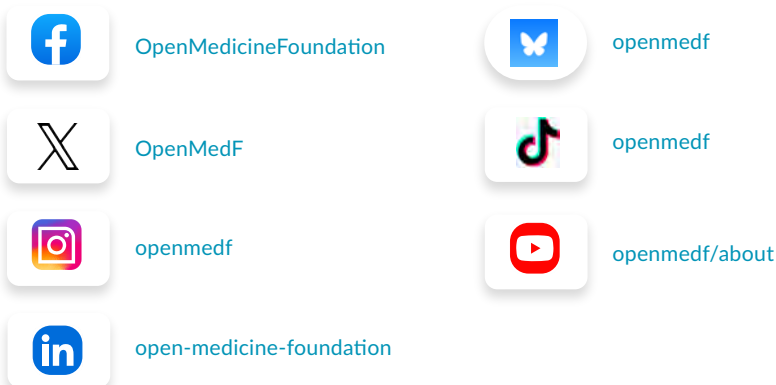
The Healthy Futures Society honors individuals who choose OMF as their partner in creating a personal legacy through planned giving.

Other ways you can help our cause

For more ways to support our mission, please visit our [Ways to Donate](#) page.

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