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**November 2013  
Newsletter**

## Check Out Our New Board Members and Other Volunteers

This summer we got caught up on a lot of administrative housekeeping. We updated our bylaws, updated our policies and hosted the [first virtual tour of our organization](#). We also had many tell us they wanted to join our organization as chapter (support group) facilitators, ambassadors or in other volunteer roles. We also expanded our board members to include representation of fibromyalgia, Gulf War illness and many other states.

We think you'll be impressed with the skills these folks bring to neuro-endocrine-immune advocacy and awareness. And, aren't they a fine-looking bunch?



Read about the new directors [here](#), our new ambassadors [here](#), our new administrative volunteer [here](#) and our new advisor [here](#). We are training these individuals now. This was the first round. We have others who showed interest in joining our organization. We will be contacting them soon.

Would you like to help? [Fill out this form](#) and let us know how.

## Help Us and We Help You

We are pleased to announce that four patients won \$100 Citgo fuel cards in our random drawings in the last few months. The winners are Barbara Rosita Spivey, Kathy Harris, Beth Bucella Beal, Heather Walstrom and LaLonna Dickens-Collins. We are continuing these drawings now on [our Facebook page](#). We also have given them to patients in need, including two homeless patients. We expect to run out this December.

### Time to Vote Again!

You can help us to help patients. PANDORA Org is again trying to win more fuel cards to be used in defraying advocacy travel costs and to help patients in need. Cast your vote for PANDORA Org daily up until December 1 at this [Citgo Fueling Good page](#).



## Our President Speaks to Crowd at First PALTAD Forum



Our organization was invited to join many other Lyme disease organizations and tell about our work at the first [Partners against Lyme and Tick-Associated Diseases forum](#). Lori Chapo-Kroger (far left in the photo) asked how many present were first diagnosed with fibromyalgia or chronic fatigue syndrome. Quite a few raised their hands. She said that is the reason our organization embraces advocacy on behalf of patients with all of these diseases.

We were pleased to know many already knew of our organization's rich history and activities. We also made many new contacts for networking in the future.

We were glad to see Lyme advocated working smarter, together. At the end of the forum,

**Donate Now**



## ME/CFS Clinician Wants to Find Severely Ill

Dr. Charles Lapp has [put out the call](#) for severely ill ME/CFS patients. He said the International Association of CFS/ME and the Centers for Disease Control and Prevention are wanting to identify and assist bedbound patients. He said to [contact him](#) with the patient's initials (not full name), city of residence, email address and telephone number.

## FDA Changes Prescription Guidelines for Pain Medications

In a move that is sure to have an impact millions, the Food and Drug Administration has put new limitations on hydrocodone medications. This has attracted national news, including the "News Hour" on [PBS](#) and "The Diane Rhem Show" on [NPR](#).

You may remember that our organization [sent in a letter](#) against these changes because the decision should be between the doctor and the patient, taking into account individual circumstances. However, [a recent study raises questions](#) on the effectiveness of opioids to treat fibromyalgia pain.

advocates agreed to create a network to advance a national presence, cohesive message and collaborative advocacy.

## NEIDS Advocacy Shopping

As though made for our organization and the patients we serve, quite a few companies will make a donation to us when people shop through their online store. Check our [Funding Page](#) to shop through [Give Back America](#) and [iGive](#). You can shop your favorite stores, too. Just look at all the store options you have.



### NO EXTRA COST TO YOU -- COMPANY DONATES TO US -- PATIENTS BENEFIT

We also have an [Amazon Store](#) for your holiday shopping needs.



## Our Grant to Blue Ribbon to Help Make Documentary

ME/CFS patient Ryan Pryor, along with Nicole Castillo, [is making a documentary](#) that shows ME/CFS research is cutting edge science, the disparity in care and why. In August, from the MCWPA advertising account, [we gave them \\$2,000](#) to be used toward making this documentary.



They have already put out two videos: [trailer 1](#) and [sneak peak](#). Their long-term goal is to encourage more physicians to provide health care for these patients through a foundation and a fellowship program. We are also working toward that goal.

## Top-Rated Nonprofit Two Years in a Row

Due to the positive reviews from the public and those we serve, [our organization has been included in the few "Top-rated Nonprofit Charities"](#) by Great Nonprofits. This is the second year we have received this status and hope it brings more awareness to the plight of those with neuro-endocrine-immune diseases.



## Two New Support Group Chapters Added

In the last two months, two new support group chapters have joined PANDORA Org. That makes [three across the nation](#). All the support group chapters will change their name to include PANDORA Org and the area they serve. Shauna Mitchell is the chapter facilitator in Montgomery, Alabama; Charlene White is chapter facilitator in Traverse City, Michigan; and Lori Chapo-Kroger is chapter facilitator of the original one in Grand Rapids, Michigan.



