Public Comment
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Center of Excellence for Myalgic Encephalomyelitis (ME)
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My name is Lori Chap-Kroger, RN. I am the President of Pandora Org, whose mission is to improve lives of neuro-endocrine-immune patients, through assistance, advocacy, education and awareness. I am also a Myalgic encephalomyelitis (ME) patient. I am uniquely qualified to discuss the need and positive effect of Centers of Excellence for Myalgic encephalomyelitis (ME) would have for me personally as well as the million other patients and their families struggling throughout the United States to receive necessary medical treatment and support.

Myalgic encephalomyelitis, also referred to ask chronic fatigue syndrome is a severe, complex neurological disease that affects all body systems. The Chronic Fatigue Syndrome Advisory Committee (CFSAC) made recommendations to the Secretary of Health for a Center of Excellence on multiple dates, and CFSAC members unanimously approved a list of highest recommendations during the May, 2013 meeting. [1] Through what I have learned personally as well as professionally, it is clear that a Center of Excellence for ME/CFS would advance patient health, research and education. ME patients have suffered long enough and we believe the mission of the CDC and the NIH is to implement a plan for Centers of Excellence for ME/CFS immediately.

Centers of Excellence for ME/CFS are imperative because ME/CFS is a multisystem disease that needs a multidisciplinary approach in order to be successful. Primary Physicians, emergency departments and standalone specialties are not equipped to treat a complex illness such as ME. Myalgic encephalomyelitis is not well understood in the medical community and even today many physicians deny the condition is real. These beliefs offer an opportunity to teach the medical community about ME/CFS and affords an ideal vehicle to advance research, expand treatment options and open lines of communication necessary to offer the highest quality of medical care to those who need it the most. Many of these patients cannot find knowledgeable healthcare, they face obstacles in accessing social services and do not have the physical and emotional strength to be their own advocates. For this reason, there is a great need for several strategically placed Centers of Excellence for ME/CFS throughout the United States. A preferred platform for a Center of Excellence for ME/CFS is one that would facilitate evaluation, treatment, research, and public/provider education. These could take the form of appropriately staffed physical locations, or be virtual networks comprising groups of qualified individuals who interact through a variety of electronic media. Outreach and availability to underserved populations, including people who do not have access to expert care, should be a priority in this effort.

Clinical Component

Most clinicians are not familiar with the complex nature of ME/CFS and how it negatively impacts multiple body systems at the same time. Even with advocacy and current research, the belief among many in the medical field is that ME is psychological in nature, and therefore do not take biological based symptoms seriously for those patients. Despite the lack of clinician education the FDA states. *"We consider ME/CFS to be in the category of serious or life threatening diseases.*

Centers of Excellence for ME/CFS would greatly improve patients' health by reducing impediments with delayed diagnosis and improving quality of care. The current medical system is set up for acute care, which is based on an eight-minute office visit model to diagnose and treat illnesses. Myalgic encephalomyelitis (ME) patients require long visits, which is not supported under current traditional primary care physician office visit models. In addition, standard labs and diagnostic tests in the office are not designed to diagnose ME/CFS. Our research has shown that clinics and care providers who have ME/CFS patients aren't equipped to handle their care and are unsure how best to treat their condition. Centers of Excellence for ME would streamline and tailor office visits and assessment times, which would empower the patient and offer stable ongoing long-term medical treatment and support.

My personal journey took more than two years of being bounced back-and forth among 16 doctors before I received a diagnosis at the Mayo Clinic. After my diagnosis, doctors did not know how to treat or manage my symptoms, so it took an additional year to find a doctor who was knowledgeable with ME/CFS. I imagine a day when patients could go to their primary physician with symptoms, and after standard tests rule out other conditions, a patient is referred to a Center of Excellence for ME/CFS. The patient would undergo more in-depth testing and labs done such as: Tilt table tests, Vo2 max testing, cytokine and immune markers, viral load and other tests. These tests and labs would assist care providers in precise diagnosis and appropriate treatment options, which are essential to everyday life.

To understand my situation more clearly, I'd like to share that I live in a rural area with harsh winters. In my area, I cannot locate any medical provider within a one hundred forty mile radius that understands Myalgic encephalomyelitis. In order to receive quality care I must travel two and one half hours, each way. I am not able to drive that long distance by myself and a family member must drive me. In order to do that, my family member must take paid/unpaid time from work, which causes a negative financial impact on them and their family. In addition to the financial impact, the seven-hour day typically causes a flare of symptoms and leaves me bedbound for weeks before I fully recover. Now, if I need to see one of the handful of experts across the country, I'd be on a waiting list for up to three years. I would travel by plane, of which I cover the costs, and in many instances pay out-of-pocket for tests and treatments. If a one-day trip causes worsening of symptoms and negative financial impacts, can you imagine what a multiple day trip would do to a patient and family?

In 2012, PANDORA Org conducted a survey to determine if patients have access to knowledgeable healthcare of their disease, how long they searched for a diagnosis and how many doctors they saw before being diagnosed. Over a thousand people with neuro-endocrine-immune diseases (ME, fibromyalgia, and tick borne illnesses) responded to the survey. Over half of the respondents are not satisfied with their medical care because their physicians do not have the proper training to deal with the complexity of their condition. Furthermore, 71% visited four or more doctors before receiving a diagnosis. And, 68% traveled one or more hours to see a well-informed knowledgeable doctor. Only 21% of respondents were able to receive a diagnosis or medical advice for the disease within one year from when their search began. 80% of patients had to spend more than a year trying to find a diagnosis and proper medical advice. 5% of those surveyed took over twenty years to receive a diagnosis.

