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February 2014 Newsletter

Time is Running Out on a Sweet Supplement Deal

ProHealth and PANDORA Org have joined together in February to raise funds for physician education and advocacy. Purchase your supplements from ProHealth in February, and our organization receives 10%.

**You have a big chance to make a big difference...
And get the healthy supplements you need at a great price!**

**Less than two weeks left!
[Order now!](#)**



More Gas Cards for Patients and Advocacy



Back in November of last year, we were a contestant again in the Citgo Fueling Good gas card voting contest. And thanks to your votes,

WE WON! For the second year in a row.

[See a video of the Citgo presentation to our president at a PANDORA Org Grand Rapids Support Chapter meeting.](#)

Look for an announcement in the near future on how we will be distributing the gas cards to patients.

Teaching Doctors Where They Are - This Time in Michigan

A chance conversation at a hospital during a family member's outpatient operation has led to another opportunity for us to educate more doctors about neuro-endocrine-immune diseases.



Our president, Lori Chapo-Kroger, will give a 1-hour course on ME/CFS and fibromyalgia to a morning shift and an evening shift in both the post-op and post-anesthesiology units at the [Mercy Health St. Mary's Hospital](#).

Of course, we will share with them the sensitivities these patients have to certain anesthesia chemicals and how surgery can trigger the diseases or cause symptoms to get worse if someone already has the disease.

Would you like to become a PANDORA Org ambassador and arrange for physician education of NEIDs in your local area? [Let us know.](#) We plan to have an ambassador training session in April.

More Physician Education in March



Our organization was invited to present information at a mental health fair that will be on March 11 at the [University of Alabama Huntsville School of Medicine](#). We think this is a great opportunity to explain to future

doctors how to distinguish between neuro-endocrine-immune diseases and mental health disorders, as well as how psychologists and psychiatrists can best assist NEIDs patients to cope with the misunderstanding, loss and frustration of having one of these diseases.

We want to thank the [Kristen Brooks Hope Center](#), which provides a suicide hotline, for

Donate Now



Continuation of CFSAC Meeting Scheduled for March 11

Due to a snow event in Washington D.C., the fall 2013 Chronic Fatigue Syndrome Advisory Committee meeting was cut back to just one half-day session. This left many patients unable to give their public comment and some unfinished committee business. The CFSAC has scheduled a makeup day on [March 11](#). [You can watch the meeting through a webinar.](#)

When Is That Supposed to Happen?

We know it's hard to keep up with all the events in NEIDs advocacy and education work. Partly for our own needs, but also to help patients, we set up a calendar on our website.

[Check it out!](#) Let us know if we are missing something important.

NEIDs Events						
Sun	Mon	Tue	Wed	Thu	Fri	Sat
22	23	24	25	26	27	28
29	30	1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31	1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31	1	2	3	4	5	6

Legend
 Events | (Upcoming Meeting) | Webinars & Conferences | PANDORA Org Physician Education | NEIDs.org User Research Chapter | Fundraising

including us in this opportunity.

ME/CFS Treatment Team Call to Action

It's time to do an email to FDA officials. We have continually been working with other ME/CFS Treatment Team advocates to get at least one drug approved for ME/CFS.



And we're making progress!

We have seen the FDA take into consideration disease impact in approving obesity drugs and in allowing a vaccine to be used in a university, even though it does not have FDA approval. ME/CFS, a disease that can leave someone bedridden for decades, demands the same respect as other diseases.

[Only a few minutes. Please send your email today!](#)

Two from PANDORA Org To Give Presentations at the IACFS/ME Medical Conference in March

The bi-annual International Association of CFS/ME medical conference is around the corner, scheduled for March 20-23. PANDORA Org president Lori Chapo-Kroger and contracted communications specialist Tina Tidmore will be giving an oral presentation on Expanding Access to Knowledgeable Care of NEIDs - An Alabama Case Study during the [March 22 session](#).

We will be there all four days.

**If you see us, introduce yourself.
We'd love to meet you!**



Open Medicine Foundation Funding Research into B12



Recently, our partners at the Open Medicine Foundation raised over \$150,000 in [crowdfunding](#) for a study into the benefits of using B12 and folate for a simple and inexpensive treatment in patients with certain gene mutations, including MTHFR, one found in many NEIDs patients. Two doctors, including our medical advisor Dr. Andy Kogelnik, will lead the study.

This follows some good results Dr. Charles Lapp has seen in high doses of B12.

Urging More Communication from the Dept. of HHS

According to our president's November 2013 Chronic Fatigue Syndrome Advisory Committee testimony, communication is a major problem in the ME/CFS patient and government agency relationship. Lori Chapo-Kroger asked if some congressional limitations are preventing Dept. of Health and Humans Services agencies from doing what experts and patients want. If so, why isn't this being communicated? If not, what is the reason?



Step-up Gvmt Communication

[See Lori's testimony that was given to CFSAC members.](#)

Dave Hatfield Represented Patients on GWI Research Panel

One of our recently added board members sat on the Dept. of Defense Gulf War Illness Research Program panel as a consumer reviewer. [David Hatfield, D.M.](#), represented patient concerns in reviewing which



Next CDC Phone Call is about Neurocognitive Testing

On February 25 at 3 p.m. EST, the Centers for Disease Control and Prevention will host another ME/CFS patient conference call.

