Lunch & Learn Recap: BHC's Education Impact

November 21, 2024

Announcements

- Subscribe for Zoom recaps, updates, and invitations for future events.
  - https://batemanhornecenter.org/outreach/newsletter/
- BHC Research is recruiting for two Long Covid studies. Visit https://batemanhornecenter.org/research/ to apply or for additional information.
- Lunch & Learn series is open for presenters. Email outreach@batemanhornecenter.org if you are interested in presenting to the BHC community.

Comments and questions from participants do not necessarily reflect BHC guidance or endorsement. Lunch & Learn topics are selected by the lived-experience presenter.

Tahlia Ruschioni, BHC Deputy Executive Director and Education Director, presented about Bateman Horne Center's medical education program.

- BHC has captured the attention of important institutions and is now seeing the perspective about ME/CFS shift among individuals withing those institutions.
- The medical education program at BHC is important because we target trusted high-quality outlets where clinicians can receive their continuing medical education credits (CME) such as Grand Rounds, Project ECHO (worldwide), and international conferences. Providing education at these outlets requires that BHC proves there is a knowledge gap and that we are reaching the clinicians at that institution/university/medical center in a way that the institution deems important. It can require a lot of groundwork for BHC as the accrediting institution vets our organization, speakers, and content. It is further complicated by the fact that we are an outside entity.
- BHC has provided education at high profile outlets over the past two years. Two notable outlets are the:
  - Grand Rounds at Dartmouth

  - University of Rochester Medical Center where Dr. Yellman gave three Grand Round lectures to Highland Hospital internal medicine, the entire internal medicine department at Rochester, and the neurology department at Rochester, respectively. In three days, 330 clinicians were taught about ME/CFS, long COVID, and other infection-associated chronic conditions. This was made possible by three patient partners in addition to Tahlia. Follow-up comments were received from participants showing that they are having a paradigm shift. They also indicated the desire to send medical residents to BHC for hands-on training which will help us to get more Drs. like Bateman and Yellman.
- In addition, BHC has created incredible international partnerships with Emerge Australia, ICanCME in Canada, CHIR group in Canada, and UK Doctors with ME.
- BHC is now connected to the Federation of State Medical Board (FSMB) where we will work to get ME/CFS written into medical exams.
- The following is taken from Tahlia’s October medical education report. This only includes unique individuals that we are able to track. It doesn’t include YouTube views or traffic to our website. (Several lectures have been given since this report.)

Program Overview (2022–2024)

- Healthcare Professionals (HCPs) Reached:
  - 2022: 2,810 HCPs
  - 2023: 3,370 HCPs
  - 2024 (Jan–Oct): 5,783 HCPs
  - Total (2022–2024): 11,963 HCPs reached across 45 states and 89 countries

- Accredited CME:
  - MERC offers five enduring CME courses, including the only CME focused on postexertional malaise (PEM). These courses have educated healthcare professionals across 29 medical disciplines and are available through 2025.

- Project ECHO:
  - 2022: 14 ECHO sessions focused on breaking down the diagnostic criteria for ME/CFS and related comorbid conditions.

  - o 2023–2024: 11 sessions addressed care management using a case-based approach.
  - o MERC also participated in six additional nationwide and international ECHO programs.

• Professional Training & Education o Hosted four residency rotations, three observerships, one visiting fellowship, two master’s capstone projects, and one doctoral capstone project, totaling 1,130 hours of clinical training.

2024 Impact Overview
MERC has achieved significant progress in broadening its reach, expanding educational offerings, and strengthening its global presence.

Healthcare Professional Reach:
• 5,783 HCPs reached (Jan–Oct 2024) — surpassing the total reach from previous years combined.
• Global Impact: Educated healthcare professionals across 89 countries and 45 U.S. states. Partnerships with leading organizations such as the CDC, NIH (RECOVER), Israeli Ministry of Health, Centre hospitalier de l'Université de Montréal (CHUM), Emerge Australia, ICanCME, and the EDS Foundation of Canada further amplified MERC's international influence.

CME Programs:
• MERC's CME offerings have reached a global audience through platforms like VuMedi and Medscape, continuing to shape medical practice worldwide.

Influencing Medical Governing Bodies:
• BHC is working with the Federation of State Medical Boards (FSMB) and United States Medical Licensing Exams (USMLE) to integrate ME/CFS content into board exams and curricula.
• Contributed the comorbid conditions chapter to a special issue of Health Sciences Review, focusing on infection-associated chronic illnesses and related conditions.

