

THE NATIONAL FORUM

The National CFIDS Foundation

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NCF APPEALS TO PATIENT COMMUNITY TO RAISE ADDITIONAL \$40K FOR NEW RESEARCH BASED ON PATENT FINDINGS

By Alan Cocchetto, NCF Medical Director December 2, 2020 – Copyright 2020

In 2019, Dr. Kenny DeMeirleir was issued a world patent on a new CFIDS discovery, the increase of asparaginyl beta-hydroxylase (ASPH) in the cells of patients [1]. As a result, the NCF approached Dr. Jack Wands, Professor of Gastroenterology and Medicine at Brown University Medical School, to share DeMeirler's patent with him. The NCF approached Wands because he is a world expert on ASPH. After a Zoom meeting with Wands and his team, the NCF determined that it would be worthwhile to fund a \$ 100,000 research grant to Wands for "CFIDS and ASPH." To date, the NCF has already raised \$ 60,000 towards this research and is now appealing to the patient community to help in this fundraising effort. You may be asking, "What is ASPH and why is it important?" Asparaginyl beta-hydroxylase is a transmembrane protein and the member of the alpha-ketoglutarate-dependent dioxygenase family [2]. In the last few decades, accumulating evidence has indicated that ASPH expression is upregulated in numerous types of human malignant cancer and is associated with poor survival and prognosis [3]. The ASPH protein

aggregates on the surface of tumor cells. ASPH is highly expressed in cancers of the liver, pancreas, stomach, colon, breast, prostate, lung and brain. ASPH is necessary and sufficient to promote tumor cell migration, invasion, motility and distant metastatic spread both in-vitro and in-vivo [4]. The NCF feels that it is imperative to pursue this research because we have identified a specific protein that may serve as a critical link to a radiation exposure-induced oncogenic cancer process. We do anticipate collaborative assistance between Dr. Wands' research group at Brown University and Dr. Mothersill's group at McMaster University. In a Zoom meeting with Wand, the NCF learned that pancreatic cancer patients develop a "Chronic Fatigue Syndrome-like illness" several years before the full-blown development of pancreatic cancer. In epidemiologic work done by the National Cancer Institute, CFIDS was associated with an increased risk of non-Hodgkin lymphoma (NHL) and cancers of the pancreas, kidney, breast, as well as oral cavity and pharynx [5]. According to Gail Kansky, NCF's President, "Now is a critical time for the patient community to donate to the NCF to fund Dr. Wands' research group at Brown University. Covid-19 has proven to be a challenge to our typical fundraising efforts." Patients can send donations directly to the National CFIDS Foundation, 103 Aletha Road, Needham, MA 02492 or can phone the NCF at 781-449-3535. As a true charity, the NCF has no paid positions and all money raised goes directly to fund research. To date, the NCF has funded \$ 4.5 million dollars in directed research grants. If you are able, please help us to help you by donating to this important research!

References: 1. Methods and means for diagnosing and and/or treating a fatiguing illness; Applicant: ProteaBiopharma NV; Inventors: Roelant CHS, DeMeirleir KL; World Patent # WO2019/012159; Issued: 17 January 2019 2. Recent advances in research on aspartate β -hydroxylase (ASPH) in pancreatic cancer: A brief update; Hou G, Xu B, Bi Y, Wu C, Ru B, Sun B, Bai X; Bosn J Basic Med Sci 2018 Nov 5;18(4):297- 304. 3. Diverse molecular functions of aspartate β -hydroxylase in cancer (Review); Zheng W, Wang X,Hu J, Bai B, Zhu H; Oncol Rep 2020 Dec;44(6):2364-2372. 4. Inhibitors of beta-hydroxylase for treatment of cancer; Inventors: Wands JR, De La Monte S,Aihara A, Olsen MJ, Thomas JM; Applicant: Rhode Island Hospital, Midwestern University; US Patent Application # 20200361925; November 19, 2020 5. Chronic fatigue syndrome and subsequent risk of cancer among elderly US adults; Chang CM,Warren JL, Engels EA; Cancer 2012 Dec 1;118(23):5929-36.

"Now is a critical time for the patient community to donate to the NCF to fund Dr. Wands' research group at Brown University. Covid-19 has proven to be a challenge to our typical fundraising efforts."

Gail Kansky, NCF President

PRESIDENT'S MESSAGE

By Gail Kansky – Copyright 2020

HELP! Seriously, we want to shut down! Why? Because we're nearly there and want to finish up. No other charity would be as anxious to shut down as we are. Every other charity spends massive amounts of money for salaries. We spend zero! We're all patients and have been following the scientists of Chernobyl for years. We know they're right about the cause being radiation because we made sure our entire cohort was tested for radiation a decade ago. All were positive and even our severity – mild, moderate, and severe – showed up on alpha-waves. But we want to finish and actually have a simple treatment in order to feel great again. We only need one thing for that: money! If you ever wanted to send us some money to help us out, now is the time! We're in the home stretch of our work and want to finish. Like you, we want to have a normal life without the pain, without the fatigue, without all the horrible things that have come our way with CFIDS/ME. And we can have that if we only had enough money to pay for the research that we know will point it out. It won't end up to be a costly drug from the pharmacy because the pharmaceuticals will have to find out what to use and then go through three trials! We need money to pay for just one clinical trial for a simple fix years before Big Pharma finds out and can put it into a costly pill. We want CFIDS/ME to be something we once had. We will remember the life we had and enjoy our freedom from horrible symptoms even more. But we desperately need money to get there. If you are only able to send a small donation, many of those will add up and we'll be able to put this horror we live with behind us and begin living a new life along with you. Therapeutics are on the horizon. We're on the home stretch of our journey. Help us end it for yourself and for all of us. Help us reach the time to shut down because our work is finished and you get to enjoy the rewards along with us! Our last issue of the Forum is on the horizon. We just need the money to see it end. If you can afford to donate, now is the time! Help us get there so we can celebrate together. Please understand that your generosity will have an enormous impact for you and for us. If you'd like your donation to be anonymous, just let us know with your donation.