[Patients can call in to the number they give and enter a passcode.](#)

Neuropsychologist Gudrun Lange is noted for documenting cognitive dysfunctions in ME/CFS patients.



You must [submit your questions for the CDC or for the scientist](#) ahead of time.

Public Service Announcement Still Airing



Don't be surprised if you see a commercial of awareness for ME/CFS. Starting in September last year, the Prevalence video public service announcement has been airing during the "Insider Exclusive" television show and is [on their website](#). At the end, people are directed to [ResearchME.org](#).

Clonidine Drug Trial for ME/CFS Fails

Cort Johnson [reports on a study](#) that theorized that sympathetic nervous system arousal might be at the root of ME/CFS symptoms. Even failed research provides answers that progress our understanding of the disease.

Two Ways to Donate through Ebay



If you're buying or selling on Ebay, [you can use it to donate to our advocacy and education projects.](#)

GWI research applications should be approved for funding.



We are pleased to have broadened the scope and reach of our activities by including patients with other NEIDs on our board. We expect Dave will again serve on future panels.

Helping Each Other



Quilts, computers, store gift cards: just a few items that can be donated to PANDORA Org to be given to other patients in need.

Do you have something others could use? [Tell us about it](#)

Let's Get It Right Team Coordinates Message to IoM



On January 27, the [Institute of Medicine Committee on a Diagnostic Criteria for ME/CFS](#) held its first meeting, which included public comment. We were one of 7 advocates or organizations asked to give a 7-minute presentation. Afterward, other patients made public comments.

To make sure we didn't repeat ourselves, many of us worked together in a "Let's Get It Right" group. You can see a list of our activities, including watching our January 27 presentation, [on our website](#).

[Find out more about the Let's Get It Right team.](#)

NfmCPA Survey Reveals Prominent Fibromyalgia Symptoms

In preparation of the FDA Fibromyalgia Patient-Focused Drug Development Workshop, the National Fibromyalgia and Chronic Pain Association did [a patient survey](#) with very interesting results.

Formulary Watch Article Highlights Complex Illnesses

Our president, Lori Chapo-Kroger, has been published in a medical journal. Her commentary on obstacles to drugs being approved for complex illnesses was



published in the February issue of Formulary Watch. It's titled "[Holes in the drug marketplace: How do we overcome these obstacles?](#)" Her analysis shows the approach to simple diseases needs to be modified when considering drugs for complex illnesses.

Amazon Commission



Shop through [our Amazon store](#) for any item they offer, and we receive a commission. No additional charges.

PANDORA Org Ambassador to Attend the FDA Patient-Focused Workshop for Fibromyalgia



On March 26, the FDA will host the [fibromyalgia Patient-Focused Drug Development meeting](#) at 1 p.m. EST at their White Oak Campus. Jodi Sorenson-Wroblewski, our newest ambassador, will be there to tell the FDA that patients need drugs that work without the sometimes debilitating side effects.

You must [register for the meeting](#) by March 20. We conducted an [Advocates Extraordinaire™ training session](#) when the FDA meeting was scheduled in December last year. This will help you know how to speak effectively to the FDA so they create a report that drug companies can use to design better treatments.

New Brochure for those Recently Diagnosed

Physician Education Continuing in Alabama

In January, Dr. David McLain, a rheumatologist, gave a continuing medical education course to doctors at St. Vincent's East in Birmingham, Ala. This is part of a series on neuro-endocrine-immune diseases that we motivated the healthcare system to sponsor.

Dr. McLain's topic was on latest treatments of fibromyalgia, including recently studied ones, such as low-dose Naltrexone. He said many fibromyalgia patients can see improvements within a week. The presentation noted that many patients are benefiting from taking low doses of quite a few medications that target different pain mechanisms.



Look for an announcement soon on a tick-borne diseases physician course in Ala.

Kogelnik Getting News Media Attention



Through a coordinated effort of the Blue Ribbon Foundation and Washington correspondent Lewellyn King, our medical advisor Dr. Andy Kogelnik has received some news media attention.

He was [interviewed on a radio program](#) and participated in a [press conference at the National Press Club](#).

Physician education is a main goal of the Blue Ribbon Foundation, which received a \$2,000 grant from us last year.

Please support all efforts to improve patient healthcare by education physicians.

I Have What?

A guide for people recently diagnosed with a neuro-endocrine-immune disease.

Fibromyalgia
Myalgic Encephalomyelitis
Chronic Fatigue Syndrome
Tick-borne Infections
Gulf War Illnesses

If you have been diagnosed with one of these chronic, multi-systemic illnesses, know you are not alone in your journey.

Your life has changed, but you can still have a life full of purpose, joy and hope.

Published in 2014 by

PANDORAorg.net

Thanks to a grant from Purdue Pharma, we have published [a new brochure](#) for those newly diagnosed with a neuro-endocrine-immune disease.

We expect this will be distributed primarily through doctors' offices. [Contact us](#) if you know a good place for them to be distributed.

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