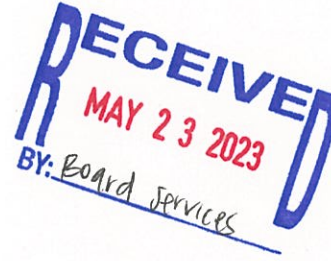


ATTACHMENT C

RESPONDENT(S) ARGUMENT

May 18, 2023

Certified Mail – Return Receipt Requested



Board Services Unit Coordinator
California Public Employees' Retirement System
P.O. Box 942701
Sacramento, CA 94229-2701

RE: **Respondent's Argument** in the Matter of the Reinstatement from Disability of AMY M. EDELEN, Respondent, and the DEPARTMENT OF CONSUMER AFFAIRS, Respondent

Dear CalPERS Board Members:

In light of new and additional evidence, this letter is to respectfully request that the Board decline to adopt the Proposed Decision of the Administrative Law Judge in the above named matter and instead vote to approve continuation of Amy Edelen's disability retirement that began in 2010, most recently approved by CalPERS in April 2020.

On April 3, 2023, Stanford Health Care's PACS and ME/CFS Center reconfirmed that Amy is still disabled from working, due in part to the specific set of symptoms listed on the original application for disability retirement. Stanford also confirmed diagnosis of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and prescribed additional medications, restrictions on mental and physical exertion, dietary restrictions and lifestyle changes. See Attachment A.

Amy continues to be unable to engage in any kind of employment – especially a position which requires consistent and regular attendance, a stationary upright position and mental exertion in an indoor office environment under fluorescent lights using a computer or phone – due in part to the headaches, severe fatigue and sensory processing impairment noted on the original application and multiple Physician's Report(s) on Disability submitted to CalPERS by certified mail.

In addition to Stanford's ME/CFS Clinic, the following specialists are currently treating Amy:

- Dr. Nelli Boykoff Perkins, M.D., Neurologist, Headache Specialist, Sutter Health (treating Amy since September 2022 by referral 1/27/22 requested in October 2021)
- Dr. Morton Teich, M.D. and Allergist-Immunologist, Board certified in environmental medicine and specializing in treatment of ME/CFS, HPA Axis Dysfunction and other chronic diseases (private practice, treating Amy since November 2022 through referral by #MEAction, a chronic fatigue syndrome advocacy group)
- Anupam Chahal, M.D. and Rheumatologist, Sutter Health (referred on 11/8/22, appointment upcoming in July 2023 due to concerning lab results from August 2022)

- Dr. Anne Mahree Priest, Doctor of Osteopathic Medicine and Primary Care Physician (treating Amy since 2016 through assignment by United Healthcare)
- Maryann Simpson, Nurse Practitioner, Embody Wellness, private practice specializing in women's health, autoimmune diseases, chronic illness, hormone therapy (treating Amy with prescribed medications based on lab results since 2018)
- Dr. Grace Fernandez, DC, Chiroworks (treating Amy's central nervous system, muscles, tissues and joints weekly since 2016)
- Feet and Body Reflexology (treating Amy frequently since 2017)

Sutter Health has also referred Amy to:

- Stanford's Autonomic Disorders Clinic initiated in Fall 2022 initiated by Dr. Perkins, M.D. and Neurologist (Dr. Dhaliwal, M.D. and Cardiologist, also suspects dysautonomia, a medical condition in which the nerves of the autonomic nervous system are damaged)
- Sierra Rheumatology on 12/29/21 and 10/10/22 but it was discovered they do not treat fibromyalgia or do disability paperwork
- Sutter Health's Institute for Health & Healing on 2/15/22 (a nationally recognized pioneer in integrative health, combining conventional medical wisdom with science-backed complementary therapies to treat chronic illness) but it was discovered that they do not have appointments available due to the impact of the pandemic and medical doctors on staff choosing to move out of California

Other records previously submitted to CalPERS by certified mail that do not appear to have been reviewed or considered include:

- Physician's Report on Disability completed by Dr. Anne Priest, DO on May 5, 2022 with medical records and labs
- Physician's Report on Disability completed by Maryann Simpson, NP on January 18, 2022 with medical records and labs
- Letter to CalPERS explaining disabling symptoms by Dr. Anne Priest, DO dated July 31, 2021
- Informational letter to CalPERS on Amy's behalf by Melissa DeKellis dated May 23, 2022
- Treatment records and labs and medications prescribed by Dr. Michelle Raithel (Wilkerson), ND, Revolutions Naturopathic for fibromyalgia and ME/CFS, gut/brain axis, nervous system, IV therapy (June 2021-2022)
- Treatment records and labs and medications prescribed by MaryAnn Simpson, NP, Embody Wellness for hormone therapy, fibromyalgia, chronic fatigue, autoimmune disease (back to 2018)
- Letter confirming weekly treatment by Dr. Grace Fernandez, DC, Chiroworks (back to 2016)

