# BHC CONNECT

FALL 2023

A newsletter from your friends at Bateman Horne Center of Excellence

#### Welcome

Welcome to the fall issue of BHC CONNECT. We have great things to share with you, including research updates, helpful resources, celebratory milestones, upcoming events, our gratitude, and learner feedback.

This edition of our newsletter looks a little bit different, and there are a few reasons for that. We care deeply about our readers, and research and polling suggest most people benefit from simple, distractionfree formatting, allowing for an easier read and efficient access to content and valuable tools.

We hope you enjoy the new look and that your reading experience is enhanced.



### A look at what's inside...



### Long COVID Research

Bateman Horne Center is conducting two clinical trials studying long COVID.

First, the long COVID drug trial is testing whether a combination of celecoxib and valacyclovir reduces fatigue and other symptoms in women with long COVID. BHC is recruiting participants between the ages of 18-65.

The combination of celecoxib and valacyclovir may inhibit herpes virus activation and replication. In the study, two different doses of valacyclovir, in combination with one dose of celecoxib, will be tested.

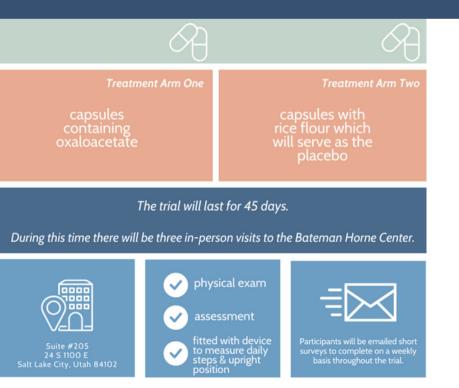
Eligible participants will be compensated \$100 for the screening visit, \$10 weekly for survey completion, and \$50 for all subsequent in-person visits.



blood & urine collection Participants will be emailed short surveys to complete on a weekly basis throughout the trial.

# Click Here for the Drug Trial

# Click Here for the Medical Food Trial



Another long COVID study is a medical food trial, testing oxaloacetate, an energy metabolite, which holds a key place in the TCA cycle also known as the Krebs cycle - the cycle that is essential for the generation of energy in our cells.

This clinical trial will study the effects of oxaloacetate on improving fatigue in long COVID patients.

Eligible participants will be compensated \$50 for each in-person visit. At the end of the study, participants will be provided with a 45-day trial of oxaloacetate, if they are interested.

Visit our website for more information and to complete the study survey(s) expressing your interest in enrolling.

Research shows chronic illness can create chaotic internal processes which often have profound effects on the way we experience ourselves, other people, and life in general. Chronic illness can leave us feeling significantly different than those around us and navigating this is one aspect that can make our journeys particularly difficult. In addition, chronic illness can create a sense of disorientation regarding who we are and our direction. One way we can lessen our suffering is by identifying and validating these experiences as "normal" psychological and social aspects of chronic illness.

According to the CDC, six in ten Americans have chronic illness, with many chronically ill individuals denying symptoms in themselves and hiding symptoms from others. The diagnosis process can often be a long road, and once a diagnosis is established it can often result in simultaneous relief and fear. We become relieved in knowing there is some kind of organization to a chaotic experience, while anxious about what the implications of the diagnosis are on our lives. Knowing that worry and stress can exacerbate chronic illness symptoms, successfully adapting and developing a personalized treatment plan are key.

Chronic illness patients report experiencing depression and anxiety which manifest in various ways: physically, psychologically, emotionally, behaviorally and relationally; which can affect quality of life, lead to fatigue and increased pain, impact our interpersonal relationships, and diminish adjustment. Patients can better cope with anxiety and depression by incorporating strategic approaches such as: engaging in appropriate medical interventions (including psychotherapy); reframing the thoughts we have of our experiences, symptoms and selves; healthy expression that bears witness to our chronically ill lives; being flexible in adjusting to our changing needs; mindfulness practices; and reducing or eliminating unhealthy and unsupportive relational dynamics; which allow for increased tolerance of difficulty, attainment of peace and joy, and a better handle on diseaserelated challenges.

