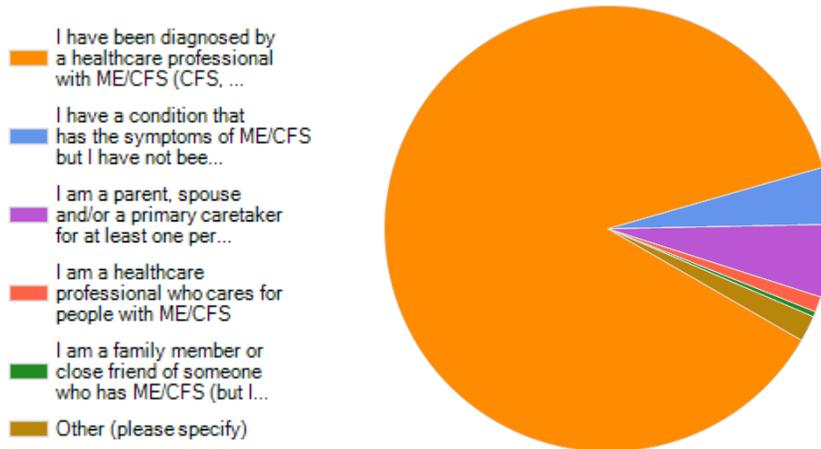




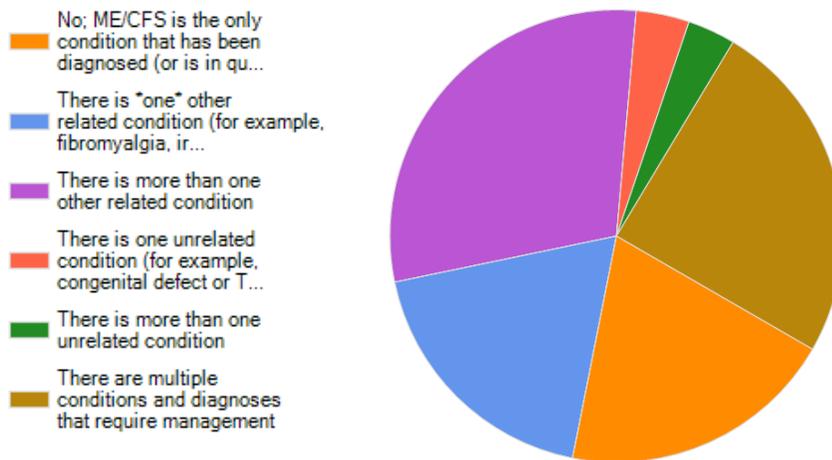
## ME/CFS Road to Diagnosis Survey

Conducted January 2014, 263 respondents

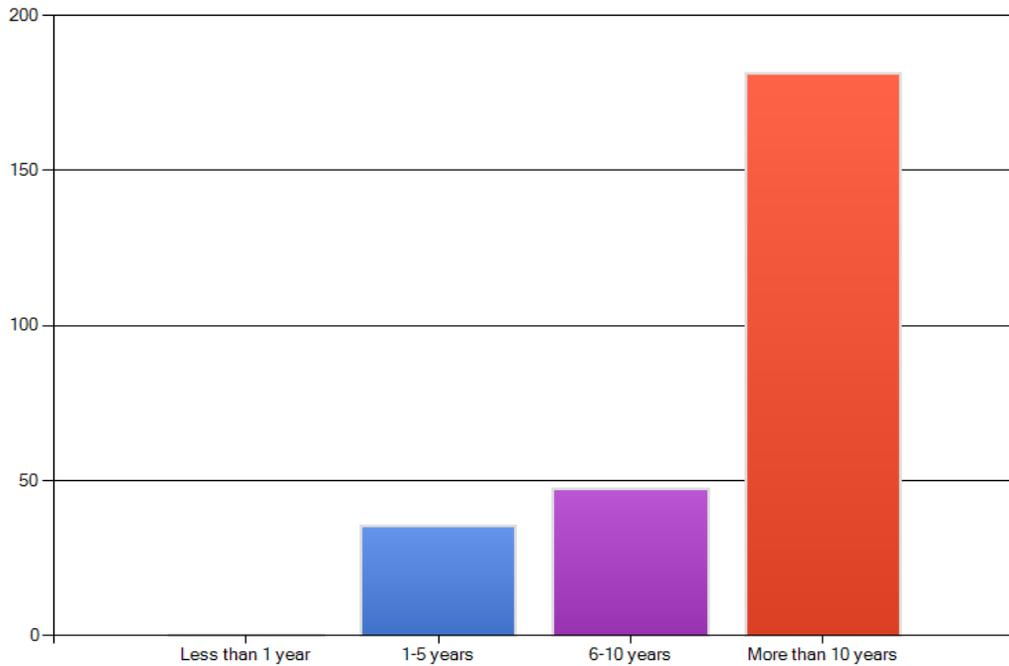
1. Which one best describes your (primary) relationship the ME/CFS?



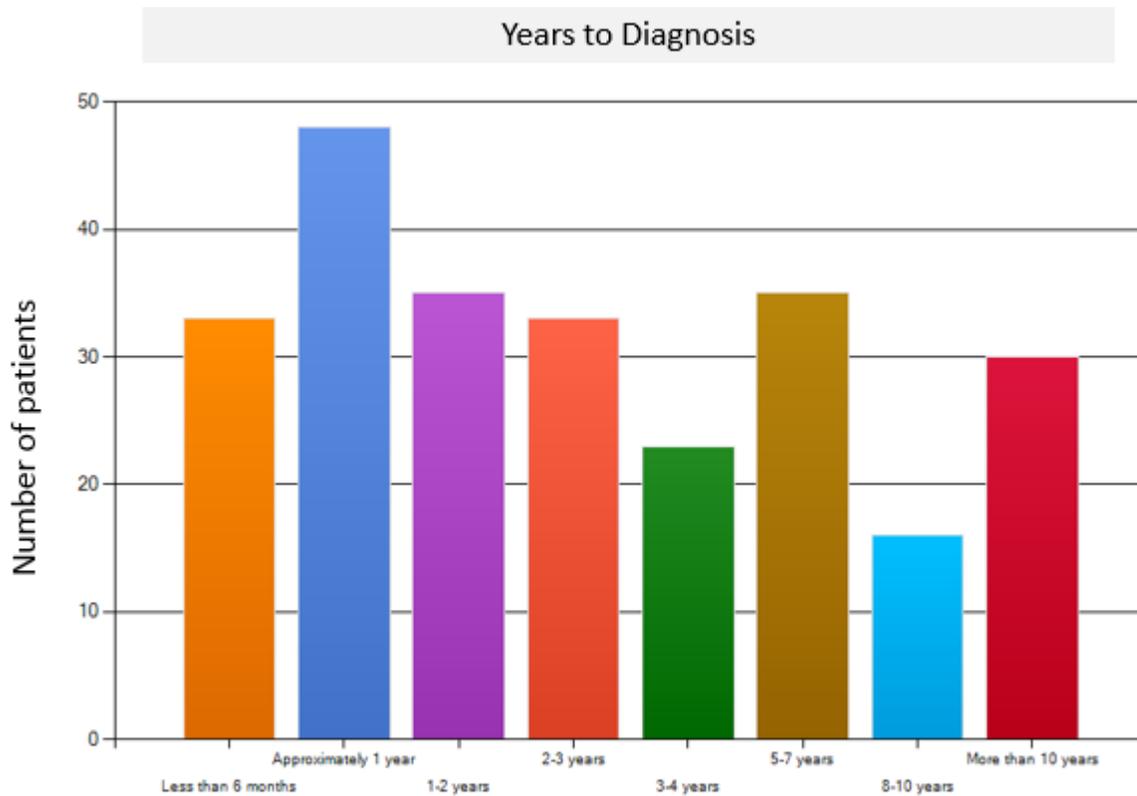
2. Are there other diagnoses that you or the person you're close to with ME/CFS has to manage?