- Treatment and diagnosis by Athena Papadacos, Ph.D., Psychologist, Pacific Trauma and Counseling Center (2019)
- Treatment and labs by Get Wellness/MPL Wellness, chronic illness therapies (2015-2019)
- Emails documenting attempted cost prohibitive appointment with Nancy Mullan, M.D., specialist in chronic disease and genetics (2015)
- Tonya Barger King, Nuskin Neutraceuticals and Nature's Own Way to Ultimate Health, nutritional support, colon hydrotherapy, energy healing, detoxification support (back to 2014)

Neither Independent Medical Examiner (IME) that Amy was sent to specializes in treatment of fibromyalgia or ME/CFS nor comprehends the complexity and severity of Amy's chronic illness which includes multiple aspects outside each IME's area of education and experience.

Fibromyalgia is NOT a rheumatic disease. ME/CFS was only recently defined and coded in the ICD-10 (October 2022).

Amy's original specialist, Dr. Michael Powell, DO and Rheumatologist (deceased) was a Stanford Fellow and pioneering expert researching and treating fibromyalgia and chronic fatigue syndrome in his specialized private practice, the Fibromyalgia Treatment and Education Center. Dr. Powell was also a cellular microbiologist using a Functional/Integrative Medicine approach, genetics, epigenetics and nutrigenomics. He worked in partnership with Michael Clanahan, Physician's Assistant, to both educate and well care for patients. Dr. Powell also partnered with neuropsychologist John Leonard, Ph.D., the developer of NeuroBehavioral Programs (now called Neupathways Loop Systems), to assist patients with drug-free pain management. Amy's functional percentage, energy level, pain level, brain function, headaches, insomnia, stress level, sinusitis and intestinal problems were tracked and grouped under the umbrella condition "fibromyalgia" as ME/CFS was not yet coded in 2010.

Neither IME is trained in nor licensed to practice Osteopathic Medicine. Doctors of Osteopathy (DOs), including both physicians and surgeons, are governed by the Osteopathic Medical Board of California separate from the regular Medical Board. In addition to completing the same regular medical school as MDs, DOs are required additional training in osteopathic manipulative treatment (physically manipulating body tissue to treat patients) with focus on the musculoskeletal system and how nerves, muscles and tissues work together. DOs must also "successfully complete rigorous, periodic continuing education requirements that meet the standards of the American Osteopathic Association (AOA)" (https://www.ombc.ca.gov/bd_activity/about.shtml).

Neither IME is trained in nor practices functional/integrative medicine, a foundation paramount to comprehend Dr. Powell's practice records, methods, notes and labs and how those relate to fibromyalgia and ME/CFS. Functional/Integrative medicine is a newer and innovative "individualized, patient-centered, science-based approach that ... requires a detailed understanding of each patient's genetic, biochemical, and lifestyle factors... for the practitioner to become oriented to identifying the complexity of disease..." (<https://www.ifm.org/functional-medicine/>).

Neither IME is an Allergist or Immunologist, despite both fibromyalgia and ME/CFS containing neuro-immune aspects.

Neither of the IMEs specializes in autoimmune disease, women's health or hormone therapy.

Neither of the IMEs is qualified as a Psychologist, Psychiatrist, Occupational Therapist, Physical Therapist, Naturopathic Doctor, Doctor of Chiropractic, Acupuncturist nor Massage Therapist, all of which are health care specialties with their own specific laws and regulations, educational requirements, licensing exams and California State governing boards.

Understanding of all the above health care areas is integral for competent review of Amy's medical records.

Regarding IME Dr. Anderson, **his finding of no rheumatic evidence actually strengthens a diagnosis of fibromyalgia**. Again, fibromyalgia is NOT a rheumatic disease. Per the American College of Rheumatology, "Fibromyalgia is not from an autoimmune, inflammation, joint, or muscle disorder. Fibromyalgia is not a form of arthritis (joint disease). It does not cause inflammation or damage to joints, muscles or other tissues. However, because fibromyalgia can cause chronic pain and fatigue similar to arthritis, some people may advise you to see a rheumatologist. As a result, often a rheumatologist detects this disease [fibromyalgia] (and rules out rheumatic diseases). **For long term care, you do not need to follow with a rheumatologist. Your primary care physician can provide all the other care and treatment of fibromyalgia that you need.**" Two local rheumatology practices were contacted for Amy via referral by Sutter Health and it was discovered that neither Sierra Rheumatology nor Sacramento Rheumatology treats fibromyalgia. Neither practice completes disability paperwork either, as that is the responsibility of the Primary Care Physician in the HMO system.

Dr. Anderson asserted false superiority over Amy's Primary Care Physician/Osteopathic Medical Doctor who sees Amy approximately every other week with hands on treatment of her physical body. He also expressed condescension and disdain for health care practices and methods outside his own experience in rheumatology and geriatric care, an opinion without merit, especially as Amy fell ill at age 38 and is only 50 years old currently.

