Fall Newsletter

Bateman Horne Center
RESEARCH | CLINICAL CARE | EDUCATION



Why We Keep Building

TAHLIA RUSCHIONI, EXECUTIVE DIRECTOR

Long before I stepped into healthcare leadership, I understood what these illnesses could do to a person and their family. My sister and father both live with ME/CFS. For years, I've watched them navigate a medical system that often does not understand the complexity of multisystem diseases.

Then, in 2020, I developed Long COVID and found myself navigating many of those same challenges.

I've experienced these illnesses as a family member, caregiver, patient, and healthcare professional. Each experience has reinforced something I believe strongly:

People deserve care that is informed, coordinated, and grounded in science. More importantly, they deserve a healthcare system that recognizes and responds to their needs.

Dr. Bateman understood decades ago that these patients needed something different. She saw people who were being overlooked, misunderstood, and too often left without answers, and she dedicated her career to changing that. This enduring commitment continues to shape who we are and what we're working to build.

Even with the progress we've made, I know there are far too many people who still cannot access the care they need. I think often about those who remain waiting for help, and the families doing everything they can to find answers. We want to reach more of them, and we're working hard to make that possible. But expanding access takes more than determination. It requires funding, resources, and partnerships that allow us to build programs that can grow and endure.

What I can promise is that we haven't lost sight of the patients and families counting on us.

That's what this year's work has been about. Honoring what Dr. Bateman started, strengthening what she built, and finding new ways to extend our reach.

We don't have all the answers, and we certainly don't have all the resources we need. But we have an incredibly dedicated team, decades of experience, and a community of people who believe, as we do, that quality medical care should be accessible and equitable.

Thank you for believing in us and for helping us carry this work forward. We are honored to share this mission with every one of you.

With gratitude,

Tahlia Ruschioni

TAHLIA RUSCHIONI
EXECUTIVE DIRECTOR, BATEMAN HORNE CENTER

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Hear more from Tahlia in conversation with Emily Kate Stephens on Episode #43 of the Make Visible podcast: *Patient-Focused Care and Practitioner Education*

Access to Care: Meeting Patients Where They Are

Ask almost anyone living with a complex chronic illness, and they can likely describe the moment they first wondered whether they were too complicated to be helped. It often comes after test results return normal even though symptoms are very real, and the path toward answers grows harder to see as the months and years pass.

For many people living with ME/CFS, Long COVID, fibromyalgia, and related conditions, that feeling is compounded by distance, disease severity, and the complexity of their care, all of which can stand between them and the help they need.



At Bateman Horne Center, we've spent decades working to understand these illnesses and provide the specialized care so many patients struggle to find. We believe that the complexity of someone's illness should never be the reason they are left without options for care.

Providing that level of care takes time. BHC clinicians spend hours reviewing medical histories, evaluating overlapping conditions, and developing treatment plans. It's what these patients need and deserve, but it also limits how many people our clinic can serve.

Our developing Access to Care model is one of the ways we're working to change that.

This fall, BHC began piloting a new model designed to extend BHC's expertise beyond our clinic. Through comprehensive evaluations involving our medical team and allied health professionals, including physical, occupational, and speech-language therapists, we're developing individualized recommendations that reflect each patient's complex medical needs and daily functioning.

Importantly, our work doesn't end with a care plan. We provide consultative support to the patient's local clinician, helping them understand and carry forward our recommendations.

We're piloting this program with some of the most severely affected patients, and that decision is intentional.

By designing care around those facing the greatest barriers, we hope to develop a model that can eventually benefit a much broader population.



This is an early pilot, and we expect to learn and refine our approach alongside patients, caregivers, and clinicians. Making it sustainable and expanding its reach will require continued collaboration, resources, and financial investment.

The generosity of our donors and partners has brought us this far. With continued support, we can strengthen this model and work toward making specialized care more accessible, regardless of where patients live or how complex their needs may be.

BUILDING ACCESS NOW

Help support the next chapter of our ongoing efforts to make Access to Care a reality for more individuals who deserve to be seen, heard, and treated.

Clinical Care Updates



Reflections from Dr. Jones: "You Are Not the Wrong Kind of Sick"

Years ago, I cared for a patient who couldn't get access to a medication that was clearly helping her. We appealed and were denied, again and again. One day, frustrated, she asked me, "Am I just the wrong kind of sick?"