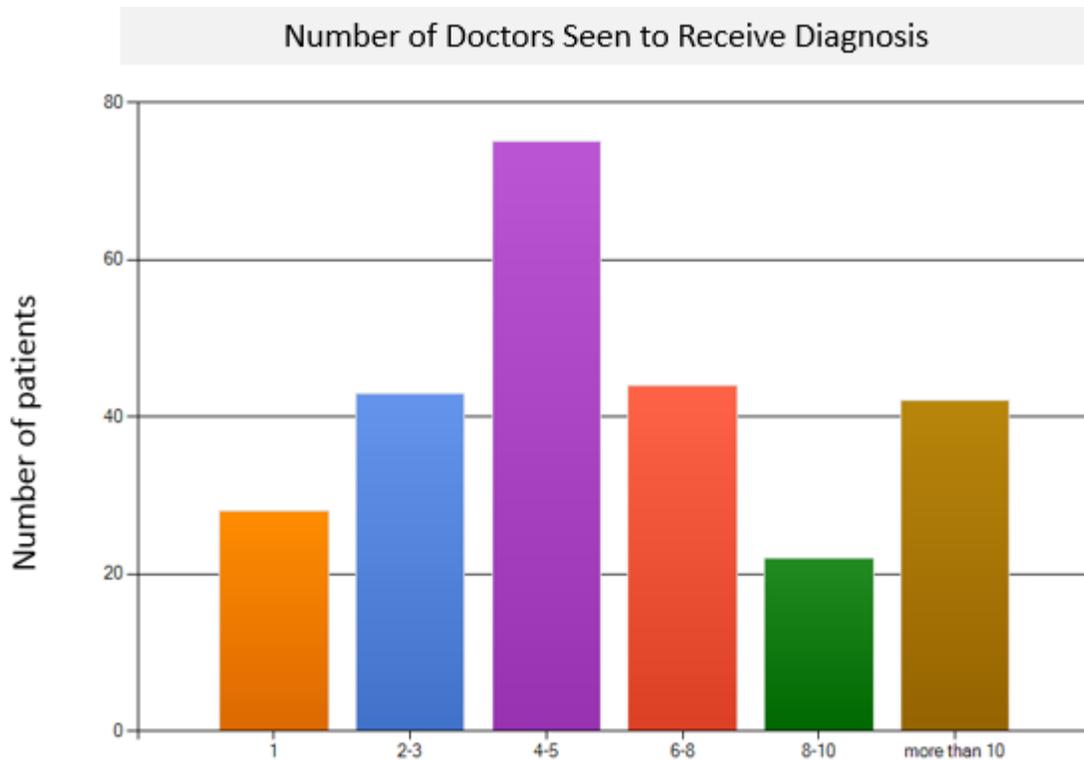
3. How many years since the ME/CFS began?



4. How long did it take you (or the person closest to you) to receive diagnosis?



5. How many different doctors did you (or the one closest to you) have to see prior to receiving a diagnosis?



6. Please briefly describe your road to diagnosis:

1	Although I knew that I was an ME poster child, no MD could diagnose me until I was able, after a long wait, to go see an immunologist specialized in ME and finally everything made sense ...
2	I was the lucky one. My primary physician diagnosed me. He has now retired and I am left without my advocate and am unable to find another doctor who can help. Finding a doctor who is ME/CFS "friendly" or knowledgeable has, so far, for me been impossible, leaving me completely dispirited.
3	When the diagnosis was made, very little was known about ME/CFS which is unfortunately still the case. There was limited exclusion diagnosis at which point the decision was to diagnose ME.
4	Developed after surgery/virus while I was in grad school. The first three years was very up and down and so I was able to keep thinking I was just unlucky and things would settle down. By the third year, symptoms (flu-like, vertigo, jet-lag) became so bad I had to quit working but it still took another year before I had a diagnosis. Saw a GP (who eventually diagnosed CFS), therapist (who told me I was depressed *because* I was physically sick not the other way around and eventually had to break the news that I needed to consider applying for disability -- which took 20 income-less months to get), neurologist (who said CFS & FMS didn't really exist), rheumatologist (who diagnosed FMS), ENT specialist (for vertigo but who just focused on my weight), cardiologist, a DO/homeopath (who confirmed CFS diagnosis). I've been lucky that I've mostly had providers who have taken my symptoms (esp. my severe pain) seriously, even if they haven't known what was causing it or understood ME/CFS well. I do wish I had known about pacing from the beginning. Might have been able to maintain more functional capacity. Today I am completely housebound except when I need to see a specialist. My GP makes housecalls.

5	<p>Some physicians seem to think that if they cannot find a cause for a patient's symptoms, then there is no physical cause. I knew my illness was not psychosomatic, but even now with ample blood work to support my diagnosis of ME, my primary care physician tells me, "You know, your health problems are psychological, right?" Very discouraging. Someone needs to educate the medical community. My immunologist told me a year ago that she has discovered that ME patients have the correct relative numbers of blood cells (and, hence, a "normal" CBC), but the absolute number of cells is about 25% too low. Why is this information not being disseminated?</p>
6	<p>Our pediatrician did not diagnose my daughter's POTS because he did not perform the tilt table test correctly. He sent us to another pediatrician who did not diagnose CFS because he, we learned later, did not believe in CFS. We also went to an ENT doctor who thought my daughter's problems were caused by heartburn. Only a chance visit from a neighbor who happened to be a neonatal intensive care doctor led us to the doctor who diagnosed POTS and later CFS.</p>
7	<p>I developed fibromyalgia in my early '50's (about 10 years ago). I pushed myself to keep working, keep working. I was so afraid I would have to live under a bridge if I lost my job. About 3 years into having fibro, I became more and more ill. I was completely exhausted all the time and seemed to catch &amp; keep every virus that was going around. At the same time, it was as if my neurological system was on overload. No matter how tired I was, I couldn't sleep in the daytime, and had trouble sleeping at night. I discovered the Fibro &amp; Fatigue clinic in Atlanta, a 5-hour drive from my home. The Atlanta doctor tested my immune system, found my natural killer cells were phlegmatic, my R-Nase-L was over the top, and several viral and bacterial titers were off the charts. No local doctor seemed to be able to look for or recognize ME/CFS (or possibly didn't "believe in it."). Why not?</p>
8	<p>CFS dx over 20 yrs ago. IBS dx 6 yrs ago. Fibromyalgia dx 3 yrs ago. The 'road' to dx has changed as the conditions have changed. The 'attitude or knowledge' of medical professionals IS the HURDLE, as many still do not realize nor acknowledge the negative impact upon ones 'quality of life' with these disorders. The worst is comments by these professionals along the lines of "its all in your head", first line treatment options utilized are Biologics, medications, etc, that further compromise the UNDERLYING causes of conditions relating to the Immune system, metabolic or systemic malfunctioning, and so on. The elusiveness and variations of these conditions in each individual are simply not considered in the Medical Field to be real, or treatable effectively. Overcoming these realities for patients are slow coming and patients have to be their own doctors, do their own research, and request specific testings. It is simply disheartening.</p>
9	<p>Got mono in my 20s. First MD said don't worry it is no big deal. After going to the ER, I was referred to a MD who had to go thru a bunch of blood, sleep and brain tests. I was diagnosed with chronic mono which just became CFS.</p>
10	<p>I had a viral infection in September 2004 and have never been the same. It took until November 2011 until I got a diagnosis of ME/CFS from an MD experienced with treating patients with ME/CFS. I was in a large HMO until 2008; in 2008 I switched to more open insurance. In April 2008 an out-of-network MD diagnosed me with Lyme and other issues. After extensive treatment by the out-of-network MD, my previously diagnosed "asthma" was essentially gone along with high titers of microplasma pneumonia, something the HMO never test me for even though asthma treatments they prescribed made me sicker. The symptoms that bother me the most, insomnia and MCS, were just as bad as when I first went to the out-of-network MD. The out-of-network MD measured high titers for CMV, EBV, HHV6 and PV19 on multiple occasions, never treated me for them and never told me they were indicative of ME/CFS; that MD was obsessed with Lyme and Lyme co infections. In 2011, a person with CFS told me that she thought I had CFS by the way I described my symptoms and referred me to the MD that subsequently diagnosed me. I believe the majority of medical professionals are ignorant of ME/CFS and cause harm, directly (by misinformation and inappropriate treatments) and indirectly, to patients with ME/CFS.</p>
11	<p>Allied NATO Government is hiding millions of infectious NON HIV AIDS cases (like mine) under the "Chronic Fatigue Syndrome (CFS)" ICD-code. - Dr. Lorraine Day was on Joyce Riley's military show THE POWER HOUR (9/12): "...HIV-Negative AIDS cases falsely reported and treated as CFS cases may be one of the biggest cover-ups we have seen." <a href="http://www.cfsstraighttalk.blogspot.com">www.cfsstraighttalk.blogspot.com</a></p>