Dr. Anderson seemed entirely unaware that somatic symptoms are part of a fibromyalgia diagnosis and did not comprehend that in Osteopathic Medicine "somatic dysfunction" is "a diagnostic term defined as impaired or altered function of related components of the somatic (body framework) system: skeletal, arthrodiar, and myofascial structures and related vascular, lymphatic, and neural elements."

Further, Dr. Anderson misled both CalPERS and the Administrative Law Judge. He was not honest and forthright in the hearing regarding symptoms reported to him by Amy and submitted to his office in writing with assistance by Melissa DeKellis. For example, Amy told him she must rest before and after showering/bathing yet he said she has no difficulty. Another example is that he failed to relate her post illness weight gain to the gut dysfunction symptom of fibromyalgia.

Dr. Anderson based his mistaken opinion in large part on his own misperceptions and **his misuse of the outdated tender point exam**, a diagnostic tool that has not been recommended by the American College of Rheumatologists (ACR) since 2010. **Physician estimate of somatic symptoms was also eliminated** from the ACR Fibromyalgia Diagnostic Criteria in 2011. The more current 2016 ACR Fibromyalgia Diagnostic Criteria (see also Attachment B) is as follows*:

- **Generalized pain, defined as pain in at least four of five regions, is present.**
Amy has all over body pain, as explicitly documented in her medical records.
- **Symptoms have been present at a similar level for at least three months.**
Amy has had severe fibromyalgia symptoms for more than a decade, as documented in her medical records.
- **Widespread pain index (WPI) score is greater than or equal to 7 and symptom severity scale (SSS) score is greater than or equal to 5, or widespread pain index (WPI) score is 4 to 6 and symptom severity score is greater than or equal to 9.**
Amy's WPI score is 19, her SSS score is 9, and her symptom severity score is 12. Amy's SSS symptoms experienced regularly include: muscle pain, IBS, fatigue/tiredness, thinking or memory problem, muscle weakness, headache, pain/cramps in the abdomen, numbness/tingling, dizziness, insomnia, depression, constipation, pain in upper abdomen, nausea, nervousness, chest pain, blurred vision, itching, Raynaud's, ringing in ears, vomiting, dry eyes, shortness of breath, loss of appetite, rash, hearing difficulties and hair loss, as documented in her medical records.
- **A diagnosis of fibromyalgia is valid irrespective of other diagnoses. A diagnosis of fibromyalgia does not exclude the presence of other clinically important illnesses.**

IME Dr. Gupta was not asked by CalPERS to address symptoms beyond headaches and her report did not accurately reflect the frequency and severity of Amy's headache symptoms. Melissa DeKellis accompanied Amy to that appointment to facilitate communication but was not permitted to assist or even enter the building. At hearing, Dr. Gupta stated she was not aware that a neurologist specializing in treatment of headaches was and is caring for Amy and has not yet been successful in eliminating the headaches using multiple prescription medications and Botox injections into the head, neck and shoulders. Dr. Gupta did confirm existence of some of Amy's other symptoms at the appointment and noted "fibromyalgia?" in her report.

It is very concerning that the hotline complainant, whose identity has not been revealed, gave CalPERS false information in violation of Government Code Section 20085, punishable by both imprisonment and fine. It is unclear why CalPERS staff did not verify the content of the complaint as a first step. Contrary to what the complainant told CalPERS, the contents of Sacramento Superior Court files clearly show:

- Amy was officially represented by family law attorney Stephanie Bamberger (see Response to Petition for Dissolution filed in 2018). *Outside of the contents of the case files, attorney Stephanie Bamberger prepared the draft Marital Separation Agreement, attorney Andrea Watkins was retained issue by issue from 2019 through 2022, and both Melissa DeKellis and Claudia Gonzalez provided secretarial and practical assistance.*
- The Department of Social Services filed and handled the child support case.

- Under penalty of perjury, in his Response to the Request for DVRO dated November 9, 2020, Amy's former husband, Scott Edelen, stated: "I work as a special agent for the State of California working as an Internal Affairs Investigator... I have been a police officer since 1996... Amy... has a diagnosed cognitive impairment... mental incapacitation... her judgment is severely impaired..." In other court filings, Scott requested court-ordered psychological evaluation of Amy.
- Moon, Schwartz and Madden (jointly retained in early 2020) handled community property division of the parties' CalPERS retirement accounts and prepared the QDRO filed in 2022.

