

BHC CONNECT

Ten Years of Impact:

Honoring Our Past, Embracing Tomorrow



"In my most optimistic dreams 10 years ago, I never envisioned that BHC could make such a difference in the lives of people with ME/CFS and related conditions around the world. I doggedly kept working and gradually found myself with like-minded people who could help make my [our] dream come true. When we pull together, dreams come true! Let's not stop now."

-Lucinda Bateman



BUILDING A FOUNDATION FOR CHANGE

2017-2022

BHC serves as the clinical core for Jackson Labs and as a clinical site for the Columbia Center for Solutions as part of two NIH-funded ME/CFS Collaborative Research Centers grants.

2021

The U.S. ME/CFS Clinician Coalition publishes *ME/CFS: Essentials of Diagnosis and Management*, emphasizing complex pathophysiology and the need for individualized care.

2021-2023

BHC plays a key role in the NIH RECOVER initiative, contributing to the ENERGIZE Trial and research shaping future treatments.

2025

Dr. Suzanne Vernon and BHC lead a landmark study in the *Journal of General Internal Medicine*, confirming ME/CFS as a severe subset of Long COVID. NIH RECOVER findings show post-COVID ME/CFS occurs at 15 times pre-pandemic rates, highlighting the need for better clinical recognition, training, and treatment.

2015

Dr. Lucinda Bateman plays a key role in developing the IOM clinical diagnostic criteria for ME/CFS.

2020

SARS-CoV-2, COVID-19, spreads worldwide, leading to a global health crisis.

2022

In partnership with the Open Medicine Foundation, launches the Medical Education Resource Center (MERC), greatly expanding clinician education reach.

BHC becomes an independent Project ECHO hub, launching the Long COVID & Post-Infectious Syndrome ECHO Program.

2024

BHC teaches clinicians in 46 states and 89 countries, while conducting patient-focused research for clinical implementation.

After a year-long effort, the ME/CFS Research Roadmap is published.



Bateman Horne Center
RESEARCH | CLINICAL CARE | EDUCATION



WILD SOCKS AND BOLD MOVES: BHC'S EVOLUTION

Lucinda Bateman, Chief Medical Officer and Founder

Most people do not know this, but in 2013, a man quietly bequeathed \$100,000 in his will to OFFER (Organization for Fatigue and Fibromyalgia Education and Research), a small non-profit organization I founded in 2002. This incredibly generous donation was meant to honor a loved one with fibromyalgia who had benefitted from OFFER's educational conferences and my clinical care.

At the time, OFFER operated on a small budget, so \$100,000 was a miraculous gift. The organization was led by a volunteer "working board" and many loyal volunteers with

fibromyalgia and what was then called "chronic fatigue syndrome". Our bank account rarely held more than \$15,000 to \$20,000, mostly from small donations and money raised through registrations and T-shirt sales at our educational conferences. OFFER operated out of a spare room in my office, with only a computer, a printer, and a telephone as our monthly overhead expenses. This small, heroic group of volunteers put on yearly educational conferences attended by 400 to 500 patients and their families. As fibromyalgia education became more available online, OFFER shifted its focus toward continuing education conferences for medical providers.

After receiving that \$100,000 donation, I challenged the board to do something big with it. One board member, the father of a son with ME/CFS, proposed using the funds to develop a **Center of Excellence** that would combine **patient care with research and education to advance treatment standards and outcomes**. The board agreed, but it took almost two years to develop and implement the plan. Part of the donation was used to hire a financial consultant to complete a feasibility report. The conclusion? The report said it would be financially impossible and achieving this goal was unlikely.