Regarding identity disturbance and development, Weymann teaches the Shifting Perspectives Model of Chronic Illness, which includes four themes: engulfment (i.e., having one's identity taken over by illness), rejection (i.e., denying the reality of one's illness), acceptance (i.e., meeting what's going on without judgment or resistance), and enrichment (i.e., going forward, making the most of our lives as chronically ill individuals). He recommends grieving losses, allowing feelings without judgment; reclaiming what was lost in new ways; developing a new sense of self as priorities and interests shift; and also having awareness of continuity of being through continuing to live life from what we personally value, with our needed adaptations.

Social isolation occurs when people lack a sense of belonging and engagement with others, have minimal social contact, and/or relationships are deficient in quality or fulfillment. It is common for chronically ill patients to experience social isolation due to the low functioning (sometimes overactive) nature of certain body systems. Contributing isolating factors include being home-bound and bed-bound, which are often circumstances in which we find ourselves that can be different than those of family, friends, and neighbors.

When chronically ill patients are able to connect with relatable people; engage in acceptance and adaptation; and secure adequate healthcare and support, healing can occur. Additional effective coping strategies include engaging in self-confidence building activities that accept disability, joining support groups, pacing, and selfadvocacy. Weymann shares, "Even if our bodies don't change - our hearts, our minds, our spirits, our coping capacities can change." We can remind ourselves, as he says, "So, it's like this right now. I don't know how it will be in the future. Since I don't know what will happen, then good things can come as well."

Integrating chronic illness into our lives looks differently for each of us. It is our hope that we can provide ideas and help equip you with solutions to aid in easing the challenges faced by you and your loved ones.



Timothy Weymann is a Licensed Clinical Social Worker, who has worked in the fields of addiction treatment; forensic psychology; program evaluation; education, research, consultation; and mental health counseling for over 16 years.

Timothy is also a chronic illness survivor, who was diagnosed with rheumatoid arthritis and fibromyalgia 10 years ago. In his work to help others heal in the face of health problems and adversity, he integrates and applies psychological research on chronic illness, pain, and resilience, with his special knowledge from the personal experience of being both a healthcare clinician and a patient.

### Recent & Upcoming Events

Long COVID & Post Viral Syndromes ECHO Who's in the Driver's Seat	10/5/23	Brayden Yellman, MD Jennifer Bell, FNP-C
Central America Long COVID ECHO	10/6/23	Lucinda Bateman, MD
Long COVID & Post Viral Syndromes ECHO hEDS/HSD: Relationship to ME/CFS & LC	10/19/23	Braden Yellman, MD Jennifer Bell, FNP-C
Long COVID & Post Viral Syndromes ECHO The Backseat Drivers of Dysautonomia	11/2/23	Brayden Yellman, MD Jennifer Bell, FNP-C Melanie Hoppers, MD
<b>Ehlers-Danlos Conference</b> More Than Hypermobility: An Interplay of Comorbidities	11/4/23	Brayden Yellman, MD
Dartmouth-Hitchcock Medical Center Grand Rounds The Untreated Epidemic	11/6/23	Lucinda Bateman, MD
Long COVID & Post Viral Syndromes ECHO Pacing for PEM	12/7/23	Amy Mooney, OT Clayton Powers, DPT
Family Health Centers of San Diego Craniocervical Instability	12/7/23	Brayden Yellman, MD
<b>UMass Chan Medical School</b> Infection Associated Chronic Illness	12/8/23	Brayden Yellman, MD



## *Click here to view event recordings on our YouTube channel*

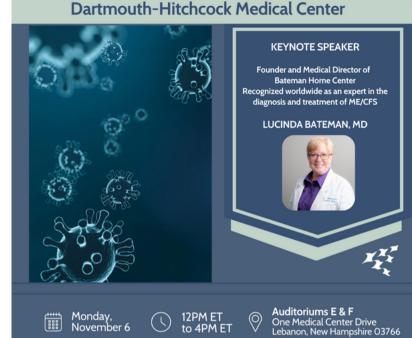
We presented at The California Physical Therapy Conference on evidencebased therapy for patients with ME/CFS and Long COVID with Post-Exertional Symptom Exacerbation (PESE). We continue to teach therapists to be aware of and screen for PEM/PESE, orthostatic intolerance, and other factors that limit tolerance for traditional therapy approaches.







