



Annual Report

2019

24 South 1100 East #205

Salt Lake City, Utah 84102

support@batemanhornecenter.org

Message From Our Executive Team

In 2019 the Bateman Horne Center (BHC) continued to mark important milestones. The addition of a new full-time medical provider and education director are historic. The new opportunities for reaching patients and healthcare providers has never been brighter. The BHC website is undergoing an update with a fresh look and new resources.

New research projects and clinical trials were launched, and talented research coordinators joined our team. BHC continues as a critical partner on two NIH-funded collaboratives and has begun to publish important insights on data analysis of our patient database.

BHC made important progress towards long term financial stability with the introduction of a membership fee as a hybrid revenue model complementary to traditional insurance reimbursements necessary to support a clinic operation that provides specialty services and consultations. Our grant and fundraising development efforts reached new levels of success to assist educational offerings and to support healthcare access for financially vulnerable patients.

Your ongoing support is needed and appreciated.

BHC Executive Team



Suzanne Vernon, PhD
Research Director

Rob Ence, MBA
Executive Director

Lucinda Bateman, MD
Medical Director



Program Highlights

The Bateman Horne Center (BHC) journey started at the turn of the 21st century with a committed vision to advance the diagnosis and treatment of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), and other related comorbidities.

BHC fosters clinical success for the care and treatment of ME/CFS and FM using clinical intelligence derived from data analytics of patient records in the quest for improved medical care for current and future patients.

BHC engages collaborative partnerships to inform healthcare consumers and providers to deliver enhanced quality and improved outcomes through innovation, applied technology, and efficient distribution of knowledge.

Clinical Care

BHC maintains an expert consultation and clinical care center to provide patients an in-depth differential diagnosis, develop a health management plan, and establish well-defined participants for targeted clinical trials for ME/CFS and FM.

Recent Milestones

- Hired an early career physician trained in internal medicine and rheumatology.
- Implemented a new financial model to improve clinic sustainability.
- Created a virtual consultation option to provide guidance for non-BHC patients and their primary care providers.
- Launched virtual BHC patient-only Q&A exchanges with BHC specialists.

What's Next

- Expand healthcare provider capacity as funding allows and encourage mentoring and professional shadowing opportunities.
- Balance BHC providers' clinical demands with growing research and educational outreach opportunities.
- Expand BHC's technology capacity in telehealth, teleconferencing, and updated electronic health record systems.

Research

BHC conducts research to define core signs, symptoms, and decrements in specific functioning. BHC continues to drive biomarker discovery by sharing biological samples and clinical information with the brightest scientists around the world.

Recent Milestones

- Diagnosed/enrolled a unique cohort of ME/CFS patients who have been sick for < 4 years.
- Awarded NIH Small Business Innovation grant with Serimmune.
- Completed a phase 1 & 2 trial to investigate a new drug, CT38, in the treatment of ME/CFS.
- Launched clinical trial with Teva Pharma.
- Launched clinical trial with Tonix Pharma.
- Awarded FDA contract for assessment tools.

What's Next

- Create an optimized data discovery repository to extract research-quality patient phenotypes to identify potential biomarkers and treatments.
- Sponsor and conduct pharmacological and non-pharmacological clinical trials for ME/CFS based on knowledge garnered from BHC clinical and research.
- Conduct testing and measures for impaired physical function and orthostatic intolerance.

Education

Patient and Provider

BHC creates, aggregates, and delivers educational resources and programming for patients and care partners for self-management and empowerment. BHC provides informed and comprehensive educational resources and training for healthcare providers to improve access to quality care. Early and informed intervention of ME/CFS, FM, and related comorbidities, can significantly improve patient outcomes and disease management.

Recent Milestones

- Launched online support groups for ME/CFS FM.
- Continued online classes exceeding 7000 views.
- Hosted the 2nd U.S. ME/CFS Clinician Coalition.
- Hired an experienced education director.
- Keynoted addresses to NIH and the American Academy of Environmental Medicine.

What's Next

- Refresh and update content for BHC website
- Produce ME/CFS educational video shorts with Utah Medical Association seed funding.
- Create innovative healthcare provider instruction illustrating diagnostic tools and targeted treatments.
- Continue monthly education and Lunch & Learn series.

Strategic Value Proposition

BHC addresses ME/CFS and FM limitations including narrow options for patients to access quality clinical care, underfunding of research initiatives, and need for informed educational resources for patients and healthcare providers.

Global End Goal:

People with ME/CFS, FM, and related comorbidities live improved lives through universal access to evidence-informed, precision medicine.

Mission

We empower patients, advance research, and improve clinical care for all those impacted by ME/CFS, FM, and related comorbidities.

Vision

We envision a world where patients with ME/CFS, FM, and related comorbidities are readily diagnosed, effectively treated, and widely met with empathy and understanding.

Development and Charitable Giving

BHC exists to address the gap between no care and broadly available evidence-informed precision medicine by making the discoveries actionable and informing decisions about ME/CFS patient health. Without BHC, many of these discoveries run the risk of not being validated because the disease course varies for patients, there is a lack of consistently applied diagnostic criteria, and small sample sizes have all hampered replicating important discoveries. Our mission resolve is to change that paradigm.

BHC maintains an aggressive and progressive agenda. Development funds are required throughout the year to enable the amplification of research programs, creation and deployment of educational programming, and to support patient access to resources.

Development Funding Priorities

- **Educational Programming** – creation and production of resources for patients and healthcare providers
- **Friends of Shauna B Horne Fund** – providing financial support for access to clinical care for financially vulnerable individuals with ME/CFS, FM, or related comorbidities.
- **Innovative Research** – fosters BHC-led research projects
- **Provider Recruitment** – assists in the start-up costs of recruiting new providers

The Bateman Horne Center (BHC) is a non-profit, interdisciplinary Center of Excellence where clinical care, research, and education meet to collectively advance the diagnosis and treatment of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), fibromyalgia (FM), and other related comorbidities.



Board of Directors

Mary Sue Rominger, Chair

Ted Kaly, Vice Chair

Veldon Sorensen, PhD, Treasurer

Angela Linford, Secretary

Peggy Allen, MS, NP

Dave Mason

Akiko Okifuji, PhD

Jessica Turner

Paul Shephard

Rob Ence, Executive Director, MBA, *(Advisory)*

Message From The Board Chair

As we look forward to 2020, BHC is once again positioned to meet the many diverse challenges that ME/CFS and FM bring. We were so pleased to welcome a new physician, Dr. Brayden Yellman, to BHC in early 2019. His experience in Rheumatology and treating complex medical conditions proved to be a great fit. Drs. Yellman and Bateman make a great team!

We continued to increase the number of patients seen, participated in exciting ME/CFS and FM research, increased opportunities to provide patients and caregivers with knowledge and support by expanding our online and virtual reach, and provided education taught by Dr. Bateman to many medical providers.

I am proud that BHC continues to host the annual ME/CFS Clinician's Summit, and I am honored to chair the BHC Board of Directors. Our Board of Directors is a volunteer board comprised of patients, caregivers, and a scientist researching pain and FM who are highly dedicated and compassionate about helping those with ME/CFS and FM.

We need help from donors to further our important work in helping those with these very disabling and debilitating illnesses. Please support us!

Mary Sue Rominger, Board Chair