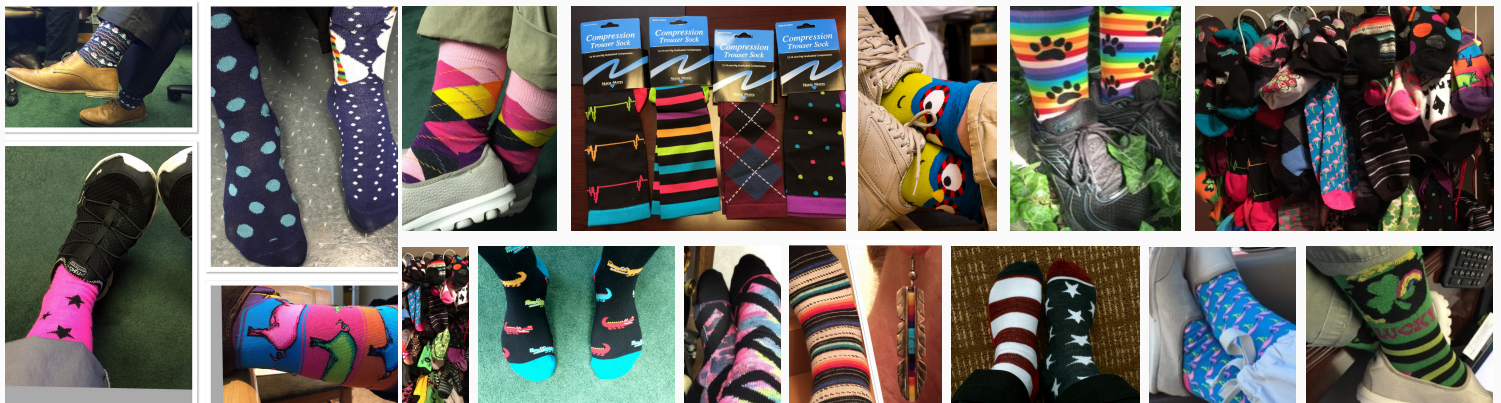
Undaunted, we persisted with a plan to combine OFFER with my 15-year-old fatigue consultation clinic, which had been operating on a shoestring budget. The board voted to name the new organization the Bateman Horne Center (BHC), honoring both me and my sister, Shauna Bateman Horne, who passed away in 2001 from complications of non-small cell lymphoma. Throughout 2015, the two entities became progressively more enmeshed.

In early 2016, we hired an Executive Director, Rob Ence, to lead the organization, and we laid plans to move to a new location. In August, we made the move from my office of 15 years into a new BHC space. It felt like a rebirth—with all the labor pains that come with it. In a bold move, BHC added a nurse practitioner, a registered nurse, another research coordinator, and an additional medical assistant, all from a single private practice when the physician retired. I shifted from my slogan of "slow and steady wins the race" to **"wear wild socks in support of biomarker development!"**

Unlike traditional Centers of Excellence funded by millions of federal dollars, BHC was built through the dedication of patients, families, volunteers, clinicians, researchers, and donors who believed in our mission.

It has been an amazing 10 years. It would take chapters to describe the full journey. What I want to emphasize today is that **change is possible**.

A decade later, I still "wear wild socks in support of biomarker development" for ME/CFS. Through the generosity and support of many, we have come so far...let's celebrate and continue our work!





REFLECTIONS FROM BHC'S EXECUTIVE DIRECTOR

Rob Ence

In the fall of 2015, freshly retired after 15 years at AARP, I was introduced to Dr. Lucinda (Cindy) Bateman by her brother, Kim Bateman, MD. At a December lunch, I listened intently as Cindy recounted her 15 years working on an illness whose name was nearly unpronounceable—a condition that profoundly impacted her sister's life. In March of that year, she launched the Bateman Horne Center of Excellence with dedicated volunteers who envisioned a nonprofit offering clinical services, research, and free education for patients and providers on misdiagnosed, marginalized illnesses. Despite the consultant's doubts about creating a sustainable model, I volunteered to help over a six-month period, and nearly nine years later, I remain deeply committed.

