Bateman Horne Center
RESEARCH | CLINICAL CARE | EDUCATION

*Mid-Year Newsletter*
July 2025

# A New Chapter of Leadership at BHC

*Mary Sue Rominger, Board Chair*

> *I see a future where we not only deliver expert care here in our clinic, but also train providers across the country, lead patient-centered research, and make expert-informed care the expectation—not the exception.*
>
> *-Tahlia*

It is with great pride that we announce the appointment of Tahlia Ruschioni to Executive Director of the Bateman Horne Center.

Since joining BHC in 2019 as Director of Education, Tahlia has demonstrated extraordinary commitment to our mission, leading transformative initiatives that have expanded our clinical education programs, supported providers worldwide, and elevated standards of care for people living with ME/CFS, Long COVID, and related conditions. Her leadership was instrumental in the launch of the Clinical Care Guide and the growth of the Medical Education Resource Center, which has now trained over 15,000 clinicians in 90 countries.

Tahlia's appointment comes as we bid farewell to Rob Ence, who guided BHC through nine years of steady growth, including our early and responsive pivot during the COVID-19 pandemic. We are deeply grateful for Rob's leadership and legacy.

Tahlia brings to this role more than two decades of interdisciplinary healthcare experience, a systems-oriented mindset, and an unwavering commitment to equity and access. As board chair, I have every confidence that her vision will carry BHC into its next era—one rooted in evidence, compassion, and bold innovation.

Together with Dr. Lucinda Bateman, who will transition into a new role focused on research and mentorship at the end of 2025, Tahlia is leading a dynamic chapter in BHC's history. I am inspired by her clarity of purpose and the way she centers both science and lived experience in our work.

Please join me in welcoming Tahlia to her new role as Executive Director.

# A Vision Rooted in Community and Purpose

*Tahlia Ruschioni, Executive Director*

As I step into the role of Executive Director, I am guided by the same belief that first brought me to the Bateman Horne Center: everything we do is for the patient and the community.

Over the last six years, I've had the privilege of sitting with patients and families, learning from their stories, and witnessing the extraordinary dedication of our clinicians and partners.

This experience—combined with my own journey living with post-infectious illness—has shaped my belief that BHC holds something truly special. We have the knowledge, the model, and the commitment to transform care for ME/CFS, Long COVID, and related conditions.

My vision is clear: to grow BHC in ways that scale our impact across clinical care, medical education, and research. Not as an abstract mission statement, but as a promise—one we fulfill every time a patient is accurately diagnosed, a provider feels prepared to help, or a study generates evidence that moves the field forward.

To achieve this, we must invest in our future: expanding our clinical team, launching training programs for the next generation of providers, and leading investigator-initiated research that answers the questions patients are living with right now.

I began here as the Education Director, and I have never stopped learning—from the best teachers I could ask for: the patients who trust us, and the colleagues who stand beside them. Together, we can build a world where expert-informed care isn't the exception but the expectation.

Thank you for being part of this community.
I am honored to grow BHC with you.

**WE CAN CHANGE CARE TOGETHER**

**1 IN 22**

ME/CFS affects 1 in 22 people who have had COVID

## RECOVERing the Truth: 1 in 22 Develop ME/CFS Post-COVID

*Rebecca Handler*

A groundbreaking study co-led by BHC's Suzanne Vernon, PhD, has confirmed what patients have long suspected: COVID-19 can lead to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Published in the Journal of General Internal Medicine, the study analyzed data from over 15,000 participants in the NIH's RECOVER initiative.

Its findings are staggering—1 in 22 people who had COVID-19 went on to meet diagnostic criteria for ME/CFS at least six months later.

The hallmark symptom? Post-exertional malaise (PEM)—a profound crash in function after even mild activity. Nearly 25% of participants reported PEM, making it the most common and defining feature in post-COVID cases.

This isn't just validation for patients—it's a call to action. Pre-pandemic, ME/CFS was thought to affect 0.2–1% of the U.S. population. Now, that number may exceed 4–5%, representing millions of new patients and a healthcare system that must catch up fast.

BHC is meeting the moment—educating providers, advocating for biomedical research, and helping translate emerging science into clinical care.

As Dr. Vernon says, "It is clear that ME/CFS exists. It is clear that it can be diagnosed. Now it just has to be so."

# ONE GUIDE ONE GOAL

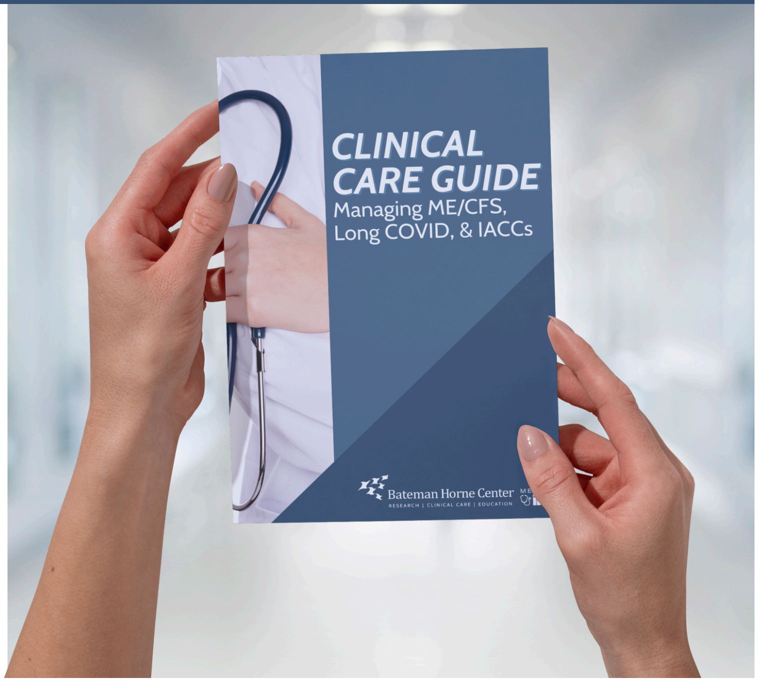
## ONE SIMPLE WAY TO MAKE A DIFFERENCE

What if just five dollars could change the future of care for ME/CFS and Long COVID?