Regarding the sub rosa video, the activities observed and filmed were consistent with the limited ability that Amy attempted to communicate to the IMEs. The report states there were 8 days of surveillance, with Amy not leaving home at all on 4 of the days. She was only out of the house for a maximum of only 13.5 of the 79.5 hours she was observed (17 percent). When she was out, she was documented in short increments of time obtaining essentials like food, attending health care appointments where she is treated lying down, and engaging in gentle short walks and movement in water that helps her fibromyalgia, migraine and ME/CFS symptoms. The rest of the time she was under surveillance, Amy was at home, mostly in bed and dealing with her illness, as can be verified by her children who were present approximately half that time and Melissa DeKellis who checks on her daily and treats her severe pain symptoms. The Facebook photos seen by the IMEs, that Amy was not informed of or asked about prior to her IME appointments, were taken of brief moments in time, mostly at home or within 15 minutes of her home in outings of very short duration. Photos do not accurately convey cognitive, mental, physical, sensory or pain state nor represent Amy's full reality.


It is not understood why CalPERS' legal counsel objected to admission of CalPERS' publications explaining disability retirement and reinstatement plus Amy's medical records into the hearing for consideration by the ALJ as both pieces of evidence provide relevant material facts.

To reiterate, Amy is still severely ill with fibromyalgia and the symptoms listed on the original application for disability in 2010. She has been in treatment for those issues continuously by a multitude of health care providers since initial disability and is still being treated by multiple specialists. Her diagnosis of ME/CFS with disability was reconfirmed by Stanford in April 2023 plus prescribed restrictions on mental and physical exertion. She has not worked, nor been able to work, in any kind of job since her last day as an AGPA at the Veterinary Medical Board.

Thank you for your attention and consideration of all information provided. Again, please vote to decline to adopt the proposed decision and instead vote to approve continuation of Amy Edelen's disability retirement.



Amy Edelen



Date



ATHERTON SQUARE
PACS AND ME/CFS CENTER
3351 EL CAMINO REAL, SUITE 225
ATHERTON CA 94027
Dept: 650-736-5200
Dept Fax: 650-497-0754
Loc: 650-723-9001
Loc Fax: 650-568-1708

4/18/2023

Amy Edelen
[REDACTED]

To Whom It May Concern:

It is our professional opinion that Ms. Amy Edelen meets the clinical criteria for Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME) as defined by the International Chronic Fatigue Syndrome Study Group (Annals of Internal Medicine 1994 Dec 15; 121(12):953-9) and supported by the Centers for Disease Control and Prevention (CDC) and Institute Of Medicine Of The National Academy. We believe that for a subset of patients ME/CFS may be triggered by an infection, including viral agents. Our working hypothesis is that CFS, also known as ME/CFS, is primarily a chronic encephalitis neuro-inflammatory disease based on increase in inflammatory cytokine and PET/MRI with brain abnormalities. Contrary to previous beliefs, ME/CFS has become recognized as a real disease with an organic bases affecting at least 1 million Americans, and may result in incapacitating physical and cognitive impairments, as well as pain and sleep disturbances.

Ms. Amy Edelen treatment has been ongoing since April 3, 2023. We have examined Ms. Amy Edelen, reviewed the medical history, and we will continue to see Ms. Amy Edelen for follow-up visits. We recommend a plan of management pace/rest, dietary changes, and anti-inflammatory medication. Until her fatigue has measurably improved, I recommend that Ms. Amy Edelen refrain from any exertion, both physical and cognitive, because it may cause an exacerbation of symptoms and set her back in her recovery.

Ms. Amy Edelen treatment plan is to limit activities, including walking, lifting, bending, and similar physical exertion and cognitive tasks that require focus. Patients with ME/CFS need frequent rest.

Sincerely,

A handwritten signature in black ink that reads "Jallisae Nedi, N.P.".

Jallisae Nedi, N.P.
PACS and ME/CFS Center
Stanford Health Care

Amy Edelen
DOB: [REDACTED]
Stanford Health Care



Name: Amy Edelen | DOB: [REDACTED] | MRN [REDACTED]

Appointment Details

AFTER VISIT SUMMARY



Amy Edelen MRN [REDACTED]

4/3/2023 1:00 PM PACS and ME/CFS Center 650-736-5200

Instructions from Jallisae N



Your medications have changed today
See your updated medication list for details.



Pick up these medications at INNOVATIVE COMPOUNDING PHARMACY - FOLSOM, CA - 820 WALES DRIVE

naltrexone 6 mg capsule

Address: 820 WALES DRIVE, FOLSOM CA 95630

Phone: 916-984-9222



Labs ordered today

ANCA
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

Aldolase
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

Anti-Ro Antibody
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

Antinuclear Antibodies, IFA
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

C - Reactive Protein
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

CBC with Differential
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

Cortisol, Am
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

Creatine Kinase, Total
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

Heavy Metals Screen, Blood
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

Hemoglobin A1C
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

Lipid Profile with Non-HDL Cholesterol (343925)
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

Metabolic Panel, Comprehensive
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

Rheumatoid Factor
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

TSH w/ Reflex FT4
Please complete by 4/3/2023
Go to EXTERNAL SOURCE

Today's Visit

You saw Jallisae N on Monday April 3, 2023. The following issue was addressed: CFIDS (chronic fatigue and immune dysfunction syndrome) (CMS-HCC).