I told her no. She wasn't the wrong kind of sick. We were trying to care for her in the wrong kind of system. More than a decade later, I still think about that question. People living with ME/CFS, Long COVID, and related illnesses ask some version of it all the time, especially when their test results don't match what they feel, or when their symptoms cross the lines between medical specialties. That question is a big part of why I joined Bateman Horne Center. Long before Long COVID pushed the medical world to take post-infectious illness seriously, Dr. Bateman and this team were doing the work: studying the biology, teaching other clinicians what they learned, and caring for the patients no one else knew how to help. I have admired that work for a long time, and I'm grateful for the chance to build on it.

What drew me most is how clinical care, research, and education feed each other here. What we see in the clinic shapes the questions research asks. What research learns comes back to patients as better care. And education may be our biggest force multiplier. There are far more patients than experienced clinicians, so every clinician we teach helps more people find knowledgeable care close to home. No one with ME/CFS should have to navigate three airports to find someone who understands their illness.

I believe in finding the size that fits the *one*. That takes scientific rigor and humility. Sometimes the honest answer is "I don't know yet." But "I don't know yet" is very different from "there's nothing here." The first is the beginning of science. The second closes the door on it.

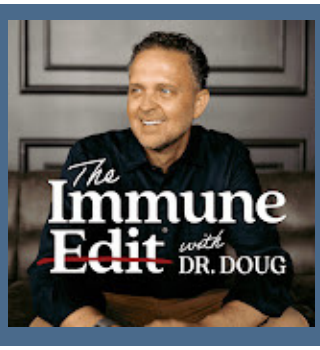
To every patient, caregiver, and supporter who has trusted this center for more than 25 years: thank you. I know more care, education, and help is needed, and my intention is to be part of the solution. I'm honored to help carry this work forward with you.



DOUGLAS JONES, MD
MEDICAL DIRECTOR

Hear More from Dr. Jones

On his podcast, The Immune Edit, Dr. Jones explains complex immune science clearly, without fear or hype. Start with the September 23 episode where he shares why he joined Bateman Horne Center and what he hopes to build here. Listen and subscribe wherever you get your podcasts, or learn more here: https://drdougjones.com/



NEW BLOG

When the Seasons Change

by Amy Mooney, MS OTR/L

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Reflections from Dr. Bateman

When I finished my residency at the University of Utah in 1991, I was already chasing a question I couldn't yet answer. My sister Shauna had been sick for at least five years with something no one could name, and none of the doctors she saw seemed to understand it. The first case definition for what we now call ME/CFS was published in 1988, only a few years before. It was very early days.

As an internal medicine resident, I specifically asked to do my weekly continuity clinic in the infectious disease department, hoping it would bring me closer to solving Shauna's mystery. Word got around, and soon, as a resident in that clinic, I was seeing the complex patients no one else wanted to see. When I formed a small, women-owned group practice in 1991, the University kept referring them. I became an expert almost by accident.



What those patients and Shauna taught me is that three vital things were missing from the equation needed to build understanding around complex chronic illness: clinical care, research, and education. Patients had nowhere to go, doctors had no training, science had barely begun asking the right questions and there was no guidance. You can't fix one without the other two. So, in 2000, when I founded the clinic and nonprofit that would eventually grow into Bateman Horne Center, I built it on all three.

Over 25 years later, that is still our foundation, and it still begins with patients. The people we see in clinic continue to set the direction for our research and for what we teach, as they have from the very beginning. The science has evolved, Long COVID arrived, and we have wrapped our arms around more of the chronic conditions our patients live with, but that commitment has not changed, and it won't.

I am so proud of the team growing around this mission, including Dr. Jones, Tahlia, and our entire staff, and am so grateful to you for sustaining it. Shauna Bateman Horne was my why. You are why we keep going.

LUCINDA BATEMAN, MD
CHIEF MEDICAL OFFICER, FOUNDER

Did you know?

Dr. Bateman is being honored at Utah Philanthropy Day on Thursday, November 12, 2026, where she will receive the Governor's Career Humanitarian Leadership Award. The award recognizes one individual whose career reflects an outstanding, lifelong commitment to serving others, and we can't think of anyone more deserving.

To learn more, visit utahphilanthropyday.org.



QUICK GUIDE TO OUR TOP RESOURCES



Research Update: Centering the Patient Experience

Research has always been one of the three pillars of Bateman Horne Center's mission, alongside clinical care and education, and this fall BHC's Research Department continues to build on that foundation alongside academic, government, and industry partners who share our commitment to ME/CFS, Long COVID, and related complex chronic illnesses.