That's the power behind One Guide. One Goal., Bateman Horne Center's grassroots campaign to transform how ME/CFS, Long COVID and other post-infectious illnesses are diagnosed and treated—one provider at a time.

Today, millions of people living with ME/CFS, Long COVID, and related conditions are still misdiagnosed or misunderstood—not because doctors don't care, but because most have never been trained to recognize these complex illnesses. That's the gap we're trying to close.

The Clinical Care Guide, developed by BHC in collaboration with a team of interdisciplinary experts and supported by the Open Medicine Foundation, is a powerful tool designed to help healthcare providers recognize, diagnose, and care for patients with ME/CFS and Long COVID. It's grounded in more than a decade of research and evidence-informed strategies—and it's offered to providers at no cost.



But getting it into their hands takes resources.

That's where you come in.

With a goal of raising $500,000 by August 31, we're inviting our community to take a simple action.

For the cost of a cup of coffee, a sandwich, or an everyday impulse buy, you can make a lasting impact.

A $5 donation (or more) helps provide a lifeline for patients, a critical tool for providers, and a step toward a better standard of care.

**And once you've given, share this campaign with five friends or family members.**

One guide. One goal. One moment of generosity that can go further than you think.

Scan the QR code or text "BHCGUIDE" to 53555

BATEMAN HORNE CENTER

# A Global Community, Connected by Understanding

*Angela Linford, Community Engagement Lead*

Our outreach sessions offer a rare and powerful experience for people living with complex chronic illnesses: a chance to be truly seen, heard, and understood.

Now welcoming more than 200 attendees at twice-monthly group sessions! Participants join from around the world, representing a wide spectrum of backgrounds, adult age ranges, illness severity, onset triggers, and lived experiences. Some are new to chronic illness; others have been navigating it for decades. This creates a forum rich in wisdom gained only from living with chronic illness.

Led by a licensed clinical social worker, each support group session blends therapeutic principles with open dialogue—affording community members the unique opportunity to share the raw realities and multitude of challenges that come with living with ME/CFS, Long COVID, and related conditions.

**Through it all, participants offer each other heartfelt support, compassionate witness, and remind each other of their inherent value**.

Many have even extended these connections beyond BHC-led sessions, creating informal meetups and online conversations to sustain friendships and further reduce isolation.

Support group topics are carefully chosen to reflect the emotional, social, and identity-based aspects of chronic illness.

## A few upcoming support group topics include:

- Who am I? Identity and Chronic Illness
- Moving from Humiliation and Shame to Humility and Pride
- Parenting with Chronic Illness: Challenges and Triumphs
- Denial, Resistance, and Gaslighting: Coping with Others' Unhelpful Reactions to Our Illness

## Get Involved

Do you have a suggestion for a future support group topic? Email *outreach@batemanhornecenter.org*

## Stay Connected

Keep up with BHC and community events like Peer Perspectives & Connections: *batemanhornecenter.org/events/*

# What the New Rapamycin Study Means for ME/CFS

*Low-Dose Alleviates Fatigue and PEM by Improving Autophagy*

*Jennifer Bell, FNP-C*

As a clinician at the Bateman Horne Center, I see the toll ME/CFS takes on people every day—especially the crushing fatigue and post-exertional malaise (PEM) that can follow even small amounts of activity. These symptoms aren't just frustrating—they're disabling. And until now, we've had few options to offer patients that target the biology behind them.

But that may be starting to change.

I recently co-authored a new study that tested low-dose rapamycin, a medication best known for its role in preventing organ rejection. We aimed to investigate whether rapamycin, administered at low doses once a week, could safely alleviate symptoms in individuals with ME/CFS by enhancing a bodily process known as autophagy.

Autophagy is a process that clears away internal debris, allowing cells to repair themselves. This is particularly important for healthy mitochondrial function. When autophagy is disrupted, oxygen consumption and mitochondrial activity can be impaired, potentially leading to increased inflammation throughout the body.

The results gave us real reasons to hope:

- Nearly 3 out of 4 participants who completed the study saw improvement in core symptoms like fatigue, PEM, and orthostatic intolerance.
- Lab results showed a boost in autophagy-related markers in subjects who reported improvement. This suggests that rapamycin may be targeting a core feature of ME/CFS and we may now have biomarkers that could help guide treatment. People who developed ME/CFS after a viral illness (like mono and COVID-19) responded especially well.

This was the first decentralized, biomarker-driven ME/CFS study of its kind. It didn't have a placebo group, so we can't draw final conclusions yet. However, the combination of clinical improvement and measurable biological changes is exciting and has prompted a more extensive Phase II trial that is presently enrolling subjects.

For patients, this study signals that relief may one day come from targeted, science-backed treatment. For clinicians, it opens a door to testing blood-based biomarkers to help identify who might respond to medications like rapamycin.

It's not a cure. But it's progress.

After years of watching this illness be ignored and misunderstood, I'm proud to be part of work that moves the field forward—one step closer to effective, personalized care.

**Rapamycin Pilot Treatment Trial for ME/CFS**