12	<p>I got the diagnosis in 18 months, but not root cause. That took 22 years. Dental mercury poisoning, persistent Lyme, hidden dental infections &amp; mold toxicity. I have recovered the health of my youth. For more, see International Academy of Oral Medicine &amp; Toxicology, <a href="http://www.iaomt.org">www.iaomt.org</a> and my new organization, Hidden River Health Challenge. Please join us in our call now being organized for a Surgeon General Report on Dental Amalgam and Health Risks. I am happy to supply information and references.</p>
13	<p>I was diagnosed with Mono in August of 1998, I recovered approx. 6 weeks later, 3-4 months later I began having extreme sleep disorders, migraines, visual disturbances, auditory disturbances, gastrointestinal issues, from there I started catching every virus, cold, flu, cough that I came in contact with, I developed secondary infections repeatedly, my immune system went haywire and I ended up in the ER in Austin, a much larger town than the one I lived in. They hospitalized me this was 1999. I spent almost a month in the hospital and had every test in the book run on me from Labs, to Psych evals, to physical therapy, finally a diagnosis of chronic fatigue syndrome with immune dysfunction syndrome was made. I was placed on a 4500 calorie a day diet as my seemed not to absorb or to burn through everything I ate rapidly with no weight gain, and sometime with weight loss regardless of a high caloric intake. My biggest frustration since my diagnosis is that I was diagnosed as a child in a hospital, having grown up and changed insurance multiple times, cities and states, and had several doctors, each time I see a new doctor it's the same story they ask if I have any chronic illnesses they should be aware of I tell them, and they do nothing. There is no treatment recommendation, no help with symptoms, and I get treated like CFS is no more an illness than freckles on your forehead. They say well you haven't required treatment to date so there seems to be no need to start now, however I can't get treatment because I've not gotten treatment how does this make any sense? I work full time when I can, I'm 31 and I've had 72 jobs because while I work hard as much as I can I always hit that period where I'm just sick, and I physically can't work, and employers don't like to hear I can't come to work this week because I can't get out of bed, or my gastrointestinal issues are a little overwhelming etc. So I lose my job for too many absences and find a new one. I've never gotten welfare, or any govt. assistance, I've always worked, when I can't I have to figure out how to keep things afloat until I can, but it would be nice if I could go to a doctor explain my problem and actually be offered some real ideas on how to treat my issues instead of my issues being disregarded because I manage my life even with my illness. If I was unemployed and didn't attempt to work would they help me then? I feel like the fact that I can cope inhibits the doctors need to treat me which is so wrong. My biggest hurdles are trying to work enough hours to pay the bills and little enough hours that I can manage my health so I can keep working. I wish I had a way to sleep consistently without feeling groggy all day, a way to regulate my diet so that my body gets the extreme energy resources it needs to perform, a pain management that didn't inhibit my ability to drive, work, or function, and some better ways of protecting myself from getting sick so my body doesn't have to work so hard. I would also like to better understand what is happening to me to make me feel this way, because honestly with everything I've read and heard I really don't know what CFS is or what it does to my insides to make me this way, I just know I'm sick and I've been sick a really long time with no answers, and what's going to happen when I get older and I can't work anymore, and I become a burden on my family because I still have no idea what to do to feel better.</p>
14	<p>It's been pure hell! Test after test DR after DR money and more money .. Muscle biopsy show myopathy had many treatments.. Been diagnose with ADHD first then Neurological disorder, autoimmune disorder then muscle myopathy. Had psychology testing. Two neurologist that gave up on me after giving me years of prednisone. Also received blood plasma treatments and other real strong autoimmune meds. Seen a MDA neurologist he said no myopathy however my neutrons are in the center of muscle and that's not right he made a referral to Mayo clinic in Rochester MN. DR Schneider said it is medical necessary to be seen and I wait for my insurance to okay it however I do not believe this will happen they have denied me before thinking its all in my head even though I have physical changes and several diagnosis . I seen my family Doctor a week ago and she has been informed throughout this whole process we just recently discussed MECFS she said I'm a match including a history of swollen lymphoids and at least two years of CFS and eye problems ..</p>

15	I was diagnosed with Fibromyalgia in 1995 and suffered mostly with muscle pain and sleep problems. The medication I was prescribed helped greatly and I thought I was managing this condition. However, in 2002, I was diagnosed with Mononucleosis, which kicked off Chronic Fatigue Syndrome. It has changed my entire life, and its debilitating effects keep me house bound much of the time, unable to work full-time or participate in many of the activities I would like to enjoy. I have found only one or two health care providers who show real empathy or any true knowledge of CFS or how to treat it. Most of my doctors just keep pushing prescription medications at me, never really looking at me as a whole person. I am on more medications than I want to be and who knows what this is doing to my health long term? It has been a long, arduous battle and sometimes I think that I will have this until I die.
16	I was the mentally unstable black sheep of my family. Actually...I still am.
17	Frustrating and demoralizing. Sadly, most doctors still do not believe CFS/ME is a real illness and everyone of them offered antidepressants and a psychiatrist as treatment! So few CFS specialists in the U.S. I live in an area where there are no CFS doctors. I am homebound with my illness and suffer in silence now. I rarely go to the even though I feel as though I must surely be dying of something. The quality of my life is similar to a terminally ill patient.
18	I was fortunate to have as my primary care doctor an MD who was fairly knowledgeable about this and also had an interest in nutritional and alternative care.
19	The lack of diagnostic criteria and the need for a "diagnosis of exclusion" creates an extremely long and arduous road to diagnosis for CFIDS sufferers. In my wife's case, this was nearly a year long process, involving the following practitioners - her GP, a cardiovascular specialist (for her tachycardia symptoms), an infectious disease specialist (to rule out AIDS, tuberculosis...), gastroenterologist (to try to understand her digestive issues), pulmonologist (to rule out asthma), a sleep specialist (to rule out sleep apnea), and a naturopath (to help manage her symptoms in the interim). With over a million CFIDS sufferers, I can only imagine the burden this places on the health care system.
20	One doctor that I was excited about, because I thought he would have some answers...he told me walk 15 mins. a day- that was what he had the nerve to tell me!
21	First ....misdiagnosed as Negative for Mononucleosis.....months later told it was the "worst case" this physician had seen ever.....recommended rest (6-8 weeks) helped in the short term but, repeated attempts to return to work, normal behavior brought on severe relapses.....Getting into a study was an experience of revolving residents and many attempts to diagnose by process of elimination, until the best and brightest resident (with the help of more definitive criteria) diagnosed Chronic Fatigue Syndrome and recognized myalgia and Encephalomyelitis as painful ,yet untreatable comorbid conditions Treated, untreated, mistreated, the condition came and went as is its cyclical nature for years. .After finding a specialist, and a focused work up was complete, the diagnosis was confirmed .....with Orthostatic intolerance, hypotension, myalgia, sleep disorders(uncontrollable and non-restorative), cognitive impairment(due to uneven bloodflow to the brain) were all confirmed as conditions of ME/CFS. I am still with this physician and have been told that the recovery of my ability to function was greatly hindered by the lengthy time of being undiagnosed or treated.....This says some recovery if my function has occurred over time, however relapses are always around the corner, and lifestyle is not recognizable.
22	It started as flu, then it was thought to be pneumonia, then a post-viral issue when I never recovered properly. Luckily my primary care physician had some basic knowledge of CFIDS. However - that said -- it is woefully inadequate that he really had nothing to offer beyond a diagnosis. I found out more useful info from the internet and books than I did from my doctor. Eventually I found a naturopath (in another state!) who has helped me tremendously. It is an absolute shame that traditional MDs haven't a clue about the importance of diet, vitamins, minerals, amino acids, neurotransmitters etc. It has been a challenge to work between the two "belief systems" as MD's are trained to be highly skeptical of supplements. I may be mostly housebound, on SSD, and unable to work --- but due to supplements I am not bedridden.
23	My primary was very savvy.she did the garbage pail diagnostics. when she told me it was cfs, she said she would have preferred cancer, at least she'd have some options.

24	Had difficulty despite my symptoms any professional wanting to clearly state my condition was CFIDS. I got on disability by basically having to declare myself mentally incompetent. I still have trouble with memory and brain fog plus major fatigue and brain fog.
25	Drs still do NOT believe in CFS but they do believe in Fibro. CFS impacts my life more than Fibro. I can't find anybody to treat my CFS and I live outside of Philly! It is ridiculous!
26	The 3rd doctor I saw mentioned something about CFIDS but was noncommittal. I ended up studying the research criteria and found a doctor (after a long search) willing to systematically do the diagnosis by ruling out alternative diagnoses. I definitely had to be an active agent in finally getting a diagnosis.
27	First I was diagnosed with mono in August of 1994 @ the age of 37..I have never been the same. My diagnosis was confirmed in 1995 at the Mayo Clinic Rochester MN!
28	I was very fortunate. I was in the care of Dr Felice Meadow, D.O.. I contracted herp-angina and for months was nearly unable to function. 8 months later, still doing little more than working and sleeping - she ran a battery of tests and theorized and then diagnosed me with Post Viral Fatigue Syndrome. When she left the area, I tried several doctors who called it junk science before I found Dr Timothy Wargo (deceased) and Salmon Falls family health care. While my current provider there is not versed in CFIDS, he has done his best to support me. I have found my best help so far with my newest physician, Dr Beth Devlin, ND. Now that my ins covers naturopaths I am being treated by someone who really "gets" it and sees the whole picture.
29	This is my granddaughter.....she has not been diagnosed but is close. Everything under the moon has been ruled out. She does have Celiac Disease.
30	No hurdles. Just a lot of trial and error. I had a terrific Dr.
31	Because my primary physician is a personal friend he initiated all tests for a diagnosis, when a doctor from CDC was sent to our area he sent me at once and I was immediately diagnosed as definitely having CFS
32	Doctors and other health professionals seemed to be clueless as to what was wrong with me however they took the approach of testing me for everything and ruled things out 1 by 1.
33	Diagnosis of exclusion. As in UK, mostly psychologically centred as we do here.
34	My road was one of frustration. I saw so many Specialists, most of whom made me feel crazy instead of taking me and my symptoms seriously. Depression was always their 1st diagnosis. The only benefit having to see so many Doctors was 'ruling out' other diseases. To this day, any new Doctor I see looks at me as if I need to be committed.
35	Diagnosis is kind of bogus seeing someone could in theory fake the condition and drs dont know what causes it or how to treat it.
36	I read an article about CFS and shared it with our Doctor because he kept saying she was still suffering from Mono after over 6 months.
37	Doctors don't address any complaints of pain or fatigue. Many assume you are a drug seeker, regardless of your medications or history.
38	The diagnosis of CFS came a month after an infection from a hysterectomy, but later on diagnosed with Fibro. I believe I have more symptoms of CFS though! There was no treatment issued and I was shown the door. It then took 4 or 5 years later and over 30 doctors to get the Fibro diagnosis.

