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Bateman Horne Center

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E-NEWS

(Formerly OFFER E-NEWS)

July 2015

Bateman Horne Center E-News is a free monthly newsletter providing information on upcoming education meetings, conferences, and other ME/CFS & FM events or programs that may be of interest. It also includes links to what's new on the website, help in managing symptoms, information about local researchers looking for participants, and current articles in the news.

IN THIS ISSUE

- [Education Meeting](#)
- [Bateman Horne Clinic](#)
- [Lunch and Learn](#)
- [In the News](#)
- [BHC Patient & Family Conference](#)
- [Painless Donating](#)
- [Info Links & Social Media](#)
- [Current Patient Studies](#)
- [Volunteer](#)

E-NEWS QUICK LINKS

- [Conferences](#)
- [Donate](#)
- [E-News Archives](#)
- [Education Meetings](#)
- [E-news Subscriptions](#)
- [Volunteer](#)

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Education Meeting

Matt Slonaker, JD

Executive Director, Utah Health Policy Project.

He will talk about patient advocacy (local, state and federal). His talk is titled:

**"What is going on with Medicaid expansion?
What is going on with the Affordable Care Act (ACA)?
How can the Fibromyalgia and Chronic Fatigue Syndrome
community interface with other advocates for the
advancement of ACA and Medicaid Expansion?"**

Wednesday, July 1, 2015 at 7:00 p.m.



Matt Slonaker, born, raised and educated in the Rocky Mountains became UHPP's executive director in September 2013. Educated at the University of Montana, he took an early interest in policy and government, first studying political science and economics, then going on to complete a law degree. Shortly after law school, Matt joined Governor Brian Schweitzer's budget team in Helena working as an economist and tax policy analyst. Washington, DC was the next career stop when Matt began work for Senate Finance Committee Chairman Max Baucus. While serving as nonprofits policy adviser and outreach coordinator, Matt had the opportunity to work on two pieces of landmark legislation: the Affordable Care Act and the American

Recovery and Reinvestment Act. Matt went from staffer to advocate upon taking a position in New York City at Care for the Homeless. At Care for the Homeless, he helped coordinate a coalition of providers of health care for the homeless in dealing with vast changes to state Medicaid policy. Happy to again be working in the West, Matt is working hard with his team and partners in the community to develop strategies that strengthen Utah's health care system.

Location:

Salt Lake County Complex, North Building, 2001 S. State Street,
SLC, UT

Park in the northeast corner of the complex.

**To view the remaining 2015 Education Meeting Schedule,
[click here.](#)**

[Back to top](#)

Bateman Horne Center: Update



OFFER, a Utah-based, charitable, 501(c)(3), non-profit organization, conceived and co-founded by Dr. Lucinda Bateman in 2002, is excited to announce that our plan to absorb and expand the Fatigue Consultation Clinic, founded by Dr. Bateman [two years earlier] in 2000, has been initiated, broadening the scope of our non-profit, now named the Bateman

Horne Center (BHC), to encompass patient care, advocacy, research, and education. OFFER and the Fatigue Consultation Clinic are immediately transitioning to our new name, reflected in our new logo:



Bateman Horne Center

CARE | ADVOCACY | RESEARCH | EDUCATION

The broader goals of this center of excellence, encompassing all that we have been doing for the last 13 years and adding the resources to significantly address the needs of underserved patients for clear diagnoses, state of the art treatment options and robust research capabilities, have been sorely lacking in the state of Utah, as it has in most of the country.

We will continue keep you informed of our rapid progress!

[Back to top](#)

Lunch and Learn

NEW MONTHLY EVENT coordinated by the Bateman Horne Center

Lunch and Learn was held at Archibald's Restaurant at Gardner Village. There were ten people in attendance. Four of those ten had never attended before, two of which were a married couple. Mary Sue Rominger made the presentation since the scheduled presenter could not attend the meeting, and the backup presenter

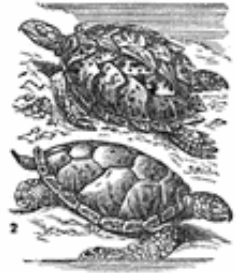
was too ill to prepare a presentation. Since it is the start of summer and vacation season, Mary Sue presented on a "Travel Tips" handout that she and her daughter developed. The group was encouraged to discuss their experiences as well. There was a lot of discussion before the presentation regarding the process and experiences of getting on disability. After the meeting, five stayed until 2:30 talking and sharing information.