MEET THE CFS/ME SCIENTIST

By Kathy Collett – Copyright 2020

[Ed. Note: Kathy Collett, one of the Forum's essential volunteers, is from Australia and was asked to interview CFIDS/ME researchers by ME Australia. Dr. Thapaliya is the first she interviewed.]

Dr. Kiran Thapaliya is a Research Fellow working at Menzies Health Institute, NCNED in Australia. His research interest lies in developing new neuroimaging methods for the direct in-vivo mapping of tissue microstructure in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. His research focuses on understanding how changes in tissue microstructure influence MRI signals and the development of new neuroimaging methods to identify biomarkers for ME/CFS. Dr. Thapaliya's recent paper (see Medical Journal Summaries in this issue) sheds light on deep within the brain to reveal increases in TW1/TW2 in white matter. T2W sequences are used in conjunction with TW1 for the detection and characterization of a variety of disease processes. The predominant information provided by T2W sequences is the presence of increased fluid in diseased tissue that results in high signal intensity. Dr. Thapaliya and the team at Griffith University tested Fukuda criteria chronic fatigue syndrome* patients and compared them to Multiple Sclerosis and Schizophrenia. Although MS can be similar to CFIDS/ME, they found their results were unique and quite different from both MS and Schizophrenia. The method they used was to detect changes in tissue microstructure. Using non-weighted MRI (magnetic resonance imaging) scans they found a significant increase in TW1/TW2 in white matter as well as in the basal ganglia resulting in contrasts to healthy controls and other neurodegenerative diseases such as those mentioned above. They state that with an increase of TW1/TW2 in white matter and basal ganglia regions it could potentially relate to an increase in myelination in CFS. Myelination refers to an increase in the fatty sheath surrounding the neuronal processes and fibers that increases the efficiency of electrical transmission. Basal ganglia are a group of structures found deep within the cerebral hemisphere. The study included 45 people with Fukuda chronic fatigue syndrome and 27 controls. *The Fukuda definition of chronic fatigue syndrome is a broader definition than the International Consensus Criteria for ME: NCNED found around 62% of Australians diagnosed with chronic fatigue syndrome met the Fukuda criteria, 32% met the criteria for ME.

How long have you been researching ME, and what brought you to this field? Not very long. I started a year ago. My PhD focused on development of neuroimaging methods to study tissue microstructure in healthy control's brain. When I heard that ME/CFS has unknown etiology, I was very excited to implement my neuroimaging methods in ME/CFS dataset.

What was the turning point for you to start testing for brain abnormalities? The brain is involved in almost all activities. In ME/CFS, impaired concentration and memory, visual and auditory changes, headache and autonomic manifestations predominate its signs and symptoms and confirm primary brain involvement. Previous work from our current team has demonstrated dysfunction in brain stem as well as in many other brain regions in ME/CFS.

What is the difference between weighted and nonweighted MRIs? T1 and T2 weighted images are the basic sequences in MRI. T1 weighted images (T1w) show differences in T1 relaxation time of tissues whereas T2 weighted (T2w) demonstrates difference in the T2 relaxation time of tissue. Sometimes T1 weighted and T2 weighted are also written as T1 and T2 images but not sure about non T1 and T2 weighted images. Here, we acquired clinical standard T1 and T2 weighted images to study structural changes in ME/CFS. Using the ratio of these two images, there is improvement in the tissue contrast that provides much better information about tissue pathology. This method is sensitive to changes in myelin in white matter as well as iron in deep grey matter regions. Why wasn't it possible to achieve the same results with a standard MRI? T1 and T2 weighted MRIs are standard MRI sequence but calculating ratio using T1w and T2w MRIs provide much better tissue contrast.

Why do you think the associated problems may result in an increase in myelination and what physical problems and symptoms would this cause? This is a very interesting finding. We observed elevated T1w/T2w signal intensity in ME/CFS, which is the opposite of CNS disorders. We are still unsure about the associated physiology changes and symptoms. We need to confirm this finding using different methodology in larger ME/CFS cohort. Do you feel you can advance this research by following up with more research on the brain? At this stage, I am very confident that brain abnormalities exist in ME/CFS and we need more data to understand the pathophysiology of ME/CFS. We have also related out MRI findings in the brain with clinical parameters to understand the relationship between MRI findings and ME/CFS. We are always looking forward to collaborating with other scientists to understand brain dysfunction in ME/CFS.

Do you feel the non-weighted MRI scans will lead to a diagnostic test? Not sure about non-weighted MRI. All T1 and T2 images are weighted---that is each is slightly affected to the other.

Do you have any potential treatments in mind? It's too early to say about any kind of treatment. We are currently working on a number of possible treatment options and testing them in the laboratory before we will take a step to a possible clinical trial.