## Finding Out the Facts before We Act

## Dutch Doctor Examines Heart Problems in ME/CFS

Some studies have indicated that ME/CFS patients die earlier from cancer and heart problems earlier than the general population. A Dutch doctor [has discovered his ME/CFS patients have heart abnormalities](#) associated with the sympathetic nervous system. The sympathetic nervous system is for activity and "fight or flight."

Heart problems, particularly diastolic dysfunction, have been documented for many years, [particularly by Dr. Paul Cheney](#).

## Brain Atrophe Study Reveals Two Forms of Gulf War Illness

Georgetown University is leading the way in studying the brain of Gulf War illness patients. What's interesting is that like ME/CFS, the abnormality is noticeable after an exercise test. [This recent study](#) may reveal why patient symptoms differ.

## CDC Shocks Nation with Lyme Prevalence Study

Not 30,000 cases, which is how many are reported to them, but 300,000 cases. That's the [estimated number of people who annually get Lyme disease](#), the CDC study reported. This has led to national news media attention, including [the "Katie" show](#) and Discover Magazine asking all patients to show [where they live on a map](#).

## Mayo Says Younger Fibromyalgia Patients Have It Worse

Contrary to what the Mayo Clinic researchers expected, [those under 39 have worse quality of life from fibromyalgia](#) than their older peers.

## ME/CFS Patient Nominated for Wego Health Advocates

Recent controversy over the Dept. of Health and Human Services and Institutes of Medicine contract to do a study to solve the controversies over ME/CFS definitions has put our organization in the crossfires. Many patients and quite a few experts have signed letters asking the contract to be canceled and the 2003 CCC to be adopted by all HHS agencies.

Starting in August, when all of this started, we worked to get accurate information to make sure we match advocacy passion with workable strategy that will lead to the best solution. This led us to discovering that the HHS has not clearly communicated to patients, Chronic Fatigue Syndrome Advisory Committee members and ME/CFS experts. The result has been that many patients and experts have been making demands on government officials that are based on misconceptions and not likely to succeed or lead to the best solution. Through two phone conversations with HHS officials and some emails, we have urged them to quickly and clearly answer the following questions:

- Can the IoM contract be canceled? If not, why not?
- Can the HHS, and all associated agencies, endorse the 2003 Canadian Consensus Criteria based on the recommendations of the ME/CFS experts, patients and because the International Association of CFS/ME endorses it? If not, why not?
- Why did you not follow the CFSAC recommendation to host a workshop and consult with CFSAC and include experts, but instead independently went to the IoM to do a study?
- Considering the IoM used a broad term of "chronic multi-symptom illness," defined Gulf War illness by just two symptoms in their treatment report and did not have enough Gulf War illness experts in the current committee looking to define the disease, what guaranteed can you give that they won't come back with something more broad, and thus more harmful, than Fukuda?
- Does the IoM contract specifically require the IoM to use ME/CFS experts as committee members?
- Does the contract require the IoM to include a patient as a committee member?

We are very concerned with the risks involved with the IoM contract. We are also very concerned with the lack of HHS communication that triggered the uproar and fear patients naturally have based on past actions. Our next action and statement on the matter will be after the HHS puts the answers to our questions out to the public and after the IoM selects the intended committee members for the study. [See our position on what the goals of any ME/CFS definition should be.](#) [See our nominations to the committee and why we made these nominations.](#)

The next CFSAC meeting will be on December 10-11 through a webinar. [Learn more about how to participate here.](#) The IoM contract is one of the topics included.

## Our Covered in Love Project Launched

Recently, a patient contacted us saying she and her family would like to make quilts and donate them to PANDORA Org to be given to patients. This was a wonderful idea! We are always looking for ways to give direct assistance to patients. Already two have been given: one to a patient scared about starting a new treatment in Michigan. The other one went to a patient who gets infusions at the Sierra Clinic in Nevada. A third one will soon be delivered to a patient who is about to undergo a scary operation and another will soon go out to a patient who has experienced family loss.



By referrals or what we observe on social media, we choose patients who are having a particularly hard time due to the neuro-endocrine-immune disease they have, difficult personal circumstances or scary treatments with severe side effects. The comfort quilts surround them in the warmth of knowing they are not alone, that people care for them. This is so important because so many people, including government officials and health care providers, don't understand our challenges. We understand and we care!

If you would like to participate by making similar items for patients, or you know a seniors group or church group that might be interested in participating, [please contact us.](#)

## Our New Collaborative Agreement with OMF

[Tom Kindlin's](#) name is often seen in articles in medical journals where he comments on the scientific soundness or lack of soundness of ME/CFS research. Please take time to give him your endorsement.

## ME/CFS Documentary Raising Lot of Funds

A second ME/CFS documentary project has raised considerable funds toward their project. [Canary in a Coal Mind](#) already has gotten the disease much awareness.

