

Annual Report

2020

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Message From Our Executive Team

The year 2020 marked a new level of support for the Bateman Horne Center (BHC) from our generous donors and grantors. Combined with a federal Paycheck Protection Plan CARES grant (PPP), this crucial support helped secure our survival during the early months of the COVID-19 lockdown when research and clinical revenues slowed dramatically. In addition, BHC took aggressive steps to maximize our financial resources with staff cross-utilization, temporary reduction of salaries, and negotiated relief for our lease space.

BHC transitioned to telehealth clinical services and delivered extraordinary educational assets including an expansion and refresh of our website. Research projects picked up momentum in the last half of the year and BHC was able to maintain staff levels and associated compensation.

Looking forward, the challenges accelerate as our society experiences the dramatic aftereffects of COVID-19 with a rise in post-viral syndromes. BHC's ability to expand our unique clinical services, including long COVID patients, and increase our provider education programs while continuing to participate in innovative research will not be possible without your financial investment and belief in what we do.

The following report highlights some of BHC's 2020 successes.



Lucinda Bateman, MD Medical Director



Suzanne Vernon, PhD Research Director



Rob Ence, MBA Executive Director

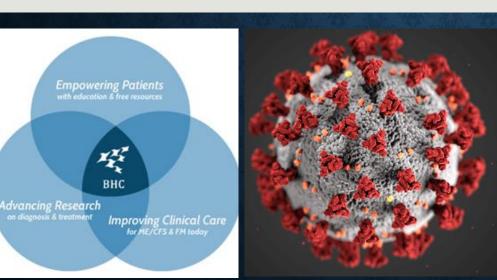
Your BHC Executive Team

BHC in Motion

BHC Strategic Approach



Clinical Testing & Evaluation Research Trials Education & Publishing



Clinical Care

Standard set & practiced by BHC

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), post-viral syndromes, and related comorbidities.

- BHC provides expert consultation and experienced clinical care providing patients with a differential diagnosis and health management plan.
- BHC drives innovative and emerging research pathways to define core signs, symptoms, and decrements in specific functioning.
- BHC provides resources and programming for healthcare providers to advance timely and accurate diagnoses and treatments.
- BHC provides informed educational resources and programming to improve understanding and assist with self-management.

Program Highlights

Research

2020 Milestones

- Published three landmark studies in the medical literature in 2020!
- Completed second year follow-up of 4-year study of the largest cohort of short duration illness ME/CFS patients ever studied providing invaluable clinical and molecular clues about causal pathways of ME/CFS.
- Selected as one of 6 clinical sites to enroll 250 patients in a study to identify blood biomarkers of fibromyalgia that differentiate from other rheumatologic diseases.
- Clinical site for RALLY to evaluate the efficacy and safety of an oral drug for the treatment of fibromyalgia.
- Collaborated with the American Institutes for Research (AIR) and the Food and Drug Administration to develop clinical assessment tools for use in ME/CFS clinical trials.
- Continued as a clinical site for a trial to test the effectiveness and safety of fremanezumab (Ajovy) on patients with fibromyalgia.
- Completed enrollment for RELIEF, a Phase III clinical trial of an oral drug for the treatment of fibromyalgia.

What's Next

- BHC will partner with Precisely to deliver automated health services to long COVID patients.
- Sponsor and conduct ME/CFS and FM clinical trials.

Clinical Care

2020 Milestones

- Served over 450 unique patients with over 1250 clinic visits.
- Created a COVID visitation protocol and telehealth program to ensure access to care during the current pandemic.
- Expanded virtual non-BHC patent consultations to assist out-of-state providers and patients.
- Facilitated 36 ME/CFS and FM virtual support groups and provider chats with 1400+ total participants.
- Produced new audio/visual patient-specific assets (see Provider Education section that follows).
- Surpassed 78,000 patient-specific YouTube education videos views across the United States and 30 countries.
- Hosted monthly Lunch & Learn virtual sessions with international participation increasing average attendance 400%.
- Surpassed 4500 patient newsletter subscribers.
- Co-sponsored and hosted Utah Millions Missing ME/CFS awareness event.

