



## The Nation's Premier Center of Excellence for ME/CFS 10 years

The Bateman Horne Center (BHC), the nation's premier Center of Excellence (COE) for ME/CFS, celebrates its 10th anniversary in March 2025.

In 2016, the national Chronic Fatigue Syndrome Advisory Committee (CFSAC) recommended establishing twelve COEs across the U.S., each supported with \$1 million annually by the NIH to deliver comprehensive care, research, and community support for ME/CFS.

**However, no federal funding was provided, and no other centers were created.**

Despite this, BHC independently built a COE model, becoming the major organization dedicated to this vision.

Over the past decade, BHC has grown a specialized, multi-disciplinary team to provide essential care, conduct groundbreaking research, and educate both patients and providers, extending its reach far beyond Utah.

Managing resources with efficiency and responsibility, BHC has achieved remarkable impact, but sustaining and growing this work now requires significant financial support.

**To ensure BHC remains a high-quality Center of Excellence, we urgently ask for your help.**

With your generosity, BHC can continue offering hope, care and expanded resources for the ME/CFS community into the next decade and beyond.

***Please consider making a lasting impact with a donation today.***



In this newsletter you can expect:

**Where We Started...Where We Are Headed**

**Education's Global Reach**

**The Future of ME/CFS Research**

**Parent & Provider Perspective**

**Bridging Isolation**

**EXECUTIVE DIRECTOR  
ROB ENCE, MBA**



## Where we started--Where we are headed

In late 1999, after almost a decade of practice, I notified my internal medicine patients (about 3,000!) that I was leaving. This was so I could hang up my shingle to learn about what we now refer to as ME/CFS. I made this my specialty!

In 2001, I moved my office to the Moreau building next door to where BHC is now.

While we still have a long way to go, things are much better today. Over the next few years, in addition to helping people one-by-one, my staff helped me carry out studies that led to FDA approval of three drugs for fibromyalgia (FM). FDA approval also meant acceptance of FM as a legitimate disease. I delivered countless educational lectures to physicians, which helped expand patient access to well-informed providers and promoted the development of high-quality online resources for FM care.

Predictably, that progress left post-infectious conditions like ME/CFS behind. My acute awareness of the unmet need led to the establishment of Bateman Horne Center (BHC) in 2015. This was a strategic effort to leverage a non-profit model to accomplish more. **Our mission** was broad--**to change the lives of people through research, education and clinical care.**

In 2020, the pandemic brought new urgency. BHC refocused to address the links between ME/CFS and Long COVID, contributing to research, advancing education on Long COVID, and joining national scientific efforts.

Sadly, millions more people now suffer from ME/CFS as a result of Long COVID. This has brought greater global awareness to infection-associated chronic conditions (IACCs), and while scientific progress may be slow, it is steadily advancing..

The current mission is to, **“empower patients, advance research, and improve clinical care for all those impacted by ME/CFS, FM, post-infectious syndromes and related comorbidities.”**

The COVID pandemic spurred BHC experts to new heights for ME/CFS, from publishing early research and delivering lectures on Long COVID’s link to ME/CFS, to joining national scientific committees.

From humble beginnings, BHC is **now a recognized leader in clinical care, scientific progress, and provider education** for this spectrum of illness. We’re proud of our journey, yet our work continues.

Thanks to the steadfast support of our patients, providers, and advocates, we remain hopeful and optimistic for the future.

**FOUNDER & CHIEF MEDICAL OFFICER  
LUCINDA BATEMAN, MD**

*Thank you for your support!*



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“THANK YOU! THIS VIDEO IS SO HELPFUL! I'VE STRUGGLED TRYING TO EXPLAIN MY EXPERIENCES WITH ME/CFS TO OTHERS. I COULD NEVER FIND A SIMPLE, RELATABLE WAY- THIS IS JUST WHAT I NEEDED. IT HELPED ME UNDERSTAND MYSELF BETTER TOO.”

”

## Building a Global Standard of Care

In 2024, the urgency for high-quality education in diagnosing and managing ME/CFS, Long COVID and other infection-associated chronic conditions (IACCs) became even clearer. At BHC, we know that **expanding access to care starts with sharing knowledge.**

This year, we made significant progress, reaching more healthcare professionals and building partnerships that are reshaping care worldwide.