BHC provides resources and programming for healthcare providers, to advance timely and accurate diagnoses and treatments.



In the News...

# The Boston Globe

Long COVID patients aim to educate doctors about their disease



Arna DiMambro Lewis, who has long COVID, is one of the patient advocates who has been organizing a Nov. 6 event at Dartmouth to bring together experts from around the country. She has been forced to make significant changes to her lifestyle because of her symptoms. She used to do yoga and hike, activities she can no longer do. JESSICA RINALDI/GLOBE STAFF

Click Here for the Full Article

Patient advocates of the #MEAction New Hampshire chapter have organized a special grand rounds presentation: "The Untreated Epidemic: Understanding Long COVID & ME/CFS," with the aim of educating healthcare providers, medical students, patients, and caregivers.

Dr. Lucinda Bateman was interviewed by Journalist Amanda Gokee for The Boston Globe, regarding her keynote address at Dartmouth-Hitchock Medical Center. She shared:

"We know a lot about ME/CFS already, so people who are taking care of long COVID don't need to start from scratch.

There's information available, for instance, about how the illness presents and how to help patients live with the illness, even in the absence of a cure.

Primary care providers need training to recognize the symptoms, since there are not enough long COVID clinics to meet the need for care."

Dr. Bateman and the team at BHC focus on research to advance effective treatment of ME/CFS, fibromyalgia, long COVID, and post-infectious conditions, including an emphasis on educating healthcare professionals in the diagnosis and management of complex chronic illness.

### Community

#### UPCOMING SUPPORT GROUPS

date   topic	description	Online		
	and the second all	Support Group		
November 14	talking with caregivers and	Support Market		
Communication &	loved ones about	Group		
Relationships with Chronic Illness	wants, needs, and	Cioup		
Chronic liness	experiences	FREE RESOURCE		
November 21	navigating chronic			
Self-trust	illness by learning	Bateman Horne Center support groups are designed		
	to have confidence in your own	to include people with ME/CFS, FM, Long COVID, and		
	experiences	co-existing conditions as well as supporters and		
		loved ones.		
December 12	keeping calm and	Led by a licensed professional with personal		
Grounding	peaceful in the eye of the storm	experience navigating life with complex chronic		
		illness, each session includes a topic and guided		
		discussion. Attendees are encouraged to participate		
December 19	strategies for positive and	to their level of comfort.		
Navigating the	fulfilling holidays	We strive to foster an inclusive and accepting		
Holidays with Chronic Illness	0	environment for all!		
		Crisis Support		
		Thoughts of suicide		
	os for Sign up fining for	<u>pg. 24 of the BHC Crash Survival Guide</u>		
Calendar via Zoom reminders		<ul> <li>National Suicide Prevention Line</li> </ul>		
Catchdar Via 200111		Dial 988		
		<ul> <li>Call 1-800-273-8255</li> </ul>		
These friendly sessions include a brief presentation		<ul> <li>Visit online:</li> </ul>		
by a volunteer participant, followed by break-out		<u>https://suicidepreventionlifeline.org/</u>		
groups to discuss the "ge				
Individuals with ME/CFS, FM, long COVID and their supporters are invited.		• Vibrant		
supporters die invited.		<ul> <li>Call 888-692-9355</li> <li>Text "Well" to 65173</li> </ul>		
		<ul> <li>Visit online:</li> </ul>		
Lunch & Learn A Free BHC Community Event		<ul> <li>Mittps://www.vibrant.org/</li> </ul>		
A Free BHC Community Event		<ul> <li><u>https://www.vibrant.org/</u></li> <li><u>https://safespace.vibrant.org/en/</u></li> </ul>		
		<u>intps://suicspace.vibrant.org/en/</u>		
		• Warm Line		
		<ul> <li>Warm Line</li> <li>not for crisis, but when you need a listening ear</li> </ul>		
		<ul> <li>Warm Line <ul> <li>not for crisis, but when you need a listening ear</li> <li>Call: 833-773-2588</li> </ul> </li> <li>MyStrength, a free online tool</li> </ul>		
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Bateman Horne Center

<u>https://batemanhornecenter.org/outreach/cris</u> is-resources/

# *Help us raise \$1 Million to provide ME/CFS medical education to providers around the world!*

As we enter the giving season, we are excited to share that our campaign slogan this year is, "Informed Medical Care for ME."