Blood Pressure
161/61



BMI
37.12



Weight
255 lb



Height
5' 9.5"



Temperature (Temporal)
97.7 °F



Pulse
88



Respiration
18



Oxygen Saturation
96%

What's Next

JUN
12
2023

Video Visit with Jallisae N

Monday June 12 11:20 AM

#|V|#


Virtual Visit Location: Due to individual state regulations, Stanford Medicine providers may not be able to conduct telemedicine visits with patients who are located outside of California at the time of their appointment. If you plan to be outside the State of California at the time of your appointment, please immediately contact your clinic to reschedule or discuss alternative care options.

Instructions on how to join a Video Visit can be found in our [FAQ](#).

Your Medication List as of April 3, 2023 11:59 PM

 Always use your most recent med list.

hydrocortisone 5 mg tablet Commonly known as: Cortef	take 1 Tablet (5 mg total) by mouth daily
levothyroxine 100 mcg tablet Commonly known as: Synthroid	take 1 Tablet (100 mcg total) by mouth every morning before breakfast
losartan 100 mg tablet Commonly known as: Cozaar	take 1 Tablet (100 mg total) by mouth daily
 * naltrexone 6 mg capsule Changed by: Jallisae Maria Nedi, NP	take 1 Capsule by mouth daily What changed: You were already taking a medication with the same name, and this prescription was added. Make sure you understand how and when to take each.
 * naltrexone 4.5 mg capsule Changed by: Jallisae Maria Nedi, NP	1 Capsule daily What changed: Another medication with the same name was added. Make sure you understand how and when to take each.
NURTEC ODT 75 mg orally disintegrating tablet Generic drug: rimegepant	take 1 Tablet by mouth
ondansetron 4 mg orally disintegrating tablet	place 1-2 Tablets (4-8 mg total) under the tongue and let dissolve every 8 hours as needed
other drug	Supplements (10 Am) - pure encapsulations ultra pack - PE Methylcobalamin 1000 mcg - Zinc -vitamin D3 - B complex -life Extension Magnesium 1500 mg - Chlorella Manna Taken 10 pm - Pure encapsulations cortisol com -progesterone 100 mg -hormone cream
tiZANidine 2 mg tablet Commonly known as: Zanaflex	take 1 Tablet (2 mg total) by mouth every 8 hours as needed
venlafaxine 150 mg extended release capsule Commonly known as: Effexor XR	take 1 Capsule (150 mg total) by mouth daily

 * This list has 2 medication(s) that are the same as other medications prescribed for you. Read the directions carefully, and ask your doctor or other care provider to review them with you.

Progress Notes

Jallisae N

Status: Signed

Stanford Hospital and Clinics
Infectious Diseases - Initial Consult

Date: 4/3/2023

Consult Service: Infectious Diseases ME/CFS

5/16/2023, 2:43 PM

Consult performed at the request of Attending; No att. providers found
 Referring Provider: Anne Priest,DO
 Reason for consult: evaluation of fatigue

ID: Amy Edelen is a 50 Y female patient.

HPI:

Amy Edelen is a 50 Y female patient presenting with fatigue since 1996. She has a past medical history of Fibromyalgia, ME/CFS, migraines and Hypothyroidism.

Prior to Illness

Amy Edelen worked full time as a Marketing Analyst and enjoyed traveling for work and leisure. She was previously married and has two kids. She was very physically active, exercised daily, and was an athlete in college.

Timeline of Illness

1996-- Was working as a Marketing Analyst working for the California Conservation Core. One of the sites she worked in had toxic mold but she did not know the severity of the mold. She was at the site for 5 days. After her 5th day she had initial symptoms of a bloody nose, cold/flu-symptoms, sneezing, coughing, and congestion that lasted for 1 week. Afterwards she began to have generalized body stiffness, myalgias, fatigue and muscle weakness. She went to her PCP who had a normal work up. Was then sent her to a Rheumatologist for positive ANA but had an unremarkable work up, but had monitored her every 6 months for possible Lupus. Seen numerous specialists with a normal work up. Eventually saw a Naturopathic MD and changed her diet and reduced stress which helped to manage her symptoms at the time.

February 2005-- Started to have sleep issues during her Pregnancy.

2008 summer-- Gained 25 pounds in a few weeks and had extreme exhaustion.

November 2008-- Had a "crash" that caused disabling fatigue, inability to focus, visual disturbances (seeing black spots), and inability to get out of bed. Started to get more severe headaches. Does not recall any triggering event, increased stress, recent travel, or illness. Started getting sore throats and tender cervical lymphadenopathy.