The next Lunch and Learn will be Wednesday, July 15 at 11:30 a.m. at the Olive Garden in Sugarhouse just off the 13th east exit on I-80. Linda Milne will be the presenter. Her topic is: Disaster Response Tips for the Chronically Ill and Disabled.

For the cost of your own lunch (your choice, from the menu*), you can enjoy camaraderie and the chance to learn from each other. This is an informal way to socialize, eat LUNCH, and LEARN something relating to FM and SEID (formerly ME/CFS).

RSVP: Please RSVP on the "OFFER Utah" Facebook page: <https://www.facebook.com/OFFERUtah?ref=hl>.

[Back to top](#)



"Nothing is impossible, the word itself says, I'm possible!"
Author: Audrey Hepburn

In the News

Post-Exertional Malaise: History, Characteristics, Evidence

By Lily Chu, MD, MS

2015 Webinar Series, June 18, 2015

Solve ME/CFS Initiative

<https://www.youtube.com/watch?v=hxJPrkWHcBo>

Missing link found between brain, immune system -- with profound disease implications

June 1, 2015

By Josh Barney

University of Virginia/Health Systems

<http://newsroom.uvahealth.com/about/news-room/missing-link-found-between-brain-immune-system-with-profound-disease-implications>

Exercise Stimulates Pain Modulation in Fibromyalgia

Laird Harrison

May 22, 2015

Medscape Medical News

<http://www.medscape.com/viewarticle/845229>

Doctors urged to take chronic fatigue syndrome more seriously

By Ashley Welch

May 15, 2015

CBS NEWS

<http://www.cbsnews.com/news/doctors-urged-to-take-chronic-fatigue-syndrome-more-seriously/>

Majority of Fibromyalgia Drug Trials Are Industry Sponsored

June 5, 2015

(HealthDay News)

Doctors Lounge

<http://www.doctorslounge.com/index.php/news/pb/55739>

Abstract of “The 4I Hypothesis: A Neuro-Immunological Explanation for Characteristic Symptoms of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome”

By Frank NM Twisk, ME-de-patiënten Foundation, Zonedauw 15, 1906 HB, Limmen, The Netherlands

ProHealth.com

June 5, 2015

<http://www.prohealth.com/library/showarticle.cfm?libid=20274>

(Full PDF Document downloadable at International Journal of Neurology Research

Website: <http://www.ghrnet.org/index.php/ijnr/article/view/1058>)

Cheap blood test reveals every virus you've ever been exposed to

By Jessica Hamzelou

04 June 2015

NewsScientist

http://www.newscientist.com/article/dn27659-cheap-blood-test-reveals-every-virus-youve-ever-been-exposed-to.html#.VY7jM_m6eUk

(Original publication in: Science 5 June 2015: Vol. 348 no. 6239

DOI: 10.1126/science.aaa0698

Comprehensive serological profiling of human populations using a synthetic human virome

Stephen J. Elledge, Suzanne D. Vernon, et. al.

<http://www.sciencemag.org/content/348/6239/aaa0698#xref-fn-1-1>)

Belle & Sebastian's Stuart Murdoch on His Unusual Creative Development

“It’s a songwriting method with creative roots in the years that bandleader Stuart Murdoch spent more or less bedridden due to chronic fatigue syndrome, a condition from which he had only partially recovered by the time he formed the band with friends in 1996.”

By Tom Murphy

June 10, 2015

Westword

<http://www.westword.com/music/belle-and-sebastians-stuart-murdoch-on-his-unusual-creative-development-6792595>

Fibromyalgia Mystery No Cure with Legalized Drugs But Marijuana Remains Effective

Posted by James Fenner

June 10, 2015 in Health

Viral Global News

<http://www.viralglobalnews.com/health/fibromyalgia-mystery-no-cure-with-legalized-drugs-but-marijuana-remains-effective/30979/>

Panel urges innovative biomedical research to improve diagnosis and treatment of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

June, 16, 2015

National Institutes of Health

<http://www.nih.gov/news/health/jun2015/odp-16.htm>

Extended-Release Gabapentin May Hold Promise for Treatment

of Fibromyalgia

Jun 12, 2015 | Bill Schu

MD®

<http://www.hcplive.com/medical-news/Extended-Release-Gabapentin-May-Hold-Promise-for-Treatment-of-Fibromyalgia>