Seed funding from key donors jumpstarted the enterprise, but a pivotal \$1 million gift in mid-2016 enabled us to hire talent, upgrade our clinic, and invest in growth. In its first ten years, BHC assembled the right providers, research coordinators, and education experts while building a network to transform how these illnesses are understood and managed. We weathered lean years and a global pandemic, forming an exceptional team and a dedicated Board and garnering generous support from visionary benefactors.

Dr. Bateman's early sacrifices and compassionate service have inspired everyone involved with BHC. Our decade-long journey is one of selfless collaboration and mutual commitment to the patient community, laying a foundation for a lasting legacy of success and influence beyond what was imagined in 2015.

10 YEARS OF PROGRESS, A FUTURE OF IMPACT

Tahlia Ruschioni, Deputy Director

Building a Foundation for Change

BHC began with a single mission: to mainstream ME/CFS. **For the past decade, we have worked to close the knowledge gap and bring Dr. Bateman's vision to life.**

Today, BHC is a recognized leader in medical education and research, equipping thousands of clinicians with the tools to diagnose and manage these conditions. In just the past three years, our BHC and Open Medicine Foundation's Medical Education Resource Center (MERC) has trained 14,000+ healthcare professionals across 29 disciplines.

We have delivered Grand Rounds at leading medical institutions, provided hands-on clinical training for current and future clinicians, and expanded Project ECHO, reaching providers across the globe.

What's Next? Scaling Our Impact

To meet the growing demand for informed care, we must expand and institutionalize these efforts. With continued support, we will:

- **Target Licensing & Board Exams** – Working with state medical boards to integrate ME/CFS and Infection-Associated Chronic Conditions (IACCs & Long COVID) into certification requirements.
- **Expand Medical School & Residency Training** – Partnering with institutions to embed ME/CFS and Long COVID education into formal curricula.
- **Strengthen Grassroots Networks** – Expanding Grand Rounds to more institutions by replicating our Dartmouth and Rochester successes, while empowering lived-experience professionals to bring this education to providers in their own communities.
- **Launch More Clinical Trials** – Conducting clinician-led research to drive evidence-based treatment development.
- **Establish a Global Standard of Care** – Partnering with medical associations and international organizations to define and implement best practices.



The Road Ahead

The past decade has been about building a foundation—**proving that change is possible.**

Now, we have the opportunity to turn progress into lasting impact. With continued investment, we can reach more providers, advance research, and ensure every patient is met with knowledge, understanding, and care. The future of ME/CFS and Long COVID care is within our reach, and **together, we can make it a reality.**



OUR PROGRESS IN ADVANCING ME/CFS RESEARCH

Suzanne Vernon, PhD

Ten years ago, the National Academies Press published *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*, a landmark report that critically reexamined the diagnosis, understanding, and treatment of ME/CFS. A committee of 21 experts across medicine, epidemiology, neuroscience, immunology, infectious disease, and physiology spent 18 months reviewing evidence, holding public sessions, and consulting specialists.

The report called for a shift away from traditional, often stigmatizing views of ME/CFS and recommended a comprehensive, evidence-based approach to redefining the disease. It emphasized clearer diagnostic criteria, research into biological mechanisms and biomarkers, and the development of effective treatments. Over the past decade, Bateman Horne Center has used this report as a research roadmap to advance both clinical care and scientific inquiry into ME/CFS.

Advancing Diagnosis and Clinical Tools

With diagnostic criteria established, we focused on equipping healthcare providers with tools to diagnose and treat patients effectively. **Our goal was to develop reliable measures of core symptoms, enabling clinicians to make diagnoses more easily and assess treatment effects in clinical trials.**

Collaborating with the University of Utah, The Jackson Laboratory for Genomic Medicine, and Columbia University, we have:

- Developed a wearable device to measure ME/CFS disease severity.
- Validated the **10-Minute NASA Lean Test** as an accessible tool for assessing orthostatic intolerance in clinical settings.
- Demonstrated that **DANA Brain Vital**, an FDA-cleared cognitive assessment app, **can objectively evaluate cognitive impairment in ME/CFS.**

Driving Scientific Discovery

We have supported ME/CFS research by providing **scientists worldwide with biological samples and clinical data** from our highly engaged patient population. This collaboration has fueled research into exertion intolerance, genomics, epigenetics, metabolomics, microbiome disturbances, inflammation, immune dysfunction, and biomarker discovery. Our patients' participation has directly contributed to **over 50 peer-reviewed publications, significantly expanding the ME/CFS evidence base.**

Key Findings From the RECOVER Adult Study:

New cases of ME/CFS are **15x higher** than pre-pandemic levels.