BHC staff, Board, and collaborators are relentlessly committed to improving lives today by increasing access to informed medical care within your local healthcare system. Evidence that the tide is shifting comes in the form of lecture requests from influential institutions across the U.S. and beyond, increased clinical treatment trials, and feedback from medical professionals.

Yet we know that millions experience dismissal and disbelief within their medical and social communities. You deserve the same level of scientific funding, approved treatments, and skilled medical care as individuals impacted by any other illness.

Our goal is to raise \$1 million in 2023. Partner with us on this urgent mission to make informed medical care accessible in local communities. Expand informed medical care today!

"Our providers have deep clinical insight about what helps treat ME/CFS, long COVID and fibromyalgia. A million dollars would allow us to tap into this knowledge and experience to test treatments in clinical trials. This would benefit patients, expand the evidence base, and create partnerships with pharmaceutical and biotech companies."

~ Suzanne, D Vernon, PhD, Research Director



Support Medical Education

$$\mathbf{C} \mathbf{G} \mathbf{G} \mathbf{G} \mathbf{G} \mathbf{G} \mathbf{G} \mathbf{G}$$

24 S 1100 E # 205 Salt Lake City, Utah 84102

Bateman Horne Center is a 501(c)(3) improving access to informed health care for individuals with ME/CFS, long COVID, and fibromyalgia by translating our clinical expertise into medical education and research initiatives. Contributions are fully tax deductible in the U.S. Tax ID 87-0687610

### Bateman Horne Center of Excellence Board of Directors

BHC is fortunate to have a professional and dedicated volunteer Board of Directors who are the stewards of the efforts and talents of those who built and sustain this organization and are responsible to represent the needs and values of the BHC Community.

### **Board of Directors**

Mary Sue Rominger Ted Kaly Veldon Sorensen Sharon Hunter Donnely Peggy Rosati Allen Luke Hansen Alan Light David B. Mason Linda Milne Jessica Turner

"It's an honor to be able to give back to BHC because what they have done and continue to do so very much for those of us suffering from postviral illnesses and fibromyalgia. From patient care to facilitating research, (both clinical and basic science), patient and medical provider education and a life line to those people struggling with the illnesses. Long before COVID made ZOOM a household word, BHC held twice monthly support groups online. It didn't matter if you couldn't get out of bed or not, you had a community sponsored and supported by BHC." EMM, Delaware

"I have been a pw ME/CFS for more than a quarter century. I feel so fortunate to learn and access support from BHC. It is a privilege to be able to make a recurring donation, so that in a small way I may show my support of the great work being done by the Center." BT. New York

"I SUPPORT BHC AND THEIR MISSION BECAUSE THEY CARE ABOUT AND TAKE THE TIME TO COMPREHENSIVELY TREAT EACH INDIVIDUAL PATIENT. THEY PROVIDE FREE EDUCATIONAL RESOURCES TO ELEVATE OTHER CLINICIANS. AND THEY DO RESEARCH THAT IS GROUNDBREAKING AND IMPACTFUL. BHC EXEMPLIFIES WHAT IDEAL HEALTHCARE SHOULD LOOK LIKE."

ANONYMOUS, DOCTOR OF PHYSICAL THERAPY

# Click to Donate

"As a senior on a fixed income, there are always spending choices to make. For me, donating to BHC is an ethical and loving decision, offered in appreciation for skillful and compassionate care throughout my ME/CFS journey. Donating is also my way to participate in their essential education for patients and medical providers outside of BHC. Truly a lasting humanitarian gift." LDM, Utah

> Click for

### Continuing Medical Education

BHC aims to help those in the medical field to learn about and increase their knowledge base of ME/CFS, fibromyalgia, long COVID, post-viral illness, and other accompanying conditions. Providing expert teaching and resources advances treatment to patients everywhere, directly improving lives through quality care.