Lectures & Conferences:
• Delivered 33 lectures to-date with 6 more scheduled through December 2024.
• Notable presentations include:
  - o NIH RECOVER (RECOVER Neuro & all of RECOVER)
  - o Schmidt Global Initiative ECHO

o American Physical Therapy Association National Conference
o University of Utah Family Medicine Department Grand Rounds
o International Conference of Clinical & Scientific Advances in ME/CFS and Long COVID (Lisbon)
o Unite2Fight (global conference)
o Emory University's Long COVID ECHO

Upcoming Lectures (Nov–Dec 2024):
• University of Utah Pediatric ECHO
• EDS Foundation of Canada annual conference
• University of Rochester Medical Center Grand Rounds (Internal Medicine & Neurology)

- BHC is also working to secure funding for a new website to ensure the content is easily accessible for clinicians, patients, and caregivers.
- In addition to education for medical professionals we create content for patients and caregivers. Our recent work includes:
    - The Basics series with Clayton Powers, DPT.
    - Life with a Low Battery: Living with ME/CFS (We plan to make more videos to tackles topics such as orthostatic intolerance, MCAS, and pacing with post-exertional malaise (PEM)).

Question and Answer

Q. How do we get this educational material to our own doctors?

A. The following handouts can be given to clinicians.

- Continuing Medical Education (CME) handout
- Project ECHO lectures (It takes providers through the diagnostic criteria, comorbid conditions, and most importantly management guidance.)
- ER Considerations
- Low Dose Naltrexone Management Overview
- Orthostatic Intolerance Management

Q. **What are the best ways to connect our willing provider champions with the right person at BHC?**

A. Have them email Tahlia Ruschioni, Deputy Director and Education Director at outreach@batemanhornecenter.org

Q. Which medical specialties are most likely to sign up for CME or other educational materials?

A. Internal medicine, family medicine, women's health, neurology, and rheumatology. Tahlia plans to place more focus on emergency medicine and cardiology in 2025.

Q. Doctors often must do appeals for medications. Do you have a way to help them with the insurance companies.

A. We are working with insurance companies in California to adopt the NASA Lean Test as a diagnostic tool for orthostatic intolerance. Once we get that done, Tahlia hopes that they will be willing to standardize prescribing certain medications.

Q. What can lived-experience individuals do to help with medical education?

A. Tahlia includes patient-partners in the education that she produces to ensure that the content meets the patients' need. Notably, all our rehab education is produced with a group of patient-partners. The most important thing for members of the community to do is disseminate the educational content and to connect physician champions to Tahlia.

Q. How to get doctors to sign up for the CMEs at BHC and look at the education? (approach and language)

A. To engage physicians, focus on how the education supports their clinical practice by improving patient outcomes, enhancing diagnostic accuracy, and providing evidence-informed strategies for managing complex cases.

Emphasize key benefits such as:

- Access to specialized training on ME/CFS and post-infectious syndromes, tailored to address gaps in clinical understanding.
- Practical tools and insights to better manage challenging conditions that affect multiple systems.
- Convenient, online CME modules grounded in the latest research, designed to fit into a busy clinician's schedule.

If CMEs are free, underscore their accessibility as a way to support professional growth without financial barriers. Avoid jargon and ensure outreach messages clearly demonstrate how this education is directly relevant to their patient population and practice.

Providers also want to feel a part of a network or community-so they aren't on an island. Highlight that many of BHC's educational programs, like the Long COVID & Post-Infectious Syndrome ECHO, offer case-based learning and a network of providers that support one another.

Providers want easily accessible, quick guidance that's based on emerging research, making them relevant to improving care quality.

Q. Are certain medical specialties more likely to be puzzle solvers (such as endocrinologists) that would be good to target with education? Are puzzle solvers better with chronic illnesses.

A. Yes, certain specialties like endocrinology, rheumatology, neurology, infectious disease, and internal medicine often attract clinicians interested in unraveling complex, systemic conditions. These specialties may naturally align with ME/CFS and Long COVID education, as their providers often manage patients with overlapping symptoms and multi-system challenges.

Q. Why have you provided education to Ehler's Danlos Syndrome (EDS) Canada and not EDS US?

A. BHC has the interest and material to provide a medical education lecture for EDS US. We welcome connections to help arrange a meeting.

Q. Do you have ideas of how to get ER doctors and cariologists to get interested in your programs?

A. To engage ER doctors and cardiologists, focus on how education can help them address common yet often misunderstood symptoms like orthostatic intolerance, tachycardia, or unexplained fatigue, which frequently present in emergency settings. Suggested messaging:

- "Learn to recognize and manage conditions like ME/CFS and Long COVID in acute settings, reducing misdiagnoses and unnecessary testing."
- "Gain insights into managing conditions with cardiovascular implications, like postural orthostatic tachycardia syndrome (POTS)."
  Outreach through professional societies (e.g., ACEP for ER doctors or ACC for cardiologists) could also enhance visibility.

  Offer educational materials that guide them in the moment (like the ER considerations handout; OI management guidance; and the 10-Minute NASA Lean Test giving them tools that are quick and easy to implement).