4.5% of infected individuals meet ME/CFS criteria (vs. 0.6% uninfected).

Nearly **90% of ME/CFS cases** occur in patients with the most severe Long COVID.

Vernon, S.D., Zheng, T., Do, H. et al. Incidence and Prevalence of Post-COVID-19 Myalgic Encephalomyelitis: A Report from the Observational RECOVER-Adult Study. J GEN INTERN MED (2025). <https://doi.org/10.1007/s11606-024-09290-9>

Pioneering Clinical Trials

Bateman Horne Center has **led multiple clinical trials on novel and repurposed ME/CFS therapeutics**, guided by a decade of clinical and research insights. Our expertise in trial design makes us a sought-after partner in developing effective treatments.

Bridging ME/CFS and Long COVID

Decades of ME/CFS research are accelerating Long COVID understanding and management. Our work shapes research efforts and improves care for infection-associated chronic conditions.

As we mark 10 years, we celebrate progress while recognizing the work ahead. Bateman Horne Center remains dedicated to advancing research, enhancing care, and advocating for those with ME/CFS and related conditions.



 **Knowledge Shared**
LIVES CHANGED

Medical Education. Research. Clinical Expertise.



GIVE NOW!



SINCE 2015, BHC HAS HOSTED

100 SUPPORT GROUPS

120 LUNCH & LEARNS

SEE WHAT TOPICS
WE ARE COVERING
THIS SPRING



batemanhornecenter.org/events/

FINDING CONNECTION

Anglea Linford, Program Specialist

Online SUPPORT GROUPS



Living with ME/CFS or fibromyalgia can feel isolating. To foster connection and support, we shifted from in-person and streamed education meetings (started with OFFER) to launching online groups in 2019. Originally, we ran two separate groups—one for ME/CFS and one for fibromyalgia—led by psychologist Elizabeth Sherlock, PhD. When many participants began joining both sessions for community rather than diagnosis, we transformed our approach into one inclusive space.

In 2020, LCSW Meredith Mehner introduced guided discussions to deepen the conversation. In 2023, Timothy Weymann, LCSW, joined as co-facilitator, further expanding our global community. What began with 17 participants now regularly welcomes up to 200+ people per session—a testament to our facilitators' expertise and the welcoming environment they create, where everyone truly belongs.

PEER PERSPECTIVES & CONNECTIONS

What began in 2015 as a simple lunch meetup evolved into a vital space for learning, sharing, and support. Originating as the Lunch & Learn series—sparked by patient volunteers and supported by board member Diane Sorensen in Salt Lake City—it grew into a monthly gathering over lunch.

When the pandemic hit in 2020, we shifted to Zoom, connecting people far beyond Utah. Now, in 2025, we've rebranded as Peer Perspectives & Connection to better reflect our focus on volunteer-led discussions, Q&A, and engaging breakout sessions that foster genuine community insights and friendships.

YOUR SUPPORT POWERS REAL CHANGE

Did you know that **92% of all funds** raised through Bateman Horne Center go **directly** to clinical care, education, and research for **ME/CFS, Long COVID, and other related conditions?**

Your generosity fuels groundbreaking advancements and critical support for patients in need.

Consider making a **one-time or monthly donation** to sustain this vital work. Every contribution brings us closer to better care, better education, and better treatments.

GIVE TODAY!

batemanhornecenter.org/donate/