Apart from the impact the brain has on the illness, are you interested in looking into damage done elsewhere in the body, created by toxins for example? Not for now. We are very much focused on working with the brain, in part because we need to understand more about its bodily effects in ME/CFS. However, another team in our group is working on natural killer (NK) cells as a model and are investigating a number of key channels that may be mirrored in other body systems.

Now that you have established problems with T1w and T2w, do you think that it will be possible to reverse the damage done to the brain? Still very early to say anything about brain damage recovery. These are just the preliminary findings. We are planning to use ultra-high field 7T scanner that has a higher sensitivity to changes in brain tissues and anatomy and superior pathophysiological information. If we can reproduce these findings in a larger cohort, then we can confirm information, then we can confirm these findings and possibly help specify targeted drugs that may recover brain damage.

How is technology affecting your work? Technology has a great influence in our current work. We have advanced MRI to acquire data with higher resolution. Many imaging processing toolboxes are available now, and better computing systems than were available ten years ago. Patient recruitment has been much easier through social media like Facebook, twitter and Instagram. I have great respect to those scientists who conducted earlier research with limited resources.

What interests you about researching the brain? The brain is one of the largest and most complex organs in the human body. When I heard that neurodegenerative diseases such as Alzheimer's disease have no cure, that really hit me hard. Then I thought that this is a very interesting area on which to focus.

Do you think Queensland is a good place to be a researcher? What is it like to be a scientist working in Australia at the moment (funding, global pandemic, any issues you think are relevant)? Queensland is blessed with top research institutes and great scientists. This is one of the best places to conduct advanced research activities, especially in my field, because we have great infrastructure available and are surrounded by experts in the field. However, it is always challenging to continue in this field because of limited funding. What is the biggest challenge in researching ME? ME/CFS has heterogenous symptoms and we require more data to understand the pathophysiology of this disease. Our biggest challenge, for now, is to acquire funding motivate participants to take part in the research. I am very thankful to all of the donors who have made great contributions toward this research. In this paper, the cohort is Fukuda criteria CFS.

Why was this chosen instead of the Canadian or International Consensus Criteria? We acquired this data in 2016. At that time, we accepted subjects that met Fukuda or ICC criteria but we combined them in analysis. However, we are aware that ICC and CCC criteria would be more stringent to classify ME/CFS patient and our future research will only accept subjects that meet ICC or CCC criteria.

What are you most proud of in your career so far? Being a recent graduate. I am proud that I can continue research and use all my skills and knowledge to investigate brain abnormalities in ME/CFS. I am also proud to work with the great team at NCNED with its national and international standing.

What would you like to achieve in your career? I would like to identify a biomarker for ME/CFS that could potentially lead to targeted drug development and benefit the wider community of ME/CFS patients.

What do you enjoy doing outside of work? Apart from research, I enjoy jogging, playing soccer and cricket, traveling, spending time with family and hanging out with friends.

JUST ASK!

By Alan Cocchetto, NCF Medical Director – Copyright 2020



The “Just Ask” column is intended to act as a means for patients to inquire about issues related to the NCF’s research activities. This column is NOT intended to act as medical advice in any way, shape or form. The National CFIDS Foundation assumes no responsibility for any action or treatment undertaken by readers. For medical advice, please consult your own personal healthcare providers.

Q: If sodium dichloroacetate is so miraculous for some CFIDS/ME patients, why is nothing more being done about it? There are numerous things that certain patients find extremely helpful and nothing ever comes to fruition unless we buy it ourselves.

A: Dichloroacetate (DCA) has been an agent used for cancer treatment by inducing apoptosis or reversing apoptosis-resistance in a cell [1]. It has been suggested for use in non-small cell lung cancer, glioblastoma as well as breast cancer to name a few. DCA acts as mitochondrial pyruvate dehydrogenase kinase inhibitor [2]. It has been previously suggested that pyruvate dehydrogenase function is altered in CFIDS/ME [3]. A couple of years ago, several papers examined the very question that you are asking [4,5]. In a prospective trial that included 35 CFIDS/ME patients, post treatment analysis identified 6 pre-treatment characteristics that allowed for the differentiation between responders (n = 13) and non-responders (n = 22) with high accuracy (P < 0.0001). Thus, approximately 35–40% of patients appear to benefit from this type

of treatment. It was thought that various comorbidities and/or other unknown factors may be responsible for non-responsiveness to treatment. Since there are still many unknowns regarding CFIDS/ME pathophysiology, this adds to uncertainty regarding treatment. I would, however, definitely refer you to these these two articles by the same author since you have expressed your interest here [4,5]. I hope that this information has been of assistance to you.

References: 1. Method of treating cancer using dichloroacetate; Inventors: Michelakis E, Archer S; US Patent Application # 20090118370; May 7, 2009 2. An abnormal mitochondrial-hypoxia inducible factor-1alpha-Kv channel pathway disrupts oxygen sensing and triggers pulmonary arterial hypertension in fawn hooded rats: similarities to human pulmonary arterial hypertension; Bonnet S et. al; Circulation 2006 Jun 6;113(22):2630-41. 3. Metabolic profiling indicates impaired pyruvate dehydrogenase function in myalgic encephalopathy/chronic fatigue syndrome; Fluge O et. al; JCI Insight 2016 Dec 22;1(21):e89376. 4. Why do some ME/CFS patients benefit from treatment with sodium dichloroacetate, but others do not?; Comhaire F; Med Hypotheses 2018 Nov;120:65-67. 5. Treating patients suffering from myalgic encephalopathy/chronic fatigue syndrome (ME/CFS) with sodium dichloroacetate: An open-label, proof-of-principle pilot trial; Comhaire F; Med Hypotheses 2018;114:45–8.