39	<p>I was first diagnosed with Lyme Disease and after months of treatments for something I never have I gave up and kept seeing my doctor with many complaints and many various symptoms as they would arise , it went on for probably over 1.5 years not sure due to memory issues . I then found myself a doctor at Boston's Woman and Infants who finally diagnosed me on Oct 31, 2006 and ever since then I have seen several doctors who claim to understand this illness but, yet all they have ever done is just put me on meds which are opiod and over the counter pain relievers . I continue to struggle and now see a doctor for pain management and he suggested I see a rheumatologist which I had to find .And will have my appt on 1/28/14. All these doctors do not seem to care they push pain meds make suggestions but never try to really listen they how no compassion and I feel just do not believe or want to learn about this illness . I do not think it is fair that we have to prove our illness we have to find our doctors and it is frustrating that everything we go through and try to explain has been brushed off and been told it is all in our heads or maybe your depressed or maybe you need to lose weight because all these symptoms could cause the body to react like this . Seriously that is bull, everyone with this illness has the same complaints and yet the medical world just doesn't. Hear our complaints or our cries for help</p>
40	<p>I started having problems in 1994, and saw several doctors before getting my diagnosis of ME/CFS in 1999. They included a gastroenterologist, a rheumatologist, a gynecologist (I had a hysterectomy in 1998), and an internist, besides my PCP. I was still working through those most of those five years. By the time I was diagnosed, I could not work any longer. What I thought would be a short term disability turned into a long term disability and I have not worked since. I firmly believe that if I had been diagnosed earlier, I could have continued to work, at least part time. Filing for SSDI involved many hurdles with the medical profession, including one doctor I was sent to that told me as soon as I walked in the door that he did not believe ME/CFS is a real illness. After the obligatory (I think) two denials, I was finally approved for SSDI benefits. I think ME/CFS contributed to me being let go from a job I had held for several years as my absenteeism had increased. It also contributed to a divorce. When I told my ex-husband about my diagnosis, he agreed I had had this problem for many years while we were still married.</p>
41	<p>Had to bring publications from both the AMA and then later the CDC to educate my doctor. Was frustrating that me not the professional knew about C.F.I.D.S. Had to see an immunologist as well as a neuropsychologist to finally get properly diagnosed and treated.</p>
42	<p>Most doctors didn't even try. They convinced me i was depressed even tho i didn't think so and antidepressants did not help.</p>
43	<p>It was - and still is - hell. I'm treated as if I am a psychiatric patient rather than someone with an actual illness 80% of the time. The majority of my care has-and continues- to come from the ER. In the early, pre-diagnosis years, I was told I had everything from AIDS to Mono, then finally a doctor settled on CFIDS two years later.</p>
44	<p>A lot of disbelief and avoidance. Once a diagnosis or prescribed treatment didn't help, I would get brushed off. One doctor even told me not to see her for anything related to my CFS as there was nothing western medicine could do. This was after I'd received a diagnosis from Cleveland Clinic. I had finally made an appointment there after years of no help and seeing multiple doctors. It took six years to get a diagnosis and seven years after that until I found a doctor with knowledge of CFS and who was willing to help me.</p>
45	<p>The vast majority of doctors and medical professionals I have dealt with know little or nothing about ME/CFS and its symptoms . . . and even less about how to treat it. I had a primary care physician who eliminated all other explanations for my symptoms, said it might be ME/CFS, told me to go read about it . . . and then left the practice. That process took over 5 years. (In the meantime I was told my symptoms—fatigue, headaches, muscle weakness, insomnia, brain fog, inability to multitask, memory difficulties—were all in my head and/or depression and/or anxiety.) After that, all the other doctors seem to go by her diagnosis, but act as if I self-diagnosed. (I did not know anything about ME/CFS until that PCP mentioned it.) None of these other doctors seem willing to learn anything about ME/CFS at all. They just tell me to go and read about it myself. I have searched and searched in my area and cannot find anyone who knows anything. There are also no support groups in my area. At first I read as much as I could about ME/CFS . . . but eventually, the whole process got too exhausting. I feel that the medical world has failed me. Everyone agrees I'm sick, but they all want to pawn me off on non-medical (and non-insured) "solutions" that don't seem to have any scientific backing. I've pretty much given up hope.</p>

46	I am an RN. I had faith in the medical community and system. I have lost most of that faith. Most physicians were "all in" until they could not come up with a diagnosis. I was chastised that I should be happy I did not have MS or Lupus. I was, but if you have a diagnosis, you at least know what you are up against. Then the depression issue arises. I questioned it myself, and tried every SSRI on the market. My symptoms did not change. I stopped seeing physicians except for my yearly physical and tried to resume my life. After a major crash, I was diagnosed by a rheumatologist. Post exertional malaise is one of my cardinal symptoms and where he started teaching me about an illness that I, as a medical professional, had preconceived notions about.
47	I was diagnosed 20 years ago by an MD that turned to treating patients alternatively. However, my primary doctors have never agreed or supported the diagnosis.
48	Even though I've been diagnosed by a healthcare professional, I've had other healthcare professionals question the diagnosis, express to me that they don't believe it exists and don't appear to understand it. They think I can work full-time along with other "normal" activities if I'm able to manage my own finances. I had the "medical expert" at my Social Security hearing say that he didn't believe that CFS/ME (and fibromyalgia) exist. But I received the benefits because of my other conditions.
49	many doctors, many wrong diagnosis, lot of frustrating mind numbing insanity ... went to Asvin in Houston TX
50	Got diagnosed on the NHS by my GP who's had experience, then I got diagnosed privately by BUPA. Happy with GP but wanted to see what help could get on BUPA. Positive attitudes, tests done as fast as my GP could sort. It's been as positive as it could be. Although I know this is very very different from a lot of people. I got lucky.
51	I was sent to a rheumatologist by my internist. My brother, who is also a doctor went with me. Blood tests were taken and sent to the Mayo Clinic. Came back with a highly elevated ANA. Fibro, Raynaud's, Sjogren's, CFS, CPS, arthritis. My life drastically changed forever.
52	I was only ever taken seriously. I was left to myself with all my symptoms. Telling me to manage my anxiety and he could do anything for me. What caused aggravation and significant drop in my health.
53	Saw different doctors for different symptoms. No one put it all together. I got the most help from a Lyme doctor.
54	My doctor told me that I have too many symptoms related to other illnesses to make an informed diagnosis of ME/CFS.
55	I had a very unusual situation in that the first doctor I saw mentioned it as a possibility. I saw other experts in different fields to rule out other possibilities. The utter lack of true knowledge of ME on the part of doctors astounds me. It took me many years and my own research to ever find something that at all helps with symptoms. I was able to get my Dr to order some tests recommended in the CCC of ICC primer. I have over 14 abnormal tests from that lab work. Please, please listen to the knowledge that is included in Canadian consensus criteria. It took one session of lab work that I brought to my Dr from this primer to learn what my doctor had not known to look for in over 16 years of illness. The knowledge is available from multiple experts in this illness. Please use the Canadian consensus criteria document to guide your decision.
56	Requesting further testing, different meds, talking with other patients
57	One doctor, after many tests said I had "Chronic Fatigue Syndrome" better known as the "Yuppie Flu."
58	un chemin de croix, incompréhension, traitée de dépressive etc etc
59	My body does not respond appropriately to illness ..no temp...Many physicians shut down when you say you have a diagnosis of MF/CFS. I nearly died of an infection because I couldn't get them to listen. It was six months before I had surgery.
60	After many doctors, tests, biopsies, a neurologist finally told me to see a rheumatologist because she thought it might be fibromyalgia. The diagnosis of FMS and CFS was actually a relief after the frustration of several other proposed illnesses and diseases.