2009-- Diagnosed with ME/CFS by Dr. Powell in Rheumatology. Started to have cognitive issues such as memory, focus/concentration. Was working at the time but struggled so stopped working.

Her fatigue is daily, severe, and incapacitating. It is exacerbated by physical activity, stress, overstimulation, drinking alcohol, noise, food, lack of sleep, menstrual period, temperature change and alleviated by decreasing stimulation and reducing her activities. During a crash, she experiences worsening fatigue, body tightness, sensitivity to light and sound. These episodes can last for 3-4 days at a time. She sleeps for 9-10 hours nightly and wakes up unrefreshed, has trouble falling asleep and has trouble staying asleep (possibly worse due to having kids). She suffers with brain fog. She also endorses orthostatic intolerance, palpitations, myalgias, arthralgias, headaches, gastrointestinal symptoms (bloating, constipation), sore throat and cervical lymphadenopathy.

Amy Edelen is no longer able to do house work, paperwork or work her regular job. Her family helps with a lot of household chores and she also has a housekeeper.

MRI brain normal 1/2021

TTE normal 3/2022

Holter monitor normal 4/2022

9/2/2022
 11:21 AM

CFS ILLNESS SUMMARY

Do you believe you have ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome)?	Yes
The date your illness first started?	10/1/2008
Please tell us: The location (continent, city) where your ME/CFS first began?	CALIFORNIA
Please select the triggering event:	Infection Vaccination Travel

9/2/2022
11:21 AM

If Infection: Stress
Gastrointestinal (GI)
Other

If Vaccination: Other

Physical activity: Play sports

Social activity: Friends
Social events
Travel

Profession: Working full-time

Education (choose highest completed level of study): College

Marital status: Married

School: Stopped

Work: Stopped

Exercise: Reduced

Daily activities: Reduced

Social activity: Reduced

What situations lead you to "crash" (select all that apply)?
Physical activity
Stress
Overstimulation
Drinking alcohol
Noise
Food
Lack of sleep
Menstrual period
Temperature change

What makes your symptoms better?
Decreased sensorial stimulation (dim lights, decrease noise, isolation, etc.)
Stress reduction activity (reduce pace of activities, acupuncture, meditation, yoga/Tai Chi/etc.)

Please note the symptoms you experience (check all that apply):
Cognitive impairment or brain fog
Fatigue
Unrefreshing sleep
Dry eyes
Palpitations
Shortness of breath/air hunger
Pain
Tremors
Numbness or tingling in extremities (fingers, toes, hands, feet)
Anything else (describe)

If other (describe):
Electrical overload, anxiety/depression, dizzy, PEM, head pressure whole head and body spasm

If cognitive impairment or brain fog:
Poor memory recall
Inability to concentrate or process information
Vertigo (spinning sensation)
Headache
Dizziness
Ringing in the ears
Visual disturbances
Sinus pain
Orthostatic intolerance (symptoms when standing that are relieved by sitting or lying down)

If pain:
Muscle
Joint
Chest

9/2/2022
 11:21 AM
 Pelvic
 Shooting pain
 Other (describe)

If other (describe):
 Are you double jointed? No
 Do you have elastic skin (if you stretch your skin, does it snap back to its original shape)? Yes
 Fatigue Very severe
 Brain fog Very severe
 Unrefreshing sleep Very severe
 Orthostatic intolerance (symptoms when standing that are relieved by sitting or lying down) Unbearable
 Flu-like illness Very severe
 Gastrointestinal symptoms (nausea, vomit, diarrhea, bloating, constipation) Very severe
 Headache Unbearable
 Heart palpitation Very severe
 Pain (muscular, joint or neuropathic) Unbearable
 Tremor Severe
 After a good night's sleep, do you feel better and refreshed? No
 Please select the types of physicians that you have seen for this condition.

Nerve
 No
 Yes
 Very severe
 Very severe
 Very severe
 Unbearable
 Very severe
 Very severe
 Unbearable
 Very severe
 Unbearable
 Severe
 No
 Primary Care
 Naturo-path/Integrative Medicine
 Neurologist-- headache clinic, thinks she has Dysautonomia
 Cardiologist-- thinks she has Dysautonomia
 Rheumatologist-- diagnosed with ME/CFS, has Hashimoto's thyroiditis
 Low-dose Naltrexone 4.5mg daily-- cuts pain by 20%

Have any of these medicines been helpful for you?