“Is ‘CFS’ still officially included in the name applied to myalgic encephalomyelitis (ME/CFS or CFS/ME) out of deference to the wittle bitty feelings of the Centers for Disease Control (who created “CFS” to mislead the public) or what? Why do pwME put up with this 32-yr obscenity?”

-Hillary Johnson (author of Osler’s Web)

VITAMIN D AND YOU WITH M.E.

By Bob Huntington – Copyright 2020

With the Covid-19 virus being a global pandemic, there has been many articles promoting vitamin D as an increase of the vitamin has been found to decrease a risk of getting a viral infection and even helpful if you get the pandemic plague. This was also a subject being discussed in the late 1900's when patients were first grappling with large outbreaks of a viral matter that became known as myalgic encephalomyelitis (M.E.) but changed to chronic fatigue syndrome (C.F.S.) when the government of the United States arranged for a committee to agree to change the name of ME to CFS. When some left the meeting and refused to agree to the name change, one physician asked the patient community to, at the very least, call it CFIDS since the immune dysfunction had already been proven scientifically. It was just a few years later in the late 1900's that patients were told to try vitamin D. The majority of patient support groups reported that many patients were taking the vitamin waiting for good results when a highly regarded Australian researcher reported that vitamin D was not only not helpful for CFIDS/ME patients



but downright dangerous. He reported that patients did, indeed, have lower levels of vitamin D but those levels were actually working against the patient by attacking their immune systems. If one took supplements of additional vitamin D, they were actually giving their bodies more weaponry to continue to attack their own bodies! One newsletter published by an ME group from Illinois wrote in their June edition a short article giving “accolades to research being done on common supplements to protect against Covid19.” Indeed, they cited an article from a university in Ireland that wrote how vitamin D could help support the immune system by decreasing the risk of a virus. The report from Ireland was correct but it does not apply to those affected with CFIDS/ME. It would actually make us more susceptible to all viruses!

SHAME ON *PSYCHOLOGY TODAY*

By Donna Sumner – Copyright 2020

On September 23rd of 2020, Psychology Today published an article on their website as part of their fall publication that was written by Temma Ehrenfeld and entitled “Is Chronic Fatigue in your Head?”. That new article was a blog that brought about many complaints from pwCFIDS/ME patients. The title was changed to “How Does Chronic Fatigue Develop?” A group from the UK, MEAction, wrote to Psychology Today and asked them to remove the article from their publication.

The author did write about the severity of ME as well as noting that it was triggered by viral means and cited some information given out by the CDC. What infuriated MEActionUK was her mentioning “chronic fatigue” and “exhaustion” which she wrote added “to the stigmatization and dismissal that people with ME already suffer.” MEActionUK feels that the author’s piece feels that the physical results of the illness stem from the brain’s signals and “can be overcome by the will of the individual if they really wanted to.”

Psychology Today’s published blog does mention that exercise is good for those with ME but it has already been proven that exercise can actually worsen those with ME as well as ignoring those ME patients who are totally bedbound. However, we feel the CDC is given too much credit by MEActionUK as the CDC is responsible for renaming ME “chronic fatigue syndrome”. Indeed, that is where the name of CFIDS came from when Dr. Seymour Grufferman told patients to combat the name of “chronic fatigue syndrome” in the late 1900’s by using the term of CFIDS since the immune dysfunction had already been proven at the time. Knowing how much the term was hated and the way it hurt the patient community, the CDC now refers to it as ME/CFS. Why they just don’t admit the grave error they made quite purposely in calling it CFS and bury that term by just using ME shows that the politics really don’t care to help all those suffering from this nasty disease.

QUICK BITS OF NEWS



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In their 11th version of The World Health Organization's International Classification of Diseases (ICD), following decades of the WHO calling CFIDS/ME "benign myalgic encephalomyelitis", they have finally removed "benign" after one advocate from abroad submitted another proposal (following dozens submitted over the years) that was approved in November of 2020. Our own CDC, who never has had any medical education proposal for ME/CFS/CFIDS, has now given their first OK to make continued education credits available for this illness via Medscape Education. Medscape offers credits for education to physicians and nurses along with other healthcare professionals.

As many articles about Covid-19 have compared the longterm effects to CFIDS/ME, similarities have been noted by many authors as well as by many countries around the world. In Harvard Medical School's Health Blog, Dr. Anthony Komaroff wrote in November of 2020, "It's not unthinkable that 50 million Americans will ultimately become infected. If just 5 per cent develop lingering symptoms, and if most of those with symptoms have ME/ CFS, we would double the number of Americans suffering from ME/CFS in the next two years." One article on CNN Health was entitled "Chronic fatigue syndrome a possible long-term effect of Covid-19, experts say".

In an article published in Village News, Dr. Nancy Klimas described CFIDS/ME as "a brain disease with systemic inflammation...individuals who have an energy system that is like a bucket that is less than half-full" and insists that the patients need to lie flat to enable the bucket from becoming empty.

