



BHC Quarterly Newsletter

August 2024

Progress at a Glance...

I hope this communication finds you well and in good spirits. On behalf of everyone at the Bateman Horne Center, I want to express our deepest gratitude for your generous support.

Thanks to your efforts, we continue to make remarkable strides in our clinical care, research and provider education programs.

Our clinical care team has been at the forefront of providing exceptional patient care. With every patient we see, we add to the body of knowledge on how to better understand and treat complex chronic diseases.

Our research team continues its partnerships that are leading to several groundbreaking treatment options. We understand that quality care begins with well-trained providers and have expanded our education program at every opportunity and to multiple disciplines.

We are excited to share some of our recent successes with you in the following paragraphs. They are a testament to what we can achieve together.

With heartfelt appreciation,

Executive Director
Rob Ence, MBA

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Research Spotlight

The BHC research team is passionate about advancing clinical research to benefit our community. Each team member brings unique skills and a shared dedication to improving patient care through impactful research. We're committed to pushing the boundaries of what's possible in treating ME/CFS and Long COVID, with the ultimate goal of making a positive difference in our patients' lives.

Milestones

- Completed an investigator-initiated, randomized, double-blind, placebo-controlled trial of oxaloacetate for treating ME/CFS fatigue. The data is being analyzed, and manuscripts are being prepared for publication—stay tuned for the results!
- Our clinical trial exploring valacyclovir plus celecoxib for Long COVID reached a major milestone: we successfully enrolled and randomized 60 participants in less than a year. With enrollment now complete, we're diving into data analysis.
- Collaborated with Dr. Vincent Lombardi from the University of Nevada, Reno, to enroll 25 participants in the NIH-funded study, "Development of humanized microbiota mouse models of ME/CFS."
- We're excited to announce the enrollment of our first participant in the RECOVER-AUTONOMIC clinical trial, testing ivabradine as a treatment for Long COVID.



Ongoing & Upcoming

- Enrollment continues for our trial of oxaloacetate for Long COVID fatigue—aiming to provide new insights into treatment options.
- The RECOVER-AUTONOMIC study is still enrolling participants, focusing on innovative treatments for Long COVID.
- We're gearing up to start a new clinical trial of Hizentra® for treating POTS in Long COVID patients.



Founder & Chief Medical Officer Lucinda Bateman, MD

Many obstacles slow the translation of science toward clinical applications, especially treatments. A good example might be multiple sclerosis (MS). The lesions of multiple sclerosis (MS) in the brain were seen on autopsy as early as the late 1800s. But it wasn't until the 1970s and 1980s when MRI scans became clinically available, that multiple sclerosis could be visualized in the brain and spinal cord of a living person.

I remember being introduced to MRI technology in medical school in the mid-1980s. Around that time it became possible to measure myelin basic protein in spinal fluid, and the combination of these diagnostic tools dramatically changed the diagnosis rate of MS.

But 40 years later we still don't have a cure for MS. On the positive side, many treatments can be helpful in controlling the progression and easing debilitating symptoms (fatigue, muscle spasms, nerve pain, cognitive impairment, autonomic nervous system dysregulation, etc). Sound familiar? This progress in the development of treatments for MS was finally possible because a relatively definitive diagnosis of MS could be made to decide who to include in clinical trials. Enrolling patients in research with the correct disease improves outcomes.

Diseases like fibromyalgia, ME/CFS, and even Long COVID have seen slow scientific progress because we can't see the disease with MRI scans or use lab tests as biomarkers. Scientists, especially pre-COVID, lacked adequate funding. These problems led to a low diagnosis rate. Without the scientific foundation to make a clear diagnosis, it has been challenging to develop good treatments. The urgent focus on COVID, and now Long COVID, should speed the scientific process.

Notably, BHC made specific efforts in the last 5+ years to take our research data and translate it into objective tests for clinical diagnosis. We focused on the 2015 IOM clinical diagnostic criteria for ME/CFS. For example, we published studies showing that orthostatic intolerance is measurable and an objective diagnosis tool in ME/CFS and Long COVID.

Now that is known across the world.

Today much of our current work, and the work of others, is focusing on how identification of comorbid conditions, such as small fiber neuropathy, mast cell activation and hypermobility. We hope this leads to more rapid diagnosis and development of helpful treatments, even if they aren't curative.