61	Symptoms, lots of tests with bizarre results that didn't indicate any conditions my doctors or specialists were aware of. Went to a very unhelpful alternative health doctor who lead me to the direction of FM, and when I went to a FM specialist years later she diagnosed me with CFS. I had to move away from the doctors who treated me for CFS and I have never since found one who treated me for CFS directly. Have had a number of people tell me that CFS was not a real diagnosis and to treat the symptoms but without an underlying something to tie all these symptoms together I feel that the treatments I've been getting have often done more harm than good. Always I am told to exercise, always I am told to be more active, but neither of these things are possible because of my CFS.
62	Local Dr's suspected ME but would not diagnose it, especially near the end when they insisted that a Psych Evaluation was the only option. I refused to comply, knowing that would blacklist me to Psych. When I was diagnosed, I was told there were no Doctor's at the Number One Leading Teaching Hospital in the United States that would Treat the disease, No medications were available, and No Cure. After Dx. I still deal with nasty attitudes, resistance and conflicting information from various specialties who do not accept compatible terms for signs/symptoms and care interventions. The entire mess makes one feel like they are not keeping up on the scientific discoveries for long-term chronic diseases, especially this one.
63	The major hurdles come from the complexity of the disease, therefore much more research is crucial in developing an understanding of the mechanisms in play
64	I was sent to counseling even with double vision and right hand tremors a cough, exhaustion, irritable bowel, constant headache, always sick and memory problems. I haven't had a fever since 1995. Yet I've been to the emergency room many times with severe infections including MRSA - each time I have to argue that I DO have an infection and demand testing. It's terrifying!
65	Wow briefly? In a nutshell doctors here in the US need to be taught how to have compassion with patients (a must) and instead of the focus being on drugs to "Band-Aid" the problems of patients they need to learn about the whole body and where the ailments are stemming from. For me all the doctors wanted to do was give me medications which ALWAYS made things worse- way too many side effects and the awful fatigue worse after taking meds. I'm no longer on any meds- I hate them. I think looking at the gut more for this condition would help right from the start. I would love to talk to doctors and or med school students and teach them from my experience. My issues started with IBS and Mono.
66	The GP:s know little or nothing about Me/ cfs. It is up to me to teach the Gp about the condition. That is, the patient has to tell the GPs that the symptoms points towards ME. If I didn't have knowledge of the existance of ME, I might not have the possibility to get diagnosed.
67	it has been a complete nightmare - they thought i had me/cfs but weren't really sure
68	I was 16 when I got sick and even though I was a very good kid and a straight A student my parents and doctors thought I was sleeping through school to be rebellious. I was taken to a psychiatrist who diagnosed me with depression after she sent me to a doctor who ruled out any medical cause. Seven years on and off anti-depressants before I was finally diagnosed with CFS. But not by my regular doctor. My mom saw it on tv and told me about it and I asked my doctor and he said he didn't think I had it and made another suggestion like how I should write daily positive affirmations. After researching CFS online I traveled to get diagnosed by a specialist. My specialist can't do much for my symptoms but at least he knows I am sick and disabled. Unfortunately I don't have a local doctor I can go to. One doctor was sympathetic when I told her I had CFS at my first visit. Then a year later she was lecturing me for not having gotten better yet and wasting my life. I was refused a sleep test by a sleep neuroscience specialist because I had day-night reversal. She told me CFS was a syndrome, not a disease, and if I could just get my sleep habits under control I could get better. I have been diagnosed with dysautonomia. I have low cardiac output and low storke volume. I have diastolic dysfunction. I took the two day exercise test at the Workwell Foundation and was said to be moderately to severely disabled because of my low anaerobic threshold - but none of this means anything to the GP's or ER doctors I go to. When I tell them it has CFS, I never know what it means to them, but it never seems to be close to my reality.
69	A real ordeal!!! In France almost very little bit of doctors believe in CFS...an assault course, the time in the wilderness, feeling to become crazy ....

70	<p>I fell ill suddenly in October of 2009 with an undiagnosed case of mono. I was not helped by my primary care physician. He told me to get off my drugs and go for a walk that I'd feel better. This was after I begged him to put me in the hospital. I was so sick I was grocery shopping at the drugstore. I finally found another primary care doctor who was worried I had M.S. So I went to a neurologist. She tested me and told me I did not have M.S., but that my Epstein Barr virus titers were high and that I might have Chronic Fatigue Syndrome and that some doctors did not believe in it. I went back to my primary care doctor who sent me to the one M.E./CFS doctor in town. She diagnosed me with M.E./CFS in September of 2010. I relapsed in October and was forced to retire from my career as an English Professor after twenty one years. I am unable to work and am semi housebound.</p>
71	<p>I became ill with a flu-like illness &amp; ear infection, it lasted for three weeks. Afterwards, I was feeling unwell, but tried hard to get back in shape, but the more I exercised, the worse I became (funny, that...) I worked for one year after my "flu", saw the doctor several times, but they couldn't find anything wrong. About 1 1/2 years after having the "flu", I collapsed at work. The only strange thing in my bloodwork was high anti TPO, but normal TSH and T4. My doctor told me to rest... and rest... and rest... to no avail. After six months he finally agreed to let me try low doses of thyroxin, that helped a little, but after another six months I was still in bed most of the time. My doctor thought I should be content, I had a diagnosis that would secure benefits (Norway) - and he couldn't find anything wrong, and then there couldn't possibly be anything wrong, now, could it? I pestered him relentlessly for another six months, until he finally referred me to an endocrinologist... (six months wait for an appointment, but who complains, we have free medical care :) who confirmed Hashimoto's and referred me to a rheumatologist, who told me I had fibromyalgia, AND something more, and referred me to a neurologist... who said I had ME. And migraines, endometriosis, IBS, asthma...</p>
72	<p>I was fortunate to get diagnosed early because of a doctor who was educated about CFS.</p>
73	<p>My family doctor diagnosed me, but a microbiologist confirmed the diagnosis. I saw many different medical professionals after receiving my diagnosis. Many thought it was in my head.</p>
74	<p>Hard to switch doctors and search out specialists in order to find a medical professional willing and interested in listening to and exploring my symptoms. Once receiving "suggestion" of CFS, some medical professionals were skeptical of its existence. Had to endure years of "juggling" excuses to friends, family, co-workers as to my inexplicable, unreliable attendance at events and work.</p>
75	<p>First 2-3 doctors thought I was a hypochondriac. The next one took time to eliminate everything else. Then went to VA, PCM sent me to Rheumatology specialist who then sent me to CFS specialist. He is excellent. Getting the VA to prescribe meds that help is a trial, but he is persistent.</p>
76	<p>M.E., which I suffer from, has caused brain damage, a devastating sleep disorder, and waves of physical debilitation and flu-like symptoms for 22 years. It has cost me my career and much of my social life. I have found more than several doctors who have dedicated their careers to treating and understanding M.E. but they are all or mostly ignored and disrespected by the NIH and the CDC.</p>
77	<p>An ENT Dr diagnosed me after several severe Sinus infections. Given so many Anti biotic then that after 20 years still can not take them. Developed Cranial Dystonia and Apraxia of eyelids. Functionally blind fibro and IBS.</p>
78	<p>For the first twelve years I alternated between illness and relative good health. While Ill Drs did tests available in '70s and '80s and found "nothing wrong." Then illness became permanent and diagnosis was made and confirmed at various times over the years. No one available in my area is very helpful. One Dr checked my blood alcohol level. Maybe I was drinking. Idiot.</p>
79	<p>I was told that they couldn't find anything wrong with me. Then I was told it must be depression. I knew that it was depression because I know what depression feels like. I couldn't walk anywhere or barely wash my hair or take a shower. I now have a shower seat and most days I have to decide if I should take a shower because it exhausts me. I took a CPET test and was told that I have some type of Mitochondrial disorder. I also had skin biopsies taken and was told that I have small fiber neuropathy - it is on the borderline of an autoimmune disorder. I also have orthostatic intolerance, autonomic neuropathy, IBS, bothered by light, noise and sleep most of the day and night. Although, some nights I cannot get to sleep until about 4 in the morning. The attitude of most doctors is that they don't know what it is so their ego makes them blame it on depression.</p>