In 2015, the U.S.'s Institute of Medicine, now called the National Academy of Medicine, described CFIDS/ME as "a serious, chronic, complex, systemic disease that often can profoundly affect the lives of patients" and just three years ago, the CDC dropped their recommendation for graded exercise therapy (GET) and cognitive behavior therapy (CBT) that the NCF has repeatedly stated to be not only unhelpful but often dangerous treatments. Just this year of 2020, the United Kingdom (UK) dropped their recommendations of these therapies. However, just as the UK dropped their outdated symptomology, most primary care physicians there as well as in the US dismiss the newer versions and are not aware of the multiple studies that have proven CFIDS/ME to be neurological. The US ME/CFS Clinical Coalition now has a website for medical providers to help them deliver better care for all of us patients. Please let your doctor know of this.

There are many who didn't believe that the researchers from Chernobyl were correct when they announced, decades ago, that CFIDS/ME was caused by ionizing radiation. Of course, there were many governments who didn't want to admit that as well. To be sure the researchers were correct, the NCF had their entire cohort tested for radiation and every one of them were positive. Those same Chernobyl researchers are still working today and they've found that the grandchildren of the workers have CFIDS/ME as well. The United Nations Treaty on the Prohibition of Nuclear Weapons reached 50 ratifications from 50 countries and, on January 22 of 2021, the ban on nuclear weapons will come into force. No, the United States was not one of those countries who signed on under President Trump but now, with a new president ready to be sworn into Office next month, that should change. Congress can and should step in to prevent such recklessness. For our sake and for the sake of generations to come, it is time to avoid a pandemic of dangerous nuclear weapons testing and proliferation.

FIRST SNOW

By Audrey Sparks – Copyright 2020



Snow is pretty

As it falls

It makes a lovely scene

...but the thought of having to shovel it

Will make me less serene!

ASK BERNIE THE ATTORNEY

By Bernard A. Kansky, Esq. – Copyright 2020

Beware, the after-effects of COVID may enhance the credibility of CFIDS/ME

Q. I have read that many, "long haulers," who have suffered severely with the Covid virus, nevertheless continue to suffer from many of the symptoms of CFIDS/ME for more than a year and some forever and many for the short and/or long-term. foreseeable future. Is there anything such a victim can do to protect his or her rights to SSA (SSDI) disability benefits as well as to short and long-term disability benefits if otherwise available to such a person pursuant to that employer's own disability plans.

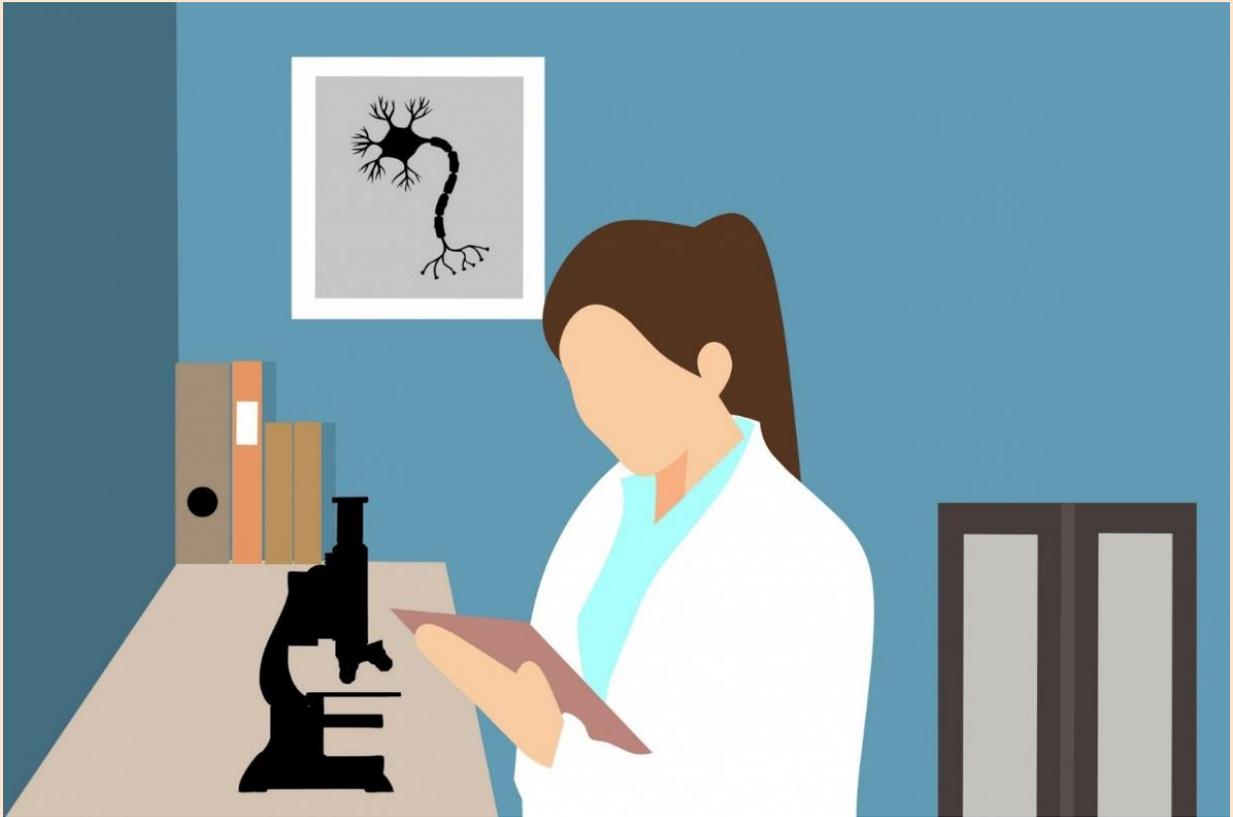
A. It is unfortunate but the fact remains that the aftereffects of the Covid virus' long haul patients has to a large extent, crystallized the multiple disabling disabilities for those who have suffered from CFIDS/ME for so many years. What is important to remember is that you can always file disability claims if you do so timely for any benefits to timely protect your legal rights, i.e., 1 year for SSA (SSDI) benefits and 2 years (or less) for short and long-term disability benefits. The key is to protect those valuable rights, timely, and in the event you recover fully before you would have qualified for any benefits, then everyone wins. However, in the unfortunate event that you remain totally disabled from the multiple disabling symptoms of CFIDS/ME, then all of your documents, filings, vocational expert reports, medical reports and nurses notes etc., will all be in order and sufficient hopefully, to qualify you for the benefits to which you are and should be lawfully entitled. One main caveat- you won't then lose or compromise your rights by reason of your having allowed too much time to elapse before filing!