Through collaboration with the Open Medicine Foundation (OMF), our Medical Education Resource Center (MERC) has become a leader in evidence-informed training. We've **reached over 12,000 healthcare professionals across 45 states and 89 countries**, equipping more clinicians to deliver compassionate, effective care.

We expanded our Long COVID & Post-Viral Syndromes ECHO series, equipping thousands of clinicians with practical tools to better support patients. Our continuing medical education (CME) courses, including the only one focused on post-exertional malaise (PEM), are bridging critical knowledge gaps in patient care.

Additionally, **we've delivered over 1,130 hours of hands-on training to clinicians, residents, fellows and medical students**—preparing the next generation to meet the needs of this growing patient community.

“

BHC'S COURSES HAVE TRANSFORMED THE WAY I APPROACH PATIENT CARE.

-Internal Medicine Physician

”

Strengthening partnerships with global leaders like the Israeli Ministry of Health, CHUM, ICanCME, and Emerge Australia, **we're setting new standards of care, together.** Collaborations with NIH RECOVER and the Federation of State Medical Boards are **driving systemic changes in medical education.**

We're particularly excited about "Mito," an initiative that simplifies complex disease information for patients and their families, amplifying patient voices and helping care networks better understand their loved one's needs.

Expanding access to care for IACCs begins with empowering every provider to manage these complex conditions effectively.

Your support of BHC's educational mission brings us closer to a future where all patients receive the understanding and care they deserve.

Thank You



DEPUTY EXECUTIVE DIRECTOR  
EDUCATION DIRECTOR  
TAHLIA RUSCHIONI



## A European Research Journey

Over the past month, I traveled through Europe for two key meetings on ME/CFS, Long COVID and pandemic preparedness. In Stockholm, I joined a meeting hosted by the Swedish ME patient group, Riksförbundet för ME-Patienter, and the Swedish Long COVID organization, Svenska Covidföreningen. I'll share more insights from this meeting in our next newsletter.

In Rotterdam, I attended the second annual Pandemic and Disaster Preparedness Center (PDPC) meeting at Erasmus University. Led by my colleague Marion Koopmans, the PDPC gathers experts across fields—from clinicians and researchers to sociologists and environmentalists—to **improve future pandemic and disaster responses**. Five major projects showcased promising early results, illustrating both the value and complexity of interdisciplinary collaboration.

A key focus was detecting emerging pathogens, with encouraging examples of local communities using new technology—such as in Rwanda, where training locals led to unexpected discoveries, revealing the interplay of science, politics and community. Social scientists highlighted the ripple effects of well-meaning interventions, like a shift from food to coupon donations, which had unintended consequences for those in need.

**Eye-opening discussions** addressed climate and land use impacts, such as how extreme flooding can bring hidden pathogens to the surface and how climate change is altering microbial communities. One talk on airflow and environmental shifts made me rethink mask-wearing habits!

The meeting underscored that preparing for future pandemics means not only focusing on what we know but being ready for what we don't. ME/CFS and Long COVID must be part of future preparedness efforts.

**Learning from COVID-19, we can aim to reduce the chronic impacts of future pandemics on health, lives and economies.**

RESEARCH DIRECTOR  
SUZANNE VERNON

**Participate in Research!**



Click or Scan!



# Answering the Call

## Transforming ME/CFS Care for the Next Generation



The Bateman Horne Center's mission to empower patients and improve clinical care for ME/CFS has always been critical, but for me, it became personal in 2014 when my daughter developed ME/CFS after a viral illness.

Like many, I heard of chronic fatigue syndrome during medical school, but I had no understanding of its profound impact. The condition was not something I had been formally taught, and as I sought help from pediatricians and specialists, I found little understanding or support. Even neurologists dismissed the possibility of ME/CFS. I felt helpless as a mother and a physician, watching my daughter suffer while we were shuffled between appointments, receiving no clear path forward. This lack of awareness and resources left us feeling lost.

It wasn't until I found the Bateman Horne Center that things began to change. Here, I found guidance, validation, and a wealth of knowledge through Dr. Bateman's expertise. The more I learned, the more I realized that my daughter's story was just one of many — thousands of families were struggling in the same way, often without support or recognition.