80	After going through the Shrink road and having taken 16 different psych meds and no improvement. Followed about 2 years of pure anguish, stress, and trauma. Then I got smart I started getting medical records, all of them. 3 and 1/2 years later I final, today had them admit my respiratory muscles are damaged.
81	Blamed it on depression, working too many hours, or other related conditions. Sometimes ignored.
82	Lack of knowledge, psychiatric biases, ignorance of the harming effect of exercise.
83	1995, after being sick for over 6 months and undergoing countless medical tests I was diagnosed with Chronic Epstein Barr Virus. Told to reduce my work hours, take vitamins and rest by a GP. Moved to MN, saw another GP who was very open minded. Did further testing and referred me to a CFS specialist. After about 2 years of being sick, I was diagnosed with CFS by this specialist. Luckily I had a very easy road to diagnosis, which is almost unheard of. It required lots of persistence, patience and money. Lots of support as well.
84	Most medical professionals do not take ME/CFS very seriously, but I have lost almost everything because of it. My friends with cancer are much healthier than I am.
85	My pcf worked with me to rule out other causes then gave me the diagnosis of CFS. She had no further assistance to offer to me, but sent me to other specialists who then just gave me more tests and more tests, but no treatment. After years of this, I stopped seeing any doctors due to the stress and futility of it. My pcf has no knowledge of treatment for CFS, and still does not to this day, 9 years after my diagnosis. She became very frustrated with me over the years when I would come back to her for help. Hurtful for me leaving me feeling hopeless.
86	No primary care doctor could determine what I had and did not perform blood test for EVB, HHV6, etc. Referred to sleep doctors - stuck in sleep clinics for 1 1/2 yrs and nothing worked and got yelled at by 3 sleep doctors bc they didn't know why their treatment wasn't working. Referred to psychologists 2x and the psychologists told them I was mentally sound and had an illness that they needed to determine. Saw a rheumatologists and they told me I was stressed out bc I was single and no kids and 40 yrs old and I walked out of her office and told her she needed her license revoked. I went to a about 15 doctors and no one could find anything out. I laid in bed very sick and only got up to use the bathroom for 6 months. After 6 months, I had a little energy and did my own research and found a ME/cfs expert (diagnosed myself) and finally after 1 1/2 yrs got an appt. with Dr. Susan Levine and was diagnosed with ME/CFS. No PCP doctors knew CFS or believed in it. Any doctor that I would mention CFS would "roll" there eyes or said they don't believe in the disease or it was all in my head.
87	Ignored, not believed, given antidepressants, then told of the dx and told to "live with it"
88	The road to diagnosis was long and frustrating. Doctors I saw generally only listened to one or two symptoms before declaring they knew what was wrong. They'd issue a prescription or recommend a therapy and when I didn't improve (and in many cases got worse) they would declare I was not physically but mentally ill. I did get depressed but it was because I was so ill and no one could or was willing to find out what was wrong with me. Medical professionals had no knowledge of CFS when I first became ill. Even now many of them do not and treat it as an emotional or mental problem.
89	I have classically presenting ME triggered by a viral infection. After being sick for 5 months and doing lots of blood test and a urine sample, my primary care doctor diagnosed me with suspected ME. After an MRI and neurological exam were done to exclude MS, the ME diagnosis was confirmed. I also have POTS, which I noticed on my own and my doctor confirmed. I believe that early diagnosis helped me start managing my illness well early on and prevented the illness from becoming more severe.
90	I was a hospital nurse - RN. Sudden ones for me - woke up one day and couldn't get out of bed. Sick for 2 weeks, went to family doctor. Tested positive for strep throat. 2 rounds of antibiotics didn't help, so was sent to infectious disease specialist. After antibiotics cleared strep throat and other bacterial infections, still sick. Epstein Barr high, so infectious disease specialist sent me to a doctor who was known to treat CFIDS since HIV negative. This was in 1991. Family doctor said he didn't believe in CFIDS, but thought I might actually be sick. Infectious disease specialist believed it existed, but said she didn't know enough about it to treat it.
91	Since I became ill in 1983, my doctors had no idea about ME/CFS, although they were sympathetic and concerned. After a few years, I developed a secondary depression which was successfully treated by a psychiatrist in 1988. He looked at my remaining symptoms, diagnosed me with CFS, and referred me to an infectious diseases specialist who confirmed the diagnosis.

92	Although my primary care physician didn't believe CFS was a discrete disease, in the absence of anything else she said I could call it that. She has always been convinced it was viral induced. Within my first year I began seeing Dr Jose Montoya. I have been uniquely fortunate that no dr I saw questioned whether I was really sick.
93	I am a single mother, when I stop working my son was 15 years. I could not find a diagnosis and I was bed ridden. My doctors said it was depression since I lost my job, and It was a lot of pressure on me. Finally an Internist gave me the first diagnosis, then I had to learn different ways to cope since this condition do not have a treatment.
94	Bias towards mental disorder by doctors, family, society. Not taken seriously. No treatment offered. Left to fend for myself. Great difficulty in getting benefits, care.
95	My daughter's pediatrician initially said she had a "virus" and it would pass. When it didn't we had blood work done to look for mono, anemia, lymes disease, ect. All her blood work was normal. After a second series of blood tests that also came back normal his response was that he didn't know what was wrong with her. I took it upon myself to call a pediatric infectious disease specialist who then diagnosed her with CFS at the age of 14.
96	Read Brain on Fire. Best description of a diagnostic journey with this type of illness.
97	Road to diagnosis was a jumble of misdiagnoses: depression, viral labrynthitis, allergies, possible tumor, etc.
98	Non-specialists know very little about the illness. The majority of doctors believe CFS is a form of depression. Most doctors erroneously believe that exercise benefits patients with CFS, and that antidepressants are a legitimate form of treatment. The name CFS enforces these attitudes.
99	Mild-to-moderate fatigue started in 1984 along with migraines. I then was diagnosed with fibromyalgia (acute-onset) in 1986 by a rheumatologist at the hospital where I worked as a medical secretary. I saw a CFS/fibromyalgia specialist in NYC in 1987 (Dr. Susan Levine) and have seen her a few times since then. My primary physician now prescribes my medication (Lyrica) for fibromyalgia. I am now 60 years old and have been on Social Security Disability since 2009. Many years ago, I did see some doctors that I was not happy with, but for the most part, I have received good care for my CFS and fibromyalgia. I also have IBS and Raynaud's.
100	Initially though I had been diagnosed with tow viral infections, monnucleosis, then a few months later I came down with another viral infection, Coxsackie B3, I was still misdiagnosed, tried to push myself on as I was told by the doctors which of course made thhe ME very much worse and I finally had to give up work. I've been ill now for 34 years and counting. The arrogance and ignorance of the medical profession is staggering. The sicketific evidence for the biomedical basis of this disease has been available for years yet the medical profession is blissfully unaware of it. Doctors/medical authorities should be legally accountable for this scandalous professional negligence. Because the doctors have so successfully slagged ME patients off for all these years, patients friends and family often don't believe them, government benefit agencies and health insurance companies are able to choose to believe it is a behavioral disorder which people can rectify, if they so choose. So there are serious financial problems for patients. Lack of care and support from family and friends in many cases. And almost universally for the 20 million patinets aroudnt he world, negligible medical care and certainly little con passion and basic human decency from many doctors.
101	I was treated like it was all in my head-imaginery. Still have that attitude with many MDS.
102	First doctor insisted I "resent my husband making me work" and "just want to be a housewife"; I did not get all that education for a career so I could scrub floors!!!! When I demanded a second opinion, the quack sent me to a doctor who does only AIDS -- who called it a "sick joke"; clearly the plan was that future doctors would see Dr.T's name and be scared off me. And then one day I was in my lawyer's office, looking like death warmed over, having been told if I couldn't get my symptoms under control I'd be fired, and she called her dad (a doctor), who conference-called us with his friend who was researching CFS -- I was such a textbook case that the guy effectively made the diagnosis even before my first appointment with him.

103	I was 20 in 1982--"EBV" was in vogue, by 1984 I was diagnosed, but, most MD's I saw did not believe diagnosis & I was given no treatments to try. Many MD's insisted I take psych tests and treat for other things, or not at all. Specialists of course only treat for the specialty they are trained for. By 1989, antidepressants were considered sufficient to treat most everyone, but I could not tolerate any (nor did I have clinical depression). My illness has gradually progressed and gotten more severe over time with other conditions added on (NMH, vestibular migraine, Chronic Lyme disease) each one having their own stigma, and divergent opinions for treatment. I was in college when I got ill; I am now semi housebound, never had a career or family or traveled, and have spent a fortune on health care costs.
104	The first 4 physicians I saw were unable to diagnose what was going on, so I was pathologized and humiliated. One physician told me, "You have Epstein Barr virus, I don't believe in it and it's certainly not chronic."
105	Luckily I lived in Atlanta at the time and they had a strong support group. I live in S. GA. now and there is nada medical support.
106	Began with a 14 day 'flu' (worst of my life) that never went away - doctors seemed to believe me at first, just kept telling me I was fine - I knew better...that continued until I moved to San Francisco from TX with intention of getting help/diagnosis/treatment - 6 months after my move, I was dx'd with CFS "due to a virus"...that was 16 years ago - since then, have rec'd no tests or treatment - have gone to ND's who have helped some but I ran out of money, energy and now am completely bedridden and almost unable to take care of myself. I am all alone now; both parents dead - no siblings - I wasn't able to maintain contact with my large circle of friends - my move well into my illness prevented me from being near friends and physically I wasn't able to maintain communication with my large circle of friends (letter writing) so I ended up losing them all, one by one, year after year. I still try to help myself and in the last year have insisted on HMO allowing me to see inhouse infectious disease doc who told me he'd help me (I gave him outline of Drs Montoya and Lerner) but never called me again...just dropped me...then I travel from Austin to Houston (am driven while I lay in back seat) to see a 'cfs' specialist...she has never run a test or suggested any treatment - instead rx's pain meds. I am broke, alone and dying.
107	My first dr said it was all in my mind till I had a positive ANA for lupus. Went to a lupus dr and didn't have lupus. This dr sent me to many specialists to make sure I didn't have something else first. Once I was checked by endocrinologist, infectious disease, neurologist the rheumatologist dxed the CFS.
108	Was initially brushed off to a psychologist by a doctor thinking it must be depression because I was so tired. Psychologists resoundingly said that I was not at all depressed or mentally ill. Doctor investigated a little further, then just left me to myself. I eventually was able to recover much of my functioning through extended bed rest. Years later, my health declined severely again. Again, I was misdiagnosed with depression, and treated for depression this time (with no positive effects), despite my mood issues resolving easily. Eventually I got so profoundly ill that I knew depression could not possibly be responsible. A nurse I knew suggested my symptoms seemed similar to ME/CFS or Fibromyalgia. I looked into it and raised the question with my doctor, who said she had been thinking that might be what was wrong (but NEVER MENTIONED IT TO ME). I pushed to have her use the CCC diagnosis chart on me. I've since had my diagnosis confirmed with ME specialists. Along the way, I had some awful interactions with doctors. At this time, I was so ill that sometimes I literally couldn't crawl to the bathroom or hold my own head up. I felt more ill then ever in my life, and it never ever let up. I was in constant pain, and suffering from a huge number of symptoms. It was torturous (and that word is not an exaggeration). I was told everything from that it "must be nice to have a nice little break" to "if you had children, you'd be fine" to "I only deal with medical things" to "you must just be having panic attacks". Many other doctors were well-intentioned, but completely at a loss. I saw one of the best diagnosticians in the area (with an incredible reputation), and he was not able to recognize that the symptoms I was describing fit under the ME/CFS umbrella, and in fact are very common with that illness.
109	Illness began after bout of meningitis & encephalitis in '89. I've had every symptom you can ever imagine & seen every ologist most who were less than helpful admitting they knew little all the while making me feel worse
110	My road to diagnosis was relatively brief by chance of geography. I lived near Radcliffe Hospital in Oxford, England, at the time (early 1990s) working very hard to discover the causes of and cures for Aids. They had seen many ME patients during this time and were relatively quick to diagnose me.