What's Next

- Migrate patient data to an enhanced and more comprehensive Electronic Health Record system .
- Recruit healthcare provider and support staff.
- Improve efficiencies with telehealth visits.
- Engage long COVID patients.
- Expand Dr. Bateman's role in mentoring, teaching, and developing new providers, research, and funding opportunities.

Education

2020 Milestones

- Rolled out updated BHC Website with enhanced offerings on COVID-19, crisis management, new patient and provider education sites, and special resources for youth, care partners, and persons with disabilities.
- Created and hosted COVID-related programming including scientific updates, medical school lectures, sheltering-in-place preparedness, long hauler roundtable, and medical care considerations letter for providers.
- Co-hosted and facilitated the 3rd annual U.S. ME/CFS Clinicians Coalition Summit (virtual) in May with 40+ health care providers.
- Facilitated the inaugural International Neuro ME/CFS Roundtable (virtual) in October with 20+ researchers and health care providers.
- Produced new audio/visual assets.
- Optimized searchability of audio/visual assets on website and YouTube.
- Delivered direct provider education to over 400 health care professionals on concepts involving the diagnostic workup and management of individuals with ME/CFS/FM, post-viral syndromes, chronic pain and fatigue, and orthostatic intolerance syndromes.

What's Next

- Develop new content and audio/visual assets.
- Expand reach to associations and medical schools.
- Continue collaborations with ME/CFS partners.

Strategic Value Proposition

BHC addresses the real-world of 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 evidenceinformed, 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 is focused and dedicated to its strategic value proposition. Development effort results have increased each year since 2016. The 2020 development efforts yielded a 43% increase over 2019. While BHC has made tremendous strides impacting medical education and research, there is still much to be done with your support to ensure a continued shift to informed, quality patient care.

Development Funding Priorities

Your support is critical to achieve BHC's goals in:

- Educational Programming creation and production of resources for patients and healthcare providers.
- Friends of Shauna B Horne Fund providing financial support to clinical care for financially vulnerable individuals with ME/CFS or FM.
- Innovative Research fosters BHC-led research projects.
- Provider Recruitment assists in the costs of recruiting and training new providers.
- Documentary Financial Sponsorship independent project to build awareness of ME/CFS and the Bateman Horne Center story.





Board of Directors Mary Sue Rominger, Chair Ted Kaly, Vice Chair Veldon Sorensen, PhD, Treasurer Angela Linford, Secretary Peggy Allen, MS, NP Sharon Donnelly, MS Dave Mason Akiko Okifuji, PhD Jessica Turner

Rob Ence, Executive Director, MBA, (Advisory)

Message From The Board Chair

As it was for many other organizations, 2020 brought new challenges to BHC due to the COVID-19 pandemic. Led by Rob Ence, BHC's Executive Director, I am so proud of the BHC staff for their teamwork, sacrifice, perseverance, and willingness in overcoming these challenges. Our staff is passionate about what they do and worked very hard to continue helping patients and in advancing knowledge and awareness about these illnesses throughout the difficult pandemic year. Through the efforts of each staff member, along with a PPP loan and numerous generous donors, we are fortunate to be heading into 2021 with robust goals to continue and even expand our mission of helping those with ME/CFS, FM, post-viral illness, and co-occurring conditions.

I am also thankful and proud of the work of the Board of Directors and the governance that they provide. The Board is a volunteer board comprised of patients and caregivers, providers, researchers, and educators who are deeply passionate and committed to BHC's mission and vision.

In 2021, we remain determined that through our clinic, research, education programs, hard work, and compassion we can continue helping those with these illnesses. We need help from donors to further this important work. Please support us!

Mary Sue Rominger, Board Chair

BHC Community

The Board of Directors are stewards of the efforts and talents of those who have built this organization and are responsible to represent the needs and values of the BHC Community defined as patients and their advocates, healthcare providers, researchers, and community educators and volunteers.