## Fecal Transplants Now Getting More Attention

Immune system diseases often affect gut flora because much of a person's immune system function is in the digestive tract. Some neuro-endocrine-immune patients [are now experimenting with fecal transplants](#) to restore proper intestinal balance. This procedure also received [national news media attention.](#)

## Blogger Gives Gluten-Free and Anti-Allergy Recipes for Thanksgiving

Lyme patient Candice is keeping to the theme of her blog, Infectiously Optimistic. For Thanksgiving, [she gave some tips for those who have special dietary needs](#) that are common in those with neuro-endocrine-immune diseases.

## ME/CFS Patient Awarded Damages after Court Says Hep B Vaccinated Caused Illness

A nine-year-old court case [was settled this summer](#) with over \$2 million being awarded to an ME/CFS patient after becoming sick from a vaccine.

Dr. Andy Kogelnik has been serving as our medical advisor for months. He is a good match for our organization because he embraces the multi-system disorders in his research and clinical care.



This summer, we looked for a way to keep ourselves active in research. Open Medicine Foundation, under the leadership of Linda Tannenbaum, is a nonprofit raising funds for Kogelnik's research. After some negotiation, we formed a collaborative agreement so that we share resources and information with each other. If you are interested in funding research, we recommend this dynamic organization that embraces all the neuro-endocrine-immune diseases. [Please sign up for their newsletter today.](#)

See Linda Tannenbaum's September presentation [part one](#), [part two](#) and [part three](#).

## Grant Funds New Brochures

Thanks to a grant we received, we are publishing new brochures. Already finished is [one about our organization's work](#). This will be great for support groups, health fairs or any time we speak to government, health administrators or doctors.

The next brochure will be a simple introductory guide for those newly diagnosed with one of the neuro-endocrine-immune diseases. We expect this one to be very popular with doctors who can give them to their patients.

If you would like some of these to distribute, [please contact us](#).



## FDA Advocacy: ME/CFS Report Out, Congress to Hear Results

We are still working with other advocates for better policies and procedures that will benefit neuro-endocrine-immune diseases. Approved drug treatments not only may improve patient quality of life, but they can validate a pathophysiology of the disease and increase awareness and physician education.

After the April Drug Development meeting and patients submitting written comments, the FDA [put out a report](#) that describes ME/CFS from the patient perspective. As we said in two press releases, we believe this report is accurate. But as we say in [two press releases](#), they failed to particularly reach out and invite drug developers, so the goal fell short.

On November 15 at 10 a.m. EST, the Energy and Commerce Committee's subcommittee on health [will hear from the FDA](#) on how well they are doing at fulfilling the laws that brought about the April ME/CFS Drug Development workshop. We expect ME/CFS to be mentioned and we submitted questions to one of the committee members that we suggest he ask FDA officials. You can read [background info here](#) when the meeting was planned in October. We understand the meeting will be livestreamed. When we have details, we will let you know on our [Facebook page](#).

## Advocates Extraordinaire Meeting Planned for FDA Drug Development Workshop on Fibromyalgia

The first FDA Drug Development workshop for ME/CFS was a learning experience for us and for the FDA. On December 10, the FDA will hold one for fibromyalgia. As we did in preparation of the ME/CFS workshop, we will hold an Advocates Extraordinaire™ training session for patients who want to give comments to influence the FDA and pharmaceutical companies. Please sign up here if you would like to participate in this training.

**When:** December 5 at 1 p.m. EST. [Register here to attend the webinar training.](#)

## Tom Hennessy Tribute Seen by Many

Our September tribute to the father of NEIDs Advocacy and Awareness Day, Tom Hennessy, drew 90 attendees. We have since uploaded [the recording of the tribute](#), which has been viewed by over 300 people.



## Results from Cannabis Use and Cannabis Receptors Leads to Proposed New Name

Clinical endocannabinoid deficiency, remember that name. [Some are proposing](#) that fibromyalgia, IBS and migraines are a spectrum of the disorder with this proposed label. Cannabis is another term for marijuana.

## Confirmed in Another Study: ME/CFS Receives Little Attention in Medical School

Prof. Lenny Jason has published some research papers exposing the inadequate training doctors receive on ME/CFS. In [a new study authored by him and others](#), only 28% of the schools that responded to their survey said ME/CFS is part of their medical curricula.

## GWJ Advocate Sets up Facebook Just for Research

The many Gulf War illness Facebook pages include anything from veterans' benefits issues to politics. A [new Facebook page](#) will now provide information on research on GWI and related diseases.

## Patients Still Struggle to Get Disability Approval

A [recent article](#) shows in one person's case that not much has changed in recent years when it comes to private disability insurance claims for ME/CFS.

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We want to thank everyone who attended. And we want you to know we are continuing to work toward finishing what Tom started.

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### Lyme Disease Advocates to Hold Education Forum in Ohio

[They are working](#) with [The Tick-Borne Disease Alliance](#), an organization we connected with in our Washington D.C. trip to PALTAD.

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