111	I came down with CFS years before there was any kind of name for it. At first, we thought it might be allergy related; then went through ruling out all other things it might be. After several years, and finally a name for it, I saw a doctor who was able to confirm the diagnosis of CFS. It took me four long years of fighting with Social Security Admin. until I could qualify for disability payments.
112	The doctors no nothing about this illness,I would have never been diagnosed if I hadn't gotten in to Dr.Klimas's clinic. All doctors before that told me that I had no healthy.
113	Told me it was all in my head. Clearly didn't believe me as long as I was still at work even though it took a truckload if complementary needs to keep me there. Without them I was bedridden. Also tendency of complementary doctors to push a narrow bandwagon of treatment rather than take a holistic approach.
114	Received CFS diagnosis, did graded exercise program which was useless and made me much worse. Investigated further via integrated Dr found dysbiosis, fungal gut overgrowth and parasite Protozoa. Then took antibiotic therapy which made great improvement but once stopping symptoms return.
115	Long process of elimination and once there was a diagnosis, no real treatment options.
116	I first became ill in 2004 and was finally diagnosed in 2007 with CFS and Lyme disease. Finding competent and compassionate healthcare practitioners has been enormously challenging. The financial burden of this disease is devastating. Additionally the physical symptoms are horrendous to deal with.
117	Two paths converged: we found Dr. John Chia on the Internet, and he was a consultant to infectious disease research colleagues of the patient's father. Neurologists were especially clueless and denigrating! One diagnosed the condition "a deaux," implicating the patient's mother.
118	dokters, specialist for stomach, neurologist, psychiatrist,cfs dokter-because I got worse over time the cfs docker sent me away-resisting alternative therapies that say they can help you
119	It was obviously a very long, torturous road. I became ill with flu-like symptoms that got progressively worse. Doctors told me that nothing was wrong. I finally convinced one to do blood work for EBV and it came back positive. That doctor told me to go on with my normal routine, NOT to stay home an rest. Years went on and I got worse. I tried new doctors who all told me that nothing was wrong with me or that I was just anxious, like many "typical women" are. I'd been to emergency rooms with a heart rate of 174 and blood pressure so low that I was passing out. The ER doctor misdiagnosed me as having an panic attack. Another cardiologist misdiagnosed me with a heart problem that I didn't have and gave me medication for it which, of course, made me feel much worse. It took over 10 years and a complete physical breakdown to find a doctor who recognized the symptoms and subsequent conditions as ME/CFIDS. The medical community is far from knowledgeable about ME/CFIDS. They are now forced to admit that it exists due to irrefutable evidence, but they still do not wish to be educated about it or bothered by patients that suffer from it.
120	I was treated horribly. I went from specialist to specialist and saw 2 different PCP's. When I told doctors I thought I might have CFS, several basically told me that it was not a "real" diagnosis and it is believed that "it's all in your head". A couple just admitted that they knew "nothing about it". When I got so bad that I could no longer work I went to my PCP and asked her to sign my FMLA and disability forms but she refused and said "that's really serious to put someone out of work, don't you know that?, I can't do that". I had to see a CFS specialist to get the diagnosis and help with completing the forms. Fortunately my employer has been totally understanding and accommodating so that I can keep my job and work from home 4 days a week. Almost no one has heard of ME.
121	I have never recovered from the onset of this illness which has never been truly accepted by many of the health professionals I have seen. a In fact have had to deal with severe debilitation and confinement to my home. Only now am I somewhat better but I am always afraid of relapsing if I exert too much. The affect on my life has been profound, and the stigma associated with CFS has made it even more difficult psychologically as well...so there are many hurdles I have tried to overcome without much support from the medical community as well as my friends and family,
122	Diagnosed with Glandular Fever. Partial recovery only, need to continue work and family care, combined with lack of understanding from doctors, led to complete collapse after ten years. Diagnosed with ME. Instructed not to return to doctor and would recover in two years. Still waiting for recovery thirty five years later.

123	<p>My wife's diagnosis took 9 years and over a dozen useless and expensive specialist appointments. By that time she not only had classic signs of ME, but also neurological, autonomic, and cardiac complications of persistent viral infection and of ME. Serology was negative for virus, but fortunately she had tissue biopsies, which confirmed persistent viral infection. She responded tremendously to IVIg, but we are not sure if we can get it in the long term. Her NKcell function was tested in multiple labs and is severely low, but 99% of physicians are indifferent to and ignorant of the seriousness of this finding. Her onset was classical viral onset- but this is ignored. The attitude of health professionals to ME is byzantine and hostile and it has gutted our family. To all of us living with her, it is a no brainer that she desperately WANTS to be healthy. The notion that this is psychosomatic is preposterous to anyone remotely familiar with the physical suffering of ME. There is a desperate need for intellectual curiosity about this ghastly disease, and urgent need for fundamental education on Post-Exertional Relapse and the biomedical underpinnings of ME. Specialists' outright hostility to ME patients creates a medical wasteland and we have to fight tooth and nail for any treatment -this is nearing 2 decades and our whole family is despairing that she will ever get better treatment or quality of life. It took half a decade until they took her cardiac signs seriously, and she now has documented and serious heart failure. She has diligently tried CBT and GET in the early years and these both made her WORSE. Please PROTECT ME PATIENTS FROM IGNORANCE!. If the IOM doesn't understand PEM, NK cell dysfunction and the severe debilitation of this disease, they have no business pronouncing diagnostic criteria for this ghastly disease. This contract risks putting our loved ones with ME back decades.</p>
124	<p>1st diagnosed with Fibromyalgia approximately 1995. The fatigue and PEM were not taken into consideration, nor was it treated. Only after becoming unable to work was CFS diagnosed. Became ill initially in 1986. Much disbelief of the impact that was on my life in the 1990's, and still in 2013. Still getting from health professionals the just try harder kind of response, total lack of knowledge and understanding. Still deemed fit to work, even though most days only function for 5 to 6 hours.</p>
125	<p>First 3 years; dismissive (they didn't even try. I was a fatigue patient, too young to be sick, obviously not depressed, and they weren't interested in me at all. I could barely shower and they ignored me.) Next 6 years: investigated me for major diseases, found +ANA but nothing else from their list, told me I was basically healthy, followed me to see if I would develop Lupus or RA, did next to nothing else. If they offered a medicine which failed (happened 2-3 times), nothing was offered to replace it. Next 3 years: although diagnosed with CFS, still no appreciable treatment. Then I went to an ME/CFS specialist, and changed all my other docs yet again, and now have some treatments which are useful but don't help me not be housebound/mostly confined to a chair. At this point, I don't tell new doctors of my CFS diagnosis because most of them are much more helpful if they don't know. I have been, for example, to ER with MS hug, (then-undiagnosed) asthma, and muscle spasms, and possibly a UTI or kidney stone (all at the same time). Because I presented with abdominal pain and they were unable to understand the dynamics of PEM, they thought I was a fraud. They lied in my chart (about how well I was breathing and how pink my skin was), gave me a facetious diagnosis and a placebo, and sent me home. I was back the next day because I still couldn't breathe well. I finally got a doc who actually listened. He still couldn't diagnose me with anything more specific than muscle spasms, but he at least got me breathing better. I am certain this discrimination was because of prejudice over my CFS diagnosis (which was in my e-chart). I have also had neurologists refuse to see me (or refuse to diagnose migraines that 3 other doctors, at least 2 of them neurologists, have diagnosed) because of the CFS diagnosis when I had in hand test results for lung muscle weakness which my pulmonologist says is neurological (and from the CFS). Note I am saying CFS because that's my official diagnosis and that's what my doctors say, but I consider myself to have myalgic encephalomyelitis (I was diagnosed with Fukuda, and I also meet CCC and ICC). I have neuropathy, presumably from the ME, as most patients do, and I don't think it's that wrong of a name. I was recently diagnosed with some kind of connective tissue disease, and when I tell doctors this instead of CFS, they are much kinder and more helpful. (If I tell them nothing they may be a bit hostile about my level of debility with no major diagnosis to account for it; I tried that. Not always, though; at another ER visit, I told them I'd told them everything they needed to know and that I might not run a fever even if I had an infection, and I think they thought I had AIDS, and they were much kinder to me than most people who know I have a CFS diagnosis.)</p>