National Institutes of Health Pathways to Prevention Workshop: Advancing the Research on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

By Carmen R. Green, MD; Penney Cowan; Ronit Elk, PhD;

Kathleen M. O'Neil, MD; and Angela L. Rasmussen, PhD

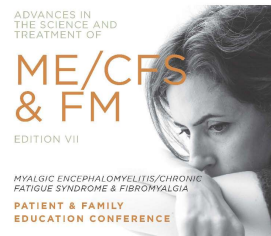
16 June 2015

Annals of Internal Medicine

<http://annals.org/article.aspx?articleid=2322804>

[Back to top](#)

BHC (formerly OFFER) Patient & Family Conference



Some of the videos from "Advances in the Science and Treatment of ME/CFS and Fibromyalgia" Edition VII BHC Provider/Patient & Family Conferences have been posted on YouTube, with more to follow in the coming weeks.

[Back to top](#)

BHC (formerly OFFER) Website: Painless Donating!

Shop at AmazonSmile and Amazon will make a donation to BHC (formerly OFFER) at no extra cost to you!

Go to: <https://smile.amazon.com/ch/87-0687610>

Shop at your favorite stores through iGive.com and BHC (formerly OFFER) will receive a donation (usually about 3%) at no extra cost to you!

Go to: <http://www.igive.com/welcome/lp9/cr49.cfm>

[Back to top](#)

Info Links & Social Media

Fatigue Consultation Clinic

Lucinda Bateman, M.D., at the Fatigue Consultation Clinic in Salt Lake City, is currently giving new patient priority to adolescents ages 12-17, who have symptoms of fibromyalgia. Please call

(801) 359-7400 to initiate a visit. Their website is:
<http://www.fcclinic.com>.

BHC's new website will be coming any day now!!

[Back to top](#)

Current Patient Studies

University of Utah is recruiting females with Fibromyalgia and healthy volunteers for sleep and pain sensitivity study

Researchers in the Department of Anesthesiology are conducting an IRB approved study for females 21-65 years of age that have Fibromyalgia and do not exercise regularly (less than 30 minutes per week). We are also recruiting healthy volunteers that do not have chronic pain and do not exercise regularly. The purpose of this research project is to examine if sleep is related to thermal and ischemic pain sensitivity and cellular aging in women with Fibromyalgia compared to healthy volunteers. After an initial visit, you will monitor your sleep using a wrist watch for seven days then return for a single testing visit where we will evaluate two different methods to test pain tolerance and threshold. **There will be compensation for your time and participation.**

For more information please contact the study coordinator at (801) 581-4232 or e-mail painresearchstudies@hsc.utah.edu
Go to: <http://healthsciences.utah.edu/pain-research-center/studies/pain-and-sleep-study.php>.

The Synergy Trial

A Clinical Trial Investigating a Combination of a CFS Nutrient Formula plus a Currently Available Medication to Treat *Chronic Fatigue Syndrome*

The Fatigue Consultation Clinic is one of four clinics nationally that are participating in this study.

Fatigue Consultation Clinic

Dr. Bateman's Research Team continues to seek research participants. They are currently enrolling in:

- **The Synergy Trial**
- Three drug studies for adolescents with FM
- One drug study for adults with FM
- A number of biomarker studies for patients with CFS.

The link to the FCC Research Department page is:
<http://www.fcclinic.com/research.htm>.

[Back to top](#)

Volunteer

BHC (formerly OFFER) is always looking for individuals willing to help accomplish our mission statement: to educate, advocate and help fund promising research. BHC is a volunteer organization and almost all of us deal with ME/CFS and/or Fibromyalgia on a daily basis. We understand limitations! Many of these jobs can be done from home, using a personal computer with an internet connection. If you have skills you'd like to share, please let us know.

These are some areas where we currently need volunteers:

1. Help with our web presence. Experienced or willing to learn.

- Adobe Flash
- Adobe Dreamweaver
- HTML
- Social Media, including Facebook, YouTube, Google+

2. AV experience. BHC has the equipment.

- Filming
- Editing

3. Patients, caregivers and clinicians who would be willing to tell their story on video for 10-15 minute segments.

If you would like to volunteer in any of these areas, please go to: <http://www.offerutah.org/volunteer.html>.

[Back to top](#)

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