Q. Any chance compounded medications will be approved by insurance?

A. Unfortunately, insurance decisions are largely dictated by policies that are out of BHC's scope. However, patients may advocate for compounded medications by working with their providers to submit appeals or documentation justifying the medical necessity. It may also help to involve patient advocacy groups that address policy changes related to medication coverage.

Q. In many electronic medical record systems (EMR) the ME/CFS code links to "learn more" but doesn't go anywhere or it's an obscure reference to fibromyalgia or other things. How can this be fixed?

A. This requires coordinated advocacy with EMR companies and medical coding organizations. Key steps include:

- Contacting the EMR company to highlight inaccuracies or gaps and requesting updates to reflect the latest ME/CFS guidelines and ICD coding references.
- Partnering with professional organizations or coalitions like Solve M.E. to advocate for these changes on a larger scale.
- Suggesting that providers and institutions raise concerns collectively can also apply pressure for updates.

  Then when you get an opening, be sure to offer education that's freely accessible and accredited through an institution or medical society.

Q. Is there a code for PEM?

A. Currently, there is no specific ICD code for post-exertional malaise (PEM). However, PEM is recognized as a hallmark feature of ME/CFS. Documenting PEM, and the functional impairment caused by PEM, in clinical notes as a critical symptom is essential, even without a direct code. Advocacy for the development of an ICD code for PEM could be a valuable future effort, as it would support better tracking and research.

General Resources

Crisis Resources

- Dial 988
    - What Happens When You Call 988? (Article)
- Dial 911
- Crisis Text Line
- Crisis resource page (BHC)

Support Groups (alphabetical order)

Lived-Experience Support Groups

- BHC Support Group 2nd and 3rd Tuesday at 1 pm MST

  - https://batemanhornecenter.org/events/
- Black COVID-19 Survivors
  - https://www.facebook.com/groups/bcsalliance/
- CFS/ME Friends
  - https://www.facebook.com/groups/CFSMEFRIENDS
- Health Stories Collaborative Creative Meetups
  - https://www.healthstorycollaborative.org/creativemeetups
- International ME Support Chat
  - 11am-1pm EST/ 5 -7pm GMT / 3-5am Melbourne time & 9-11pm EST/ 3-5am GMT/ 2-4pm Melbourne time
  - https://us06web.zoom.us/j/84362703704?pwd=bfKmegaCLNhS6KwOUve7fkcsQjs7sB.1
- Invisible Youth Support Group
  - https://www.facebook.com/groups/invisibleyouthgroup
- Long Hauler Advocacy Project
  - https://www.longhauler-advocacy.org/support-us
- Long COVID Families
  - https://www.facebook.com/groups/4345929175466216
- Massachusetts ME and FM Association Small Group Chats
  - https://www.massmecfs.org/
- #MEAction Living w/ME Support Group
  - https://www.facebook.com/groups/211058135999671
- #MEAction Long COVID Group
- https://www.facebook.com/groups/205703087068863 #MEAction Seniors Connect
  - https://www.facebook.com/groups/391269901334695/?ref=pages_profile_groups_tab&source_id=1408335399448862
- #MEAction Pillow Crafters (Group Crafting Sessions)
  - https://www.meaction.net/pillow-crafters/
- #MEAction Additional Groups
  - https://www.meaction.net/groups/
- ME/CFS Social Group
  - https://www.facebook.com/groups/1202428297198122
- ME/CFS phone support group
  - Occurs on Saturday nights at 8pm, EST.
  - Call: 609-746-1155. Punch in: 915110#. Group is open to all.
- State Specific Long Hauler Facebook Groups

  - https://docs.google.com/spreadsheets/d/1vMNCrONg1oTy5QPzajNUJffu0gk4eBR4o585NosVgsk/edit#gid=0
- Surviving with ME
  - https://www.facebook.com/groups/695317212152964
- The Mighty Group Directory
  - https://themighty.com/groupdirectory/
- The Yarrow Collective's Alternative to Suicide group is a weekly Zoom meeting. It's a free resource for folks who are struggling that is nonclinical peer support. They also have chronic illness and disability support groups.
  - https://www.yarrowcollective.org/

Caregiver Support

- Caregiver Wisdom is an online venture to support chronic illness caregivers. Current free offerings include: a monthly support group, a free online community that's off of social media, and a blog with helpful posts.
- A support group for partner caregivers (please note all caregivers are welcome) takes place the first Sunday of each month at **12 p.m. PT / 3 p.m. ET.** Focuses on monthly topics and has small breakout rooms for closer community connection. To be added to the email list, contact Kim at kim.mecfs@gmail.com.
- #MEAction's support group for all family caregivers takes place the third Saturday of each month at 12:30 p.m. PT / 3:30 p.m. ET. To be added to the email list, contact Denise at caregiver@meaction.net.
- If you are on Facebook, #MEAction has a Facebook group for caregivers
- If you are on Discord, Nia has started a channel for ME/Long COVID caregivers.