If you have any questions about the foregoing, please send a brief letter of inquiry to "Ask Bernie The Attorney," care of the National CFIDS Foundation, Inc. to 103 Aletha Road, Needham, MA 02492- 3931, along with a self-addressed and stamped self-enclosed reply envelope. For Better Health Always!

"The pain of living with chronic illness is not limited to physical suffering, but also encompasses people's reactions and expectations."

-Naomi Wittingham (30+ year CFIDS/ME patient)

MEDICAL JOURNAL SUMMARIES



Environmental Health Perspectives, Nov 2019, “Chernobyl Cleanup Workers Had Significantly Increased Risk of Leukemia,”Zablotska et al.

The authors, from medical universities in both the US and in Moscow, were funded by the NIH. Their findings show the increased risk of leukemia from low-dose exposure to radiation which can also come from CT scans. This article reported on a twenty-year study of workers after the 1986 accident at the power plant. The workers showed an increased risk of developing leukemia due to their low-dose exposure of radiation. Other exposures of low-dose radiation can be attributed to airline travel, x-ray luggage inspection, living within 50 miles of a nuclear plant, mammograms, chest X-rays and full body CT scans. The lead researcher of this study, Lydia Zabkitsja, is an MD and PhD and an associate professor of epidemiology and biostatistics at the University of California San Francisco. Low-dose radiation can cause cancer because it can penetrate the body and enter the bone marrow.

Journal of Environmental Radioactivity, 2018, “Low dose or low dose ionizing radiation-induced health effect in the human,” Tang, Loganovsky.

This extensive review suggests that radiation can cause many different problems that include vascular illnesses (ME/CFIDS disease has been proven to be in that category). Dr. Konstantin Loganovsky proposed this as causative of ME/CFIDS in a paper published in 2009 and both he and Dr. Fed Tu Yang mention the NCF in this new paper. Both are radiation experts in two different foreign countries.

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Healthcare (Vol 8, No 3, July 2012), “Healthcare responsibility and compassion visiting the housebound patient severely affected by ME/CFS,” Kinadonf et al.

This special issue was about all severe “ME/CFS” and this article was how those patients often confined to bed can be treated better using holistic models that are more compassionate by the healthcare practitioners.

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NeuroImage: Clinical (28, June 2020), “Mapping of pathological change in chronic fatigue syndrome using the ratio of T1- and T2- weighted MRI scans,” Thapaliya et al.

These Australian researchers from Griffith University and The University of Queensland applied the T1w/T2w method in order to detect any change in the brain tissue in ME/CFS when compared to healthy individuals. Significant abnormalities were found that showed a dramatic increase in both the brain’s white matter as well as in the grey matter foci. Abnormalities were found as well in the basal ganglia but the abnormalities found were the opposite of what has been found in other neurological disorders.

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Healthcare, July 14/2020, “Severe ME in Children,” Nigel Speight.

The physician who authored this paper has had a long history of treating pediatric cases of ME/CFIDS as well as advising on cases of severe cases of ME in children. One of the foremost problems is that physicians are not trained to recognize ME and, most often, fail to diagnose it. Dr. Speight also tells of how 25% of ME patients are bedbound yet so few doctors know how to handle this. To illustrate clinical treatments and appropriate management, this article offers a series of individual case reports.

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Clin Trans Res, Jul;5(3), “Brain Responses in CFS and TMD to Autonomic Challenges: An Exploratory fMRI Study,” Vuong et al.

CFS has dysfunction of the autonomic nervous system and it is also found in temporomandibular disorders (TMD) but both illnesses have pathophysiology that are not understood very well. These researchers explored whether CFS with or not with TMD had differences in brain dysfunction. All three showed increased brain function in but more activity was seen in CFS patients that had TMD. More studies are needed to see how pain and fatigue contribute to this.

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PLOS ONE, July 21 (7), “Plasma proteomic profiling suggests an association between antigen driven clonal B cell expansion and ME/CFS,” Milivojevic et al.