Dr. Bateman's vision to create a center focused on educating clinicians and caring for patients with ME/CFS was inspiring. It motivated me to shift my own focus toward these often-neglected illnesses. In time, I joined the team at BHC, driven by a desire to improve the lives of patients, especially children, who face an even greater lack of available care. It became clear to me that pediatric patients were falling through the cracks, and I knew we had to do more.

Pediatric support is vital, yet too few clinicians are trained to recognize or treat ME/CFS in young patients.

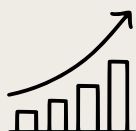
**At BHC, we're working to fill this gap by equipping pediatricians with the tools they need.** Our goal is to ensure no child faces this illness without the care they deserve.

Despite the millions affected by ME/CFS and Long COVID, there are no FDA-approved treatments. Yet, progress is being made, and I'm hopeful for the future as we continue to build awareness and transform care for the youngest and most vulnerable.

**MEDICAL PROVIDER  
MELANIE HOPPERS, MD**

### Why Support BHC's Work?

Because ME/CFS is on  
the rise...



- AN ESTIMATED 6.7 MILLION PEOPLE IN THE UNITED STATES ARE LIVING WITH ALZHEIMER'S DISEASE, WITH FIVE FDA-APPROVED TREATMENTS AVAILABLE.
- ONE MILLION PEOPLE LIVE WITH MULTIPLE SCLEROSIS, WITH OVER 20 DISEASE-MODIFYING DRUGS AVAILABLE FOR THAT CONDITION.
- PRIOR TO THE PANDEMIC, ABOUT 3 MILLION PEOPLE IN THE U.S. WERE THOUGHT TO HAVE ME/CFS.
- NOW, AN ESTIMATED 17 MILLION AMERICANS ARE LIVING WITH LONG COVID, WITH UP TO 50% OF THEM MEETING THE CRITERIA FOR ME/CFS.



## Bridging Isolation: BHC's Commitment to Connection & Support

Individuals and families with ME/CFS experience profound isolation and loneliness on top of their major life-altering disease. Whether or not informed medical care is present, there remains the basic need for human connection and understanding.

**BHC's outreach program addresses this need** by hosting two professionally-led support groups and a lived-experience driven Lunch & Learn each month that offer connections with others facing similar challenges.

The **twice monthly support groups** are led by LCSWs, Timothy Weymann and Meredith Mehner who have personal experience with chronic illness. Each session has a specific topic with accompanying discussion questions that facilitate an open conversation with the aim to listen, validate, and where appropriate, offer new perspectives that foster coping strategies. Timothy and Meredith teach therapeutic principles accompanied by practical examples that participants can implement. **The success and value of the support groups is evident in the growing attendance.**

**The Lunch & Learn** series is managed by dedicated lived-experience volunteers who share expertise, advice and insight to help others.

Launched by BHC's former board member, Diane Sorensen, these monthly gatherings over Zoom allow individuals to join from all over the world.

### **Severe ME/CFS: Care, Rights and Research webinar series:**

The severe ME/CFS community is highly underserved by medicine, science, and social services. BHC and Solve M.E. have partnered on a four-part webinar series to address caregiving, legal rights, medical care, and research, featuring experts from both industry and lived experience. Each session, averaging 1,000 registrants, provides a video, transcript, and resource guide. **Our goal is to make care and resources accessible to those with severe and very severe ME/CFS.**

*With care.*



**PROGRAM SPECIALIST  
ANGELA LINFORD**

### Upcoming Events



**Click or Scan!**

# Ways to Contribute

Bateman Horne Center of Excellence is a 501(c)3 organization.

Tax-deductible contributions are used to help fund our Research, Education and Outreach efforts.



Encourage the people you know to give by using our easy fundraising toolkit.



Support our mission through workplace giving. Some employers offer gift matching!



Give in honor, memory, or celebration of someone special by check or online.



Gifts of long-term appreciated securities are an advantageous way to support BHC and minimize gains tax.



Including BHC in your will or estate planning extends a legacy of generosity and impact beyond a lifetime.



Purchase your greeting cards from Cards for Causes and have 20% of your order donated to BHC.

[batemanhornecenter.org/donate/](https://batemanhornecenter.org/donate/)