BHC is currently collaborating with Columbia University and the University of Utah on two projects, a Good Day/Bad Day Study and a Family Genetics Study, both of which are in the final stages of planning and expected to begin before the end of the year. Neither study will be open to enrollment since participants are being identified through existing channels, but we look forward to sharing what we learn as the work moves forward.

What makes these studies especially meaningful is how they were built. Both were designed not only to include people living with severe ME/CFS, but to center them in the study design and protocols, so that the patients research has most often left out are the ones shaping it from the start.

BHC is also exploring the opportunity to participate in upcoming NIH RECOVER clinical trials, and continues conversations with pharmaceutical and industry partners about future research opportunities.



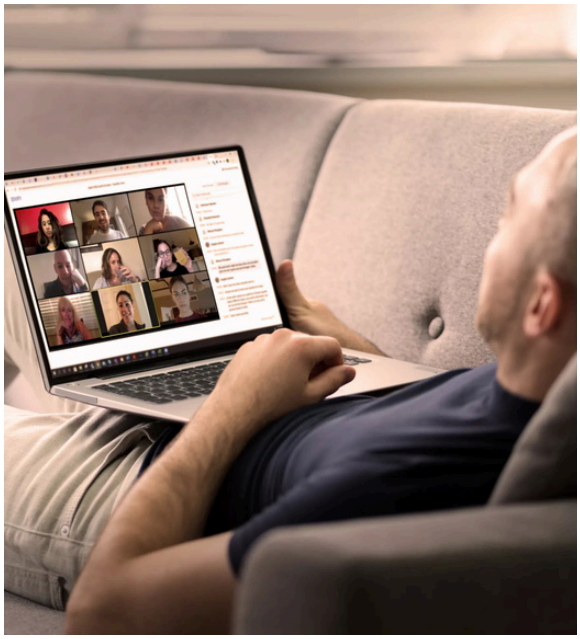
We look forward to sharing more as these projects progress and remain committed to expanding high-quality research opportunities that advance the understanding and treatment of ME/CFS, Long COVID, and related illnesses. Readers who want to hear about future studies as they open can stay connected by signing up for our mailing list, where we'll share participation opportunities first.

Timothy's Shared Wisdom

"Compassion, at its heart, is being with what is, without judgment or resistance. When the body isn't cooperating in a given moment, the practice is to not resist that reality and to refrain from judging it, or ourselves within the experience."

Timothy Weymann, LCSW
Messages from October Support Groups

Connect with Us! Support, Education & Connection



BI-WEEKLY SUPPORT GROUPS

Bateman Horne Center hosts support groups on the first and third Tuesday of each month at 1:00 PM MST. These groups offer a community of support for individuals living with ME/CFS, FM, Long COVID, and co-existing conditions.

The groups are moderated by Licensed Clinical Social Worker Timothy Weymann, who offers practical wisdom on navigating the challenges of living with chronic illness. We also share Timothy's wisdom on our social media channels, and his guidance is included in our support group recap emails.

"COFFEE" WITH A CLINICIAN



"Coffee" with a Clinician is a webinar series designed to share practical, evidence-informed guidance on ME/CFS, Long COVID, and other infection-associated chronic conditions (IACCs) that you can share with your medical provider.

Each month, clinicians walk us through an aspect of the Clinical Care Guide.

Who should attend: People living with ME/CFS, Long COVID, or related IACCs; family members and caregivers; and clinicians who want a concise, practical starting point.

"Coffee" with a Clinician is free to attend, with an optional $5 donation to support BHC's education and outreach programs.

FIND RECAPS AND RECORDINGS BELOW

Support Group Recaps

"Coffee" with a Clinician Playlist

BHC Online Event Calendar

Sign Up For BHC Emails

UPCOMING EVENTS:

November Support Groups
November 3: *Navigating the Healthcare Industry*
Register HERE

November 17: *Gratitude as a Happiness and Resilience Skill - Recognizing What We Can Appreciate in the Face of Illness*
Register HERE

December Support Groups
December 1: *Facing the Holidays with Chronic Illness*
Register HERE

December 15: *Drawing on the Power of the Group - Open Forum Discussion About Managing Life with Illness*
Register HERE

November "Coffee" with a Clinician Chapter 7: *Orthostatic Intolerance & Dysautonomia Part 2*
Register HERE

December "Coffee" with a Clinician Chapter 7: *Orthostatic Intolerance & Dysautonomia Part 3*
Register HERE



Expanding Our Reach and Impact

Throughout 2026, the Bateman Horne Center's Education Department continued to expand education for people living with ME/CFS, Long COVID, dysautonomia, and related conditions, while equipping healthcare professionals with the knowledge to provide informed, compassionate care.