This research included many well-known authors such as Dr. Lipkin, Dr. Peterson and others. They used a liquefied mass spectrometry to analyze the plasma proteomes of 39 patients and 41 healthy controls. After much testing, they found they could predict the status of ME/CFS “using a panel of proteins selected by 3 different machine learning algorithms”. These showed the immune dysregulation of CFS/ME as well as showing that these plasma proteome could very well be “a source of biomarkers” that illustrated ones functioning, their limitations that were both physical and emotional, their pain and general health and more but they admit that their findings must be done with a much larger group in order to be validated.

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Scientific Reports, #18232, “Substrate utilization of cultured skeletal muscle cells in patients with CFS,” Tornas et al.

These authors, mainly from the United Kingdom, found that CFS was a systemic since biopsies showed patients were unable to use glucose effectively due to their muscle cells operating at a dysfunctional level and the result was less mitochondrial respiration. This is the very first study to examine skeletal muscle cells from patient biopsies taken from patients with the illness.

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J Clin Med, July 30, “Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: In Efficacy of Repeat Immunoabsorption,” Tolle et al.

This pilot study was promising for a treatment but much more work must be done before it is used as some patients responded better than others and one had no improvement. It was done to help the B cell antibodies and while some symptoms improved in 4 patients, a study of just 5 patients is not considered enough proof. The studies had many phases and further work is needed and could be a promising therapy for the future.

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Molecular Neurobiology, Oct 2020, “Environmental, Neuro Immune, and Neuro-oxidative Stress Interactions in Chronic Fatigue Syndrome,” Bjerklund et al.

These Australian researchers cited evidence that showed both immunological and environmental factors were involved in CFS/ME and “factors such as low-dose ionizing radiation” is mentioned along with others for helping to develop the disease.

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J Translational Med, Sept 1; 18(1), “Neuroimaging characteristics of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS): a systemic review.” Shan et al.

Neuroimaging is a process that has been used since the early 1990’s for researching ME/CFS. But exactly what characteristics are observed and which are reproducible? These researchers looked for an answer to this and looked at a lot of the texts of articles that mentioned this method and their results. Their findings “suggest abnormal neurovascular coupling in ME/CFS.”

Front in Neurol, Sept 2020, “Characterization of Post-Exertional Malaise in Patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome,” Strussman et al.

This is the first study to come out of the NIH’s study on ME post infections and tells how much PEM can affect the patients via discussions with them. They divided 43 patients into 9 groups and used stationary bikes in 5 groups to help them understand how the disease changes over time. Exertion causes PEM to follow between 24 to 48 hours later and can last from two days to several weeks. About the only new thing this study found was that PEM could come on faster due to their exercise test than daily activities. Of course, the NIH’s National Institute of Neurological Disorders and Stroke feels more research is needed that could lead to treatments for PEM. Will that also take many decades to accomplish?

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Science, Sept. 2020, “Mapping of pathological change in chronic fatigue syndrome using the ratio of T1- and T2- weighted MRI scans,” Thapaliya et al.

These Australian researchers used a more advanced imaging technique to examine the brain and the technique stated in the title were much higher in patients compared to healthy controls in both the white and grey matter of the brain. They also found significant clusters in the brainstem. Elevated myelin and/or elevated iron were found in patients. A much larger study done in 2014 at Stanford University School of Medicine and published in *Radiology* also used a special MRI test and found much more but felt their study was too small despite it being larger than this newer one.

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Clinical Epigenetics, Vol. 12, “Changes in DNA methylation profiles of myalgic encephalomyelitis/chronic fatigue syndrome patients reflect systemic dysfunctions,” Helliwell et al.

DNA was taken from patients and healthy controls and the DNA methylation patterns could be very easily distinguished between the two groups. Very disturbed neurotransmitter pathways as well as neuropeptide reactome pathways showed the pathophysiology of the patient group. This work from New Zealand researchers showed additional changes than were previously found.

Healthcare, 8/2020, “Reductions in Cerebral Blood Flow Can Be Provoked by Sitting in Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients,” MC van Campen et al.

Scientists from the Netherlands and the United States conducted a large trial and found that 86% had orthostatic intolerance and 80%, in tilt testing, showed a reduction in cerebral blood flow. No difference was found in those that also had fibromyalgia but those with postural orthostatic tachycardia had a much higher rate of that flow than without it. Severe patients had those same results while just sitting instead of being tilt tested. Because the results from just sitting were the same as when tilt tested for those with severe ME, it was suggested that tilt testing was not needed for them.

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J Translational Med, Sept, Vol 18, “A SWATH-MS analysis of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome peripheral blood mononuclear cell proteomes reveals mitochondrial dysfunction,” Sweetman et al.

This study was on proteins used to study cells on both patients and healthy controls and 60 proteins were identified in patients but a higher number was found in subgroups and controls. They found many identified in patients were cells involved in mitochondrial and other specific disturbances such as redox regulation, apoptosis and others. They showed patients had deficient ATP production and other areas that suggested oxidative stress. This careful analysis identified the differences between the healthy controls and the patients and some of the proteins could be eventually used as biomarkers as well as defining severity and other important areas. Their extensive research may help to identify subgroups as well as identifying less severe patients. They also found areas that showed many other immune problems such as histone proteins. The authors hypothesized, “there is a metabolic dysfunction in ME/CFS resulting in insufficient energy production and triggering compensatory increases in key OXPHOS proteins to ameliorate this deficiency.”

Front. Neurol., Sept. 18, 2020, “Characterization of PostExertional Malaise in Patients With Myalgic Encephalomyelitis/Chronic Fatigue Syndrome,” Stussman et al.