Chronic Fatigue Syndrome Criteria	Yes	No	Unknown	Comments
1. Does the patient have severe and incapacitating fatigue for \geq 6 months?	X			
2. Post-exertional malaise	X			
3. Unrefreshing sleep	X			
4. Cognitive dysfunction/brain fog	X			
5. Orthostatic intolerance	X			
Primary Symptoms	Yes	No	Unknown	Comments
1. The chronic fatigue is new or has definite onset (i.e., not life-long)	X			
2. Fatigue is not the result of ongoing exertion	X			
3. Fatigue is not substantially alleviated by rest	X			
4. Fatigue results in substantial reduction in previous levels of occupational, educational, social, or personal activities	X			
Additional Symptoms	Yes	No	Unknown	Comments
a. Impaired memory or concentration	X			
b. Sore throat	X			
c. Tender cervical or axillary lymph nodes	X			
d. Muscle pain	X			
e. Multi-joint pain	X			
f. New headaches	X			
g. Unrefreshing sleep	X			

h. Post-exertional malaise	x			
If YES to ≥ 4 , then: Meets clinical criteria for chronic fatigue syndrome (CFS) diagnosis (see ICFSSG, 1994)				

ROS: 14 point ROS otherwise negative except for:

<p align="center">Constitutional</p> <input type="checkbox"/> Fever <input type="checkbox"/> Chills <input type="checkbox"/> Weight loss <input type="checkbox"/> Weight gain <input type="checkbox"/> Decreased appetite <input checked="" type="checkbox"/> Malaise/fatigue <input type="checkbox"/> Night sweats/diaphoresis	<p align="center">Musculoskeletal</p> <input type="checkbox"/> Back pain/back ache <input checked="" type="checkbox"/> Muscle pain/myalgias <input checked="" type="checkbox"/> Joint pain <input type="checkbox"/> Muscle weakness <input type="checkbox"/> Hypermobility joints
<p align="center">HEENT</p> <input type="checkbox"/> Hearing loss <input checked="" type="checkbox"/> Tinnitus <input type="checkbox"/> Hyperacusis (sound sensitivity) <input type="checkbox"/> Congestion <input type="checkbox"/> Ear Discharge <input type="checkbox"/> Ear Pain <input checked="" type="checkbox"/> Sinus pain <input type="checkbox"/> Sore Throat <input type="checkbox"/> Oral ulcers <input type="checkbox"/> Dry mouth <input type="checkbox"/> Blurred vision <input type="checkbox"/> Photophobia <input checked="" type="checkbox"/> Dry eyes <input type="checkbox"/> Eye pain <input type="checkbox"/> Eye discharge <input type="checkbox"/> Eye redness <input checked="" type="checkbox"/> Visual disturbances	<p align="center">Skin</p> <input type="checkbox"/> Rash <input type="checkbox"/> Hives <input type="checkbox"/> Herpetic lesions <input type="checkbox"/> Elastic skin <input type="checkbox"/> Pruritus/itching <input type="checkbox"/> Raynaud's phenomenon <input type="checkbox"/> Blood pooling
<p align="center">Neck</p> <input type="checkbox"/> Cervical nodes tenderness <input type="checkbox"/> Difficulty swallowing <input type="checkbox"/> Neck pain	<p align="center">Endo/Allergies</p> <input checked="" type="checkbox"/> Thyroid disease/problems <input type="checkbox"/> Diabetes <input type="checkbox"/> Allergies
<p align="center">CV/RESP</p> <input type="checkbox"/> Cough <input type="checkbox"/> Sputum production <input checked="" type="checkbox"/> Shortness of Breath <input type="checkbox"/> Wheezing <input type="checkbox"/> Chest pain <input checked="" type="checkbox"/> Palpitations	<p align="center">Heme/Onc</p> <input type="checkbox"/> Anemia <input type="checkbox"/> Bruising <input type="checkbox"/> Cancer
<p align="center">Abdominal</p> <input type="checkbox"/> Abdominal pain <input type="checkbox"/> Diarrhea <input checked="" type="checkbox"/> Constipation <input type="checkbox"/> Vomiting <input type="checkbox"/> Nausea <input type="checkbox"/> GERD	<p align="center">Neuro</p> <input checked="" type="checkbox"/> Headache <input checked="" type="checkbox"/> Dizziness <input checked="" type="checkbox"/> Brain fog <input checked="" type="checkbox"/> Tingling <input checked="" type="checkbox"/> Tremors <input type="checkbox"/> Seizures/movement disorders <input type="checkbox"/> Speech changes

<u>GU</u>	<u>Psychiatry</u>
<input type="checkbox"/> Dysuria	<input checked="" type="checkbox"/> Depression
<input type="checkbox"/> Increased urinary frequency	<input type="checkbox"/> Psychosis
<input type="checkbox"/> Hematuria	<input type="checkbox"/> Hallucinations
<input type="checkbox"/> UTIs	<input type="checkbox"/> Suicidal ideations
<input type="checkbox"/> STIs	<input type="checkbox"/> Insomnia/sleep problems
	<input type="checkbox"/> Alcohol abuse
	<input type="checkbox"/> Substance abuse

PMHx:

Fibromyalgia, ME/CFS, migraines and Hypothyroidism

Family History:

Mother: Fibromyalgia

Father: Amyloidosis

Brother: Migraines, same symptoms as her (sensory issues)

