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E-NEWS

(Formerly OFFER E-NEWS)

June 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.

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Education Meeting

There will be no meeting for June

JULY Education Meeting Preview

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?"**



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.

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

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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

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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!

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Lunch and Learn

NEW MONTHLY EVENT coordinated by the Bateman Horne Center

Lunch and Learn was held at Red Lobster in Sugarhouse. There were ten people in attendance. Two of those ten had never attended before. The location was agreeable to all because it was easy access off of I-80.

Mary Dawn presented on "Happiness and Chronic Illness." Quoting from a handout "Happiness isn't about pretending things are all sunshine and rainbows. ... It's about believing you are

worth happiness, no matter your circumstances." Happiness activities include meditation, living in the present, taking care of your body and soul, social support, doing what you love, acts of kindness, gratitude and positive thinking, avoiding social comparison and overthinking, and talking nicely to yourself. The ideas presented were from a free class Mary attended entitled Happiness 101 taught by Frank Clayton. For more information on the class or for enrollment in the next class which starts June 6 visit <http://www.saltlakementalhealth.com/happiness-classes>. Phone numbers and helpful information was exchanged by some attending. Some planned meet-ups. Locations for future lunches were discussed. Presenters are in line through November.

The next Lunch and Learn will be Wednesday, June 17 at 11:30 a.m. at Archibald's Restaurant at Gardner Village, 1100 West 7800 South in West Jordan, Utah.

<http://www.gardnervillage.com/archibalds-restaurant>. Historic Gardner Station is the name of the TRAX stop across the street. Visit www.rideuta.com for the TRAX schedule.

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>.

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"The greatest part of our happiness depends upon our dispositions, not our circumstances."

Author: Martha Washington

In the News

Association of Physical Fitness with Pain in Women with Fibromyalgia: The al-Ándalus project

By Alberto Soriano-Maldonado, et.al.

May 4, 2015

PubMed.gov

Go to: <http://onlinelibrary.wiley.com/doi/10.1002/acr.22610/abstract>

Australian Study Pinpoints Possible Gene Issues in Chronic Fatigue Syndrome

By Cort Johnson

May 22, 2015

Health Rising

Go to: <http://www.cortjohnson.org/blog/2015/05/22/australian-study-pinpoints-gene-issues-in-chronic-fatigue-syndrome/>

For Patients with Fibromyalgia, It May Not Be 'Just' a Headache Conference Coverage > APS 2015

May 18, 2015

Caitlyn Fitzpatrick

MD[®]

Go to: <http://www.hcplive.com/conference-coverage/aps-2015/For-Patients-with-Fibromyalgia-It-May-Not-Be-Just-a-Headache>

Doctors Urged to Take Chronic Fatigue Syndrome More Seriously

By Ashley Welch
CBS News
May 15, 2015

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

May 12th Is Fibromyalgia Awareness Day In Oregon Proclaims Governor Brown

By Kimberly Clark
May 12, 2015
Eugene Daily News

Go to: <http://eugenedailynews.com/2015/05/may-12th-fibromyalgia-awareness-day-oregon-proclaims-governor-brown/>

Findings from a clinical and laboratory database developed for discovery of pathogenic mechanisms in myalgic encephalomyelitis/chronic fatigue syndrome

By N.G. Klimas, et.al.
April 24, 2015

Fatigue: Biomedicine, Health & Behavior

Go to:

<http://www.tandfonline.com/doi/abs/10.1080/21641846.2015.1023652?journalCode=rftg20>

Fibromyalgia Awareness Day 2015:

NOW, THEREFORE, I, Terence R. McAuliffe, do hereby recognize May 12, 2015, as FIBROMYALGIA AWARENESS DAY in our COMMONWEALTH OF VIRGINIA, and I call this observance to the attention of all our citizens.

By Governor Terry McAuliffe
May 1, 2015

Go to:

<https://governor.virginia.gov/newsroom/proclamations/proclamation/fibromyalgia-awareness-day-2015/>

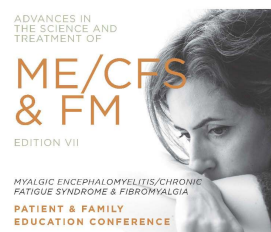
Griffith research may shed new light on cause of CFS

By Louise Durack
May 12, 2015
Griffith University

Go to: <http://app.griffith.edu.au/news/2015/05/12/griffith-research-sheds-new-light-on-cause-of-cfs/>

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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.

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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>

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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 (formerly OFFER) Website

Visit BHC's website (new website coming soon) for additional resources to important health information and CFS/FM research studies at: www.offerutah.org under Resources.

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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>.

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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>.

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