A major highlight was Dr. Lucinda Bateman's participation in the National Institutes of Health's National Institute of Neurological Disorders and Stroke (NIH/NINDS) workshop in September, where she presented to approximately 350 attendees in person and virtually. You can watch her presentation, The Autonomic Nervous System's Role in Disease, beginning at the 3 hour and 12-minute mark.

Dr. Bateman also co-authored Untangling Complexities in ME/CFS: Optimizing Outcomes in the Context of Comorbidities, a CDC-funded CME/CE course on Medscape Education that equips clinicians with the information to recognize and manage ME/CFS alongside common comorbidities.

She further extended BHC's reach to a broad audience as a panelist for the RTHM webinar, How to Manage and Treat Post-Exertional Malaise (PEM), that reached more than 1,000 live listeners. Additionally, her ongoing involvement in NIH RECOVER initiatives continues to support national research and clinical efforts related to Long COVID and ME/CFS.

Looking Ahead to 2027

We are excited to expand online and in-person training for medical providers, strengthen collaborations with organizations and clinicians, and develop new educational resources. Our priorities include building an online learning platform for clinicians treating complex chronic illness, distributing our education modules with Emerge Australia, and creating an Allied Professionals Guide modeled after BHC's Clinical Care Guide.

Our goal is to reach more healthcare professionals, address persistent knowledge gaps, and improve access to informed, compassionate care for people living with complex neuroimmune conditions.

CLAYTON POWERS, PT, DPT
DIRECTOR OF EDUCATION & STRATEGIC PARTNERSHIPS

BHC clinicians continue to share their expertise with broader audiences. Dr. Powers presented on PEM and ME/CFS at the **Dysautonomia International Conference** and the **National Physical Therapy Conference**, reaching hundreds of patients and clinicians. Additional presentations at the **Awareness4POTSies conference** further expanded BHC's educational reach.

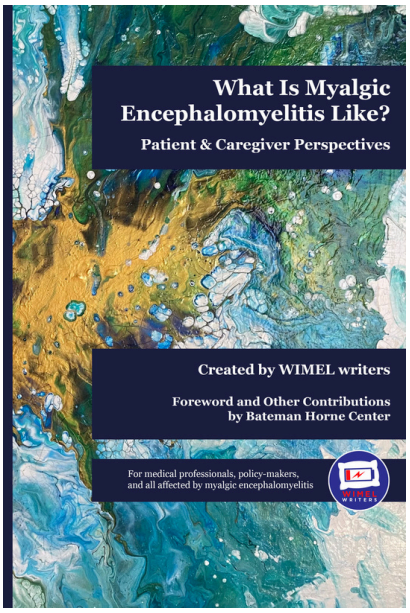


Long COVID & Post-Infectious Syndromes ECHO

Since 2022, in partnership with the University of Utah, Bateman Horne Center's Long COVID & Post-Infectious Syndrome ECHO has connected an interdisciplinary community of clinicians from major academic and healthcare organizations across the United States and internationally.

The program continues to help clinicians build knowledge and improve care for patients with complex conditions.

HEALTH UNIVERSITY OF UTAH · Project ECHO · Bateman Horne Center RESEARCH | CLINICAL CARE | EDUCATION



BHC Contributes to New Book: What Is Myalgic Encephalomyelitis Like?

BHC clinicians and medical colleagues wrote the chapter introductions for the newly released *What Is Myalgic Encephalomyelitis Like? Patient & Caregiver Perspectives*, a book by an international group of people living with ME/CFS and related illnesses. The book gathers 80 first-hand accounts of the many ways ME/CFS shows up in daily life, with the goal of deepening global understanding of a disease that has severely disabled millions of people.

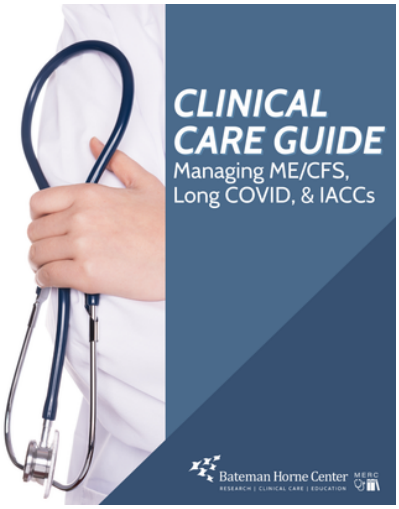
The book is written for a broad audience: medical professionals, students, policymakers, researchers, caregivers, and anyone affected by ME/CFS. Each chapter introduction offers a clinician's perspective on the stories that follow, so clinical understanding and human experience sit side by side.