Sister: body aches

Kids: healthy

Grandparents: N/A

Allergies: No Known Allergies

Social History:

Marital Status: Divorced

Working: No

Drugs: No

Alcohol: No

Smoking: No

Sexual history: no

Other Current Medications:

Current Outpatient Medications:

- hydrocortisone (Cortef) 5 mg tablet, take 1 Tablet (5 mg total) by mouth daily, Disp: , Rfl:
- levothyroxine (Synthroid) 100 mcg tablet, take 1 Tablet (100 mcg total) by mouth every morning before breakfast, Disp: , Rfl:
- losartan (Cozaar) 100 mg tablet, take 1 Tablet (100 mg total) by mouth daily, Disp: , Rfl:
- naltrexone 4.5 mg capsule, 1 Capsule daily, Disp: , Rfl:
- ondansetron 4 mg orally disintegrating tablet, place 1-2 Tablets (4-8 mg total) under the tongue and let dissolve every 8 hours as needed, Disp: , Rfl:
- other drug, Supplements (10 Am) - pure encapsulations ultra pack - PE Methylcobalamin 1000 mcg - Zinc -vitamin D3 - B complex -life Extension Magnesium 1500 mg - Chlorella Manna Taken 10 pm - Pure encapsulations cortisol com -progesterone 100 mg -hormone cream, Disp: , Rfl:
- rimegepant (NURTEC ODT) 75 mg tablet, take 1 Tablet by mouth, Disp: , Rfl:
- tiZANidine (Zanaflex) 2 mg tablet, take 1 Tablet (2 mg total) by mouth every 8 hours as needed, Disp: , Rfl:
- venlafaxine (Effexor XR) 150 mg extended release capsule, take 1 Capsule (150 mg total) by mouth daily, Disp: , Rfl:

Exam**Visit Vitals**

BP	161/61 (Patient site: Right arm, Patient Position: Sitting)
Pulse	88
Temp	36.5 °C (97.7 °F) (Temporal)
Resp	18
Ht	1.765 m (5' 9.5")
Wt	115.7 kg (255 lb) Comment: verbal
SpO2	96%

-Not taking.

3. Anti-inflammatory medications.

The objective is to decrease inflammatory cytokines.

- Increase to 6mg low dose of naltrexone

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8313851/>

- Can consider low dose of Abilify (0.1 mg twice a week-2mg daily).

While on Abilify, we will check at least once a year ECG (QT prolongation), glucose, and lipid panel

<https://translational-medicine.biomedcentral.com/articles/10.1186/s12967-021-02721-9>

4. Follow an anti-inflammatory diet.

-Mediterranean diet high in fruits and vegetables, nuts and cereals, fish, olive oil, with moderate red wine consumption and minimal amounts of red meat and dairy products)

-Avoid added sugars and refined carbohydrates which can increase inflammation in your body and further exacerbate your symptoms.

-Try incorporating fermented foods (kimchi, kombucha, kefir, sauerkraut, probiotic yogurt, tempeh, miso, etc.) into your diet, which has shown to decrease inflammatory proteins in your body as well as boost your microbiome diversity.

5. Follow up.

- Please complete the labs as discussed.

- While on therapy, we recommend you complete laboratory tests (CBC and CMP) twice a year with your PCP.

- RTC in 1-2 months.

- Letter of support will be provided.

Thank you for this consultation. We will continue to follow Ms. Edelen with you.

Eighty minutes were spent face to face with the patient during this visit. More than 50% of the visit was spent providing education and/or counseling to the patient regarding the issues documented in this note

1:53 PM 4/3/2023

Jallisae Nedi

Nurse Practitioner

Stanford Chronic Fatigue Syndrome Clinic

[3351 El Camino Real](#)

[Atherton, CA 94027](#)

O: [650-736-5200](tel:650-736-5200) | F: [650-497-0754](tel:650-497-0754)

Your Laboratory Orders

ANCA	Complete by: Apr 03, 2023
Aldolase	Complete by: Apr 03, 2023
Anti-Ro Antibody	Complete by: Apr 03, 2023
Antinuclear Antibodies, IFA	Complete by: Apr 03, 2023
C - Reactive Protein	Complete by: Apr 03, 2023
CBC with Differential	Complete by: Apr 03, 2023
Cortisol, Am	Complete by: Apr 03, 2023
Creatine Kinase, Total	Complete by: Apr 03, 2023
Heavy Metals Screen, Blood	Complete by: Apr 03, 2023
Hemoglobin A1C	Complete by: Apr 03, 2023
Lipid Profile with Non-HDL Cholesterol (343925)	Complete by: Apr 03, 2023
Metabolic Panel, Comprehensive	Complete by: Apr 03, 2023
Rheumatoid Factor	Complete by: Apr 03, 2023
TSH w/ Reflex FT4	Complete by: Apr 03, 2023

Allergies

No Known Allergies