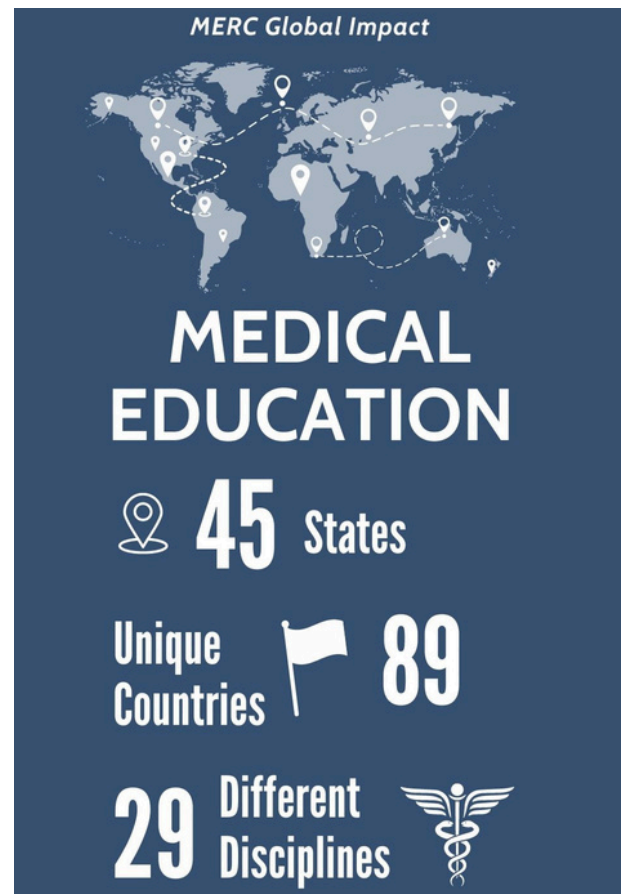
We have come a long way but there is still a long way to go!

Education

Pioneering progress for ME/CFS

The Bateman Horne Center's education department continues to make significant advancements in the field of ME/CFS and Long COVID.

- Over the past two years, our OMF-funded Medical Education Resource Center (MERC) program successfully reached healthcare professionals in 45 states and 89 countries, a testament to the global demand for informed care.
- Our recent partnership with Solve M.E. has led to a compelling four-part series aimed at empowering those who care for individuals with severe ME/CFS, highlighting our commitment to expanding support and resources.
- Looking ahead, we are engaged in several forward-thinking initiatives. We're working closely with the University of Utah to develop a new curriculum for our Long COVID & Post-Viral Syndromes ECHO program, ensuring that our educational efforts remain timely, relevant and applicable. Additionally, we're developing a core set of accredited lectures designed to be integrated into medical schools, clinical rotations, and healthcare settings, laying a solid foundation of knowledge for medical professionals.



Keep an eye out for our upcoming video release, which cleverly explains post-exertional malaise (PEM) through the analogy of a cell phone battery and its apps, making this complex topic easier to understand.

"Educating healthcare professionals about ME/CFS and Long COVID, while supporting the growing patient community, is more critical than ever.

Our small team has made a global impact with limited resources, but we can't continue this vital work without donor support.

Your generosity is essential to sustaining our efforts of expanding education and improving countless lives."

Tahlia Ruschioni, Education Director & Deputy Executive Director



Clinical Care

At the BHC clinic, we remain steadfast in our commitment to providing compassionate and holistic care to individuals with ME/CFS. Our clinicians dedicate significant time to each patient, allowing for a thorough evaluation and treatment of the complex, multi-system nature of ME/CFS and related conditions.

This deep clinical insight not only guides our own research efforts but also contributes to the advancement of ME/CFS research on a broader scale. The knowledge we gain from our clinical practice directly enhances our educational programs, benefiting both the lived-experience community and healthcare providers nationwide.

One of our core missions at BHC is to ensure that ME/CFS patients across the country have expanded access to care from medical providers who understand and effectively treat this condition.



Melanie Hoppers, MD



Brayden Yellman, MD



Jennifer Bell, FNP-C

Clinic Highlights

- **Expanding Access:** BHC providers are actively pursuing licensure in additional states to broaden patient access to specialized care.
 - **Research Advancements:** We've enrolled 20 BHC patients in a multi-site, investigator-initiated study investigating Rapamycin as a treatment for ME/CFS. This study aims to identify potential biomarkers and assess the drug's effectiveness in alleviating fatigue and brain fog.
 - **New Team Members:** We're excited to welcome Dr. Melanie Hoppers, who joined BHC in February. She has been instrumental in our education and research programs.
 - **Leadership Updates:** Congratulations to Dr. Brayden Yellman on his promotion to Medical Director and to Jennifer Bell, FNP-C, on her promotion to Clinical Manager.
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Outreach and Impact

BHC brings thousands together for support, friendship and educational programming.

Our bi-weekly support groups are led by Timothy Weymann, a licensed clinical social worker who has experience navigating life with a chronic illness. Timothy imparts therapeutic teachings and facilitates meaningful conversations that bring coping tools and connection to the lived-experience community.

The monthly Lunch & Learn series is in its 9th year of providing a space for individuals with lived-experience to share information about a topic that has been helpful in their illness journey followed by small break-out rooms that foster connection and friendship making.

Feedback

"Being here with all of you, seeing your faces, and hearing your wisdom and stories, brings a whole new level of connection. I'm truly honored to be part of this group. Thank you."

"Thank you for today's meeting. It was truly uplifting, and I'm grateful for your willingness to tackle the tough issues that help us build a strong foundation for change."

"I really needed you guys today. Thank you from the desert!"

"My first time here for Lunch and learn, wow... what an auspicious day! Gratitude to you, Sara, and the Bateman Horne Center for providing this sacred space. I have been wandering lost looking for my community and today was moving and meaningful beyond words. From my heart to all of yours..."

Help Support the Work We Do!

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.

To make a one-time or recurring donation:



Additional Ways to Give



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.