This study was done by the NIH to study PEM which worsens a CFIDS/ME patient following minimal mental or physical exertion that has been proven and published upon multiple times. The study had nine focus groups that showed core symptoms of difficulties with exhaustion, cognitive problems as well as neuromuscular. The exhaustion is not the same as before subjects were sick but were described as being more like one has with the flu. The PEM was described by patients as affecting all body parts and extremely difficult to treat. Further study was described as necessary to discover how to help patients with this all-encompassing problem. The leading NIH statistician of the study, Barbara Stussman, said, “The widespread body symptoms, the unpredictability of PEM, and the sometimes lengthy recovery greatly hindered individual’s ability to live a ‘normal’ life.” Why did it take decades for the NIH to begin to investigate the primary symptom of CFIDS/ME?

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J Translational Med, Nov 10, 2020, “Accurate and objective determination of myalgic encephalomyelitis/chronic fatigue syndrome disease severity with a wearable sensor,” Palombo et al.

As the title describes, a way to determine how much time was spent with feet on the floor was measured by a machine already available called the Shimmer. They tested healthy, moderately severe and severely ill patients and found it was accurately finding patients who were severely ill would spend less than 20% of their day with their feet on the floor (either sitting upright or standing) while those who were less severe spent more time with their feet on the floor. The researchers described that time as “Up Time”. However, they feel a larger study using more patients should be done to confirm the findings and to make them reliable for further research.

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J Translational Med, Nov, 2020, “Cytokine profiling of extracellular vesicles isolated from plasma in ME/CFS, a pilot study,” Giloteaux et al.

Professor Maureen Hanson’s team tested 35 healthy controls and 35 patients with ME/CFS where they found the relationship between plasma as well as EVs in the patients that was different in the healthy controls. This provided even further proof that there is ME/CFS immune dysregulation.

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Clinical Epigenetics, Vol 12, fall 2020, “Changes in DNA methylation profiles of myalgic encephalomyelitis/chronic fatigue syndrome patients reflect systemic dysfunctions,” Helliweli et al.

From New Zealand, these authors isolated DNA from peripheral blood mononuclear cells, sequenced them and identified major differences in patients when compared with healthy controls. By looking at a number of pathways and analyzing each one, their careful analysis showed “a disturbed neurological pathophysiology within the patient group” and the major differences are provided. Although there have been many studies in this area, this study went much further as well as identifying the previous studies that were most helpful. The nine genes that were found to be associated with methylation profiles are linked with the immune function as well as the inflammation process found in ME. This published paper gives an abundance of information on the neurological problems proven.

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Sci Rep, Nov 2020, “Deep phenotyping of myalgic encephalomyelitis/chronic fatigue syndrome in Japanese population,” Kitami et al.

As they looked for potential markers, these 20 researchers found 20 potential markers when compared with healthy controls. They found “a cluster of sleep-related molecular changes as a prominent feature of ME/CFS in our Japanese cohort.” We hope they continue on to find a real marker to diagnose and possibly treat this illness.

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J Trans Med, Nov. 2020, “Multi-omics examination of Q fever fatigue syndrome identifies similarities with chronic fatigue syndrome,” Ruud et al.

Showing the many similarities of Q fever and CFIDS/ME, these researchers found almost no differences between inflammatory markers. They also found both gut microbiome and blood metabolome were essentially the same with very, very few differences. When compared to healthy controls, the differences were striking.

IN MEMORIUM

The following names have been added to our Memorial List available on our website. Our sincere condolences to the friends and families of all those on our Memorial List.



Anne Berry, 47, passed away in 2017 from CFIDS/ME after suffering for years as she was bedbound in her home state of Illinois. A friend described her saying, “I’m missing faith in HHS, NIH and CDC.” She had been diagnosed with Sjogren’s Syndrome and complex regional pain syndrome. She is sadly missed by family and many friends.

Todd Garrison, 41, died on April 8, 2018 in Byron, Georgia. He was severely affected by ME. He is missed by his mother as well as his grandparents. (More information accepted.)

Rene Mebus, 26, died June 30, 2020 from severe ME. He graduated college with high grades in mechanical engineering. In his spare time in Germany, he was involved in the voluntary fire brigade as well as designing and creating their website. While working on his master’s degree in 2017, he came down with ME and, after a few months, suffered from severe orthostatic intolerance and became totally bedridden. He had to lie in absolute silence and darkness. He worsened more and became paralyzed and had seizures. He deteriorated further via a stay in the hospital and had immense pain. He is unendingly missed by his pwME brother, his parents, relatives, and many friends. (source: Jannik Mebus)

Cindy Siegel Shepler, 62, died in December of 2019, leaving her mother, Zelda Siegel, her husband, David Shepler, two sisters and one brother. Cindy graduated high school in Tennessee and moved across the country to California to attend San Francisco State University where she became a summa cum laude graduate. She worked for Cigna but ME/CFIDS hit her hard and she had to move back to Knoxville. She stayed active in volunteer work and met her husband. She remained very active as long as she was able and is missed by her many friends and relatives.

DONATIONS

The National CFIDS Foundation is immensely grateful to each person listed below. Every penny of their donation has gone to fund research that will eventually help us all live our lives better than ME/CFIDS has allowed thus far. Each donation to the NCF is tax deductible to the full extent allowed by US federal law as our charity is a federally approved 501(c)(3).

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