As President of national organization that participates in support of patients and their families with ME, the calls to our support line are endless with patients desperate for doctors who understand and can help them get diagnosed and treated. Very few areas have qualified doctors who can treat ME leaving the majority of patients with limited options. The few clinics that are available have a long backlog and are not an option for most patients either financially or physically. In most cases, we struggle to help them. This desperation leads to extreme deplorable living conditions, a terrible quality of life and sometimes suicide.

Compare an ME diagnosis and treatment to that of a cancer patient. The cancer patient is diagnosed quickly and immediately referred to a Cancer Center of Excellence. At the Center they receive support from a multidisciplinary team where a medical coordinator, social worker, nurse, and several doctors are assigned to their case. More importantly, the patient is considered an integral part of their own care team. They are given a packet of resources, phone numbers to each care team member, and receive comprehensive physical, emotional, and spiritual support. Their tests and treatments are covered by insurance. They are eligible for clinical trials and have access to cutting edge technology and treatments. Because of government aid, insurance and charity organizations, they are able to acquire housekeepers, prepared meals, and homecare at little or no cost. ME patients can only dream of this model.

Research and Advocacy Component

Centers of Excellence for ME would advance research, education and training. Centers that are affiliated with teaching hospitals and institutions would attract more investigators. It would transform patient care through scientific discovery. A center could disseminate information and knowledge to other hospitals. The biology of ME would filter through the institution increasing knowledgeable care. Patients would be treated with respect instead of dismissed with biased beliefs. The center would be a knowledge base for surrounding hospitals. If a patient is taken to the emergency department of a nearby hospital a well-informed staff can call the Center of Excellence to direct proper care and treatments.

It’s hard for a ME patient to know if something else besides a flare of symptoms is occurring, because they feel horrible all the time. Symptoms and pain that would send a “normal” person immediately to the hospital is easily overlooked by ME patients. But the reason patients don’t seek medical care in a crisis is because there is a real fear of being treated at an emergency department that doesn’t treat myalgic encephalomyelitis. Experience has taught them that the ED is a place where more harm is done. The next two stories will demonstrate medical and mental abused that ME patients experienced.

In relation to advocacy, the next two stories will demonstrate the need for clinical education.

I recently received these calls on our organizations help line. One person had a daughter with ME admitted to the hospital, and all of their patient rights were violated. They were denied a pediatric consult, denied transfer to another hospital, and the hospital wanted to start controversial treatments that the mother didn’t agree with. PANDORA Org was able to successfully rescue them through contacting the patient’s insurance company to get permission to leave against medical advice and to get preauthorization for admittance to a children’s hospital. It was a traumatic experience because there was an urgency to get them out of this hospital before court orders were obtained awarding the daughter to the State. In route to the children’s hospital, the mother received a call from social worker at the child protection agency. Since everything was documented and the insurance company was alerted to the matter, charges were dismissed. The second call was from pregnant woman with ME who was experiencing severe morning sickness. She was dehydrated and unable to stand on her feet. When the ED staff saw that she has history of chronic fatigue syndrome and fibromyalgia, they transferred her to the hallway. She was embarrassed because she had to keep using the emesis basin in front of other patients. They gave her 1-liter of fluids, but refused to admit her. The ED doctor sent her home, despite her OB GYN order for admittance. PANDORA Org got involved and she was admitted to the OB floor for ten days. We were able to educate the OB chief of staff and the OB department about ME.

If a center of excellence for ME were available, these tragic ED stories would not exist. Harm would not come to these patients because a center could disseminate information and knowledge to other hospitals. A center would be a valuable resource for other healthcare providers and greatly improve patient outcome.

Teaching Component

Our experts are brilliant and caring individuals who are well versed in ME. Unfortunately, some of these experts have received negative criticism by their peers. One issue is there is not a medical specialty certification for complex, systemic illnesses. Having a teaching component in med schools would be the first step towards creating this specialty. ME is not part of curriculum in medical institutions in Michigan. If there was a center of excellence, rounds and classes about ME can be taught at medical schools throughout Michigan. This would create a new generation of providers with an increased knowledge of ME and would assure a true paradigm change.

Again, there is a great need for several strategically placed centers of excellence for ME throughout the United States. A center with clinical, research and education component would positively affect lives by increasing better outcomes. Patients would have increased health and better family harmony. Research and educations aspects would help advance science; knowledge would unilaterally disseminated within institutions and to other hospitals.

Some groundwork has begun. PANDORA org successfully worked for resolutions to be passed in the New Jersey and Alabama legislatures recognizing the need for NEI Centers™ of excellence. We are currently advocating for passage of a resolution in Michigan that acknowledges the need for an NEI Center™ in the state.

PANDORA Org is a national non-profit organization whose mission is to foster research for a cure for myalgic encephalomyelitis and fibromyalgia and other neuro-endocrine-immune (NEI) disorders. Our purpose is to restore the quality-of-life for patients and their families by raising awareness through advocacy and education, promote understanding of the suffering and empowering through our many patient assistance programs. Our vision is to make myalgic encephalomyelitis and fibromyalgia understandable and curable.

1, http://www.hhs.gov/advcomcfs/recommendations/index.html. Last accessed 11/23/2014.

> *Recommendations made for a Center of Excellence for ME/CFS were made on the following dates:* Sept 2004, August 2005, May 2007, Oct 2009 and May 2013.