In the book's foreword, BHC Executive Director Tahlia Ruschioni writes, *"We believe in the power of lived experience to change medicine, not as a supplement to evidence, but as evidence in its own right."*

Bringing voice to the lived experience is not only a powerful tool, but a way to connect with the community members living this daily reality. It is also a resource worth placing in your clinician's hands.

Clinical Care Guide & Patient Stories Reach 300 Medical Training Programs

This fall, Bateman Horne Center partnered with the Whittemore Peterson Institute to mail BHC's *Clinical Care Guide*, which covers ME/CFS, Long COVID, and related conditions, and *What Is Myalgic Encephalomyelitis Like? Patient & Caregiver Perspectives*, a book of essays by people living with ME/CFS and their caregivers, to deans at 213 U.S. medical schools and to directors of 87 internal and family medicine residency programs.



The mailing capped a year of work to get the Clinical Care Guide to clinicians, and the people who train them. Earlier this year, BHC sent the guide to academic administrators who shape medical school curriculum and to 175 providers recommended by members of our community.

Adding the *What Is Myalgic Encephalomyelitis Like?* book this fall paired practical clinical guidance with first-hand accounts of life with ME/CFS, making a stronger case for including the illness in medical education. Internal and family medicine residents will become the primary care doctors most people see first, so reaching them during training is one of the most lasting ways to help patients get diagnosed sooner.

This work was made possible by generous donors and support from Open Medicine Foundation as part of our collaborative Medical Education Resource Center.

WPI Whittemore Peterson Institute · WIMEL Writers · Open Medicine Foundation® HOPE Leading Research. Delivering Hope.

Welcome to BHC!



Douglas Jones, MD
Medical Director

My patients are what drive me in this work, and I'm committed to helping them find paths forward.



Megan Oudekerk, MSN, APRN, FNP-C

I have personal ties to ME/CFS and its comorbidities, and I consider my work at Bateman Horne Center a calling to bring hope and healing.



Jennifer Bliss, AGNP-C

I thoroughly enjoy visiting with both patients and research participants, who teach me about grief, sustaining hope, and staying curious.



Lisa O' Brien
Finance Director

I'm grateful to be part of a team whose mission is so close to my heart and I look forward to helping BHC grow and thrive.



Courtney Baker
Comms/Dev Director

I'm honored to help tell the stories of people living with complex chronic illness; work rooted in years of advocacy for children and in my own lived experience.



Clayton Powers, DPT
Education Director

I work to transform healthcare through compassionate, individualized patient care and education for healthcare professionals.



Amy Mooney, MS, OTR/L Allied Prof

I am passionate about helping people with ME/CFS and Long COVID find practical ways to manage daily life within their available capacity.



Erica Loftus
Medical Assistant

I've always had a special interest in chronic illness and rare disease, and I find purpose in helping patients live their lives as fully as possible.



Bridget Valente
Patient Care Coordinator

I love being part of a team that makes a difference in patients' lives and strives to make every patient feel welcomed, supported, and cared for.

Learn more about our staff!

SCAN ME!

Ways to Give

Everything in this issue, from new voices on our team to our first Access to Care patients, exists because people decided this work was worth building. If year-end giving is on your mind, now is a good time to consider the following giving options.



Donor-Advised Fund (DAF)

A DAF lets you set aside charitable dollars and recommend grants to the causes you care about. Simply log in to your DAF account through your sponsoring organization and provide our charity name and Tax ID/EIN number from the bottom of the page. Then choose your grant amount and submit your recommendation.

Qualified Charitable Distribution (QCD)

If you are age 70 1/2 a QCD from your IRA is another tax-smart way to give. QCDs can come directly to BHC and may count toward your required minimum distribution. Your financial advisor can help you decide what's right for you.

Employer Matching

If you or someone you know works for an organization that has employer charitable gift matching, provide our charity name and Tax ID/EIN number at the bottom of the page.

Stocks/Securities & Planned Giving

Email Angela Linford, BHC Executive Liaison, at outreach@batemanhornecenter.org

Other Ways to Give

- **Mailed Check**
  Bateman Horne Center
  5187 Ascension Way, Suite 200
  Murray, UT 84123

- Credit & Debit Cards
- Digital Wallet
- PayPal
- Venmo
- Cash App Pay
- US Bank Transfer (ACH)

Charity Information

- Charity name: Bateman Horne Center of Excellence
- Tax ID/EIN: 87-0687610