126	My GP of many years was thorough enough to feel that ME/CFS was all that was left as a diagnosis in my case. Unfortunately he had no idea about treatments. I had to find a doctor on my own and it took about one year for ANY treatment ideas. Prior I saw several specialists in immunology etc who knew nothing, could find nothing wrong and had nothing to offer me. None of them tested for orthostatic intolerance or coeliacs which upon reflection astounds me. I have the former but not the latter.
127	I've been ill for over 30 years (since adolescence) & have never found effective help from either traditional or holistic medicine. I'm largely housebound, unable to work or get disability/government benefits, & am facing a frightening future at the point my savings run out when I will likely become homeless.
128	Diagnosed originally by a Kaiser Dr. who refused to do the testing to confirm diagnosis so that I could apply for disability benefits. Was able to change ins. companies, first Dr. I saw spent about 10 minutes on a physical examination for disability purposes, and stated on the form that he thought I was mentally ill, and had been for years. I convinced him to give me a referral to Dr. James Jones, then at National Jewish, who tested me for CFS and confirmed the diagnosis. I was then eventually able to get Social Security Disability. Twenty years later, when I use the term CFS or ME/CFS while speaking to a Dr., they often use the term fibromyalgia in response. I have to tell them that fibromyalgia is but one problem of the disease ME/CFS. It is discouraging that after 20 years doctors still don't know any more about it than they did when I first became ill with it. They treat individual symptoms only.
129	Diagnosis was relatively quickly, but no treatment options at all.
130	They do not understand the illness....even worse...some of them don't "believe" in that it exists.
131	My doctor was excellent and ran tests to rule out other things. A couple of years later he told me he could diagnose it, but I should find another doctor who could treat it.
132	My primary care doctor when I got sick was very unhelpful (not ordering tests, saying it was psychological, not filling out disability paperwork in a timely manner) and unfortunately I spent 3-4 years before finding a new one who was helpful. I saw many other doctors (specialists in endocrinology, rheumatology, and even CFS) but they were mostly dismissive or hostile (or just ignorant). Some seemed frightened, as in "I've seen this before, you just have get in shape and get over it otherwise you will get worse". Or "just walk 5 minutes a day and add one minute a day" when I was already out of my energy envelope doing basic daily living tasks.
133	An astute primary care doctor diagnosed me with fibromyalgia in the 80's. I saw a CFS specialist in 2000 when I began to experience cognitive problems, sleep disorder, and profound exhaustion.
134	After seeing more than a dozen doctors (multiple specialties) I researched CFS on the Internet. I suggested that to my primary care physician and she looked it up in a book, then agreed that I had CFS. However, she did not give up the idea that I had something else, and continued to send me for painful, exhausting, and expensive retests.
135	I had this illness for over 20 years. Prior to this being a recognized illness, most doctors would say is that it seems to be a mental illness. Now the name is recognizable, but many physicians don't take this illness seriously.
136	I have had to be myself my doctor. Nobody of medical professionals knowing really ME/CFS in 1991. I was very well after 5 years because a doctor talk me probability a virus. And I help a lot of people now in Québec (Canada).
137	Most doctors do not have the time to spend for proper diagnosis. Once diagnosed most doctors seem to still believe that CFS is a psychiatric condition. I have not been able to find specialized local treatment. Dr. Nancy Klimas is local but her clinic is full.
138	Attitude of medical professionals is carefree and belittle the debilitating nature of the complex symptoms, often dismissing the same as purely maligning. Knowledge of the same among the professionals is shockingly next to nil. Even prominent textbooks of medicine have given very little space for ME and even so, portray ME as a psychological problem. Road to diagnosis is often by oneself by reading about the same from prominent advocacy groups and websites, with the very rare honest appraisals from the medical journals.
139	I had been to many doctors for years that felt it was only psychological and sent me to a psychiatrist for depression. I was not taken seriously and suffered shame and frustration!

140	Started with flu- like symptoms. I was hospitalized for a week and given huge doses of antibiotics. Then falsely diagnosed with prostate cancer. Then diagnosed with EBV. Then sent to a rheumatologist and psychiatrist. Finally found Dr. Rey & Dr. Klimas. Recently I was diagnosed with sleep apnea too.
141	I knew of a doctor specialising in ME and I went straight to her
142	A long road, no doctor would diagnose Myalgic Encephalomyelitis or offer treatment, local doctor now accepts that this is what I have, but has no treatment available,
143	Initially diagnosed with post viral fatigue. Investigation & Treatment for reflux (ongoing), treatment for depression. Lucky one GP studied ME but not able to do anything (NICE guidelines) he did however refer me to a ME expert at a hospital who diagnosed ME, FM & depression. Initially symptoms cyclic severe to mild, saw him when I was mild and he said there was little they could do to help. My treatment has been mainly down to myself with some help from a clinical psychologist. Now condition is worse than moderate, have retired and am mainly house bound. No help from anyone apart from my wife.
144	11/91 I became ill for 6 months with pneumonia-like illness which wouldn't go away. When it suddenly went away, I spent 3 years with awful cognitive problems, not unlike early Alzheimer's. From there I progressed to the more normal symptoms of arthralgias, immune dysfunction, crashes when overextended, etc. Few medical professionals know anything about CFIDS. I have actually had one MD in the last few years tell me it wasn't in his medical textbooks when he was in medical school, therefore he doesn't believe it exists. I find D.O.s much easier to deal with than M.D.s. Although I currently am seeing a physician in LA, 3 hours away from where I live, who is magnificent. She is an endocrinologist and tweaks this and that and I am functioning better than I have in many years. I still don't understand why I need 3 litres of oxygen 24/7 even though my heart and lungs are fine. Everyone tells me it must be a "brain thing" but can't explain it. Something in the Medulla Oblongata? Why?
145	I heard doctors mumble,,, post viral syndrome, soldier flu, chronic mono,,, even still after the dx, and quite ill, I see doctors that tell me they still aren't convinced I have CFS - they don't understand the profound exhaustion/fatigue and PEM. So frustrating! I constantly have to bring in research for doctors to read, so they aren't stuck in research over a decade ago!
146	Self education, then education of a physician who was educable. That was hard to find. Each specialist I saw came up with their own unrelated diagnosis: IBS, seizure disorder of unknown origin, neuropathy of unknown origin, viral infections ( EBV, CMV, HHV6). I had to put the puzzle pieces together, and in fact was told I had CFS by an acupuncturist. From there I began researching the disease. So while I heard the diagnosis in one year, I could not find a physician to actually treat me for 3 years, and I was laughed out of more than one physician's office.
147	I came down with a viral infection and began experiencing severe symptoms related to CFS after that. I was primarily told to rest and felt as if my doctors thought I wasn't really sick and was over-reacting. I saw many many doctors before receiving the diagnosis of CFS. I happened to obtain testing for EBV titers because my neurologist thought some of my symptoms sounded like mononucleosis. He told me the results looked very strange to him but he didn't really know how to interpret them. After many months I advocated to be seen by an infectious disease specialist. He Diagnosed me with CFS but admitted that he really hadn't read anything about it since the 80s. Therefore, I started reading about it on my own and found a CFS specialist in order to have the diagnosis confirmed. She confirmed that I had CFS and also that I had a reactivation of Epstein-Barr virus. Unfortunately, she doesn't except my insurance and so I am not able to see her on a regular basis. All of my current doctors know very very little about the most recent research related to CFS. They also appeared very skeptical about her recommendations. My treatment is not as good as it could be. I feel negatively judged by some of my doctors.

148	In 1988 I had surgery for a ruptured tubal pregnancy. Immediately after returning to work 3 1/2 weeks later (admittedly a bit early), I caught a particularly nasty flu that was going around. For months I assumed my slow recovery from surgery was due to getting sick before I was fully recovered, but finally saw my internist 3 1/2 - 4 mos. after surgery. He immediately thought it was CFS, but sent me to an infectious disease specialist to confirm. The specialist confirmed & also thought I might be depressed as well, due to the loss of my pregnancy. I was lucky to be diagnosed so quickly, but even my own dr. let me return to work when I was clearly unwell (my co. was going through rounds of layoffs & I was afraid of losing my job) because I "couldn't do any permanent damage" to myself. I've been unable to work for 25 yrs.
149	As a clinician who works in a specialty practice in the CFS/ME field, I have seen many different "roads" to diagnosis. It is often a long one and fraught with misinformation and misdirection. I seem many people who have been treated with bogus, marginal, and sometimes harmful "alternative" or pseudo-medical therapies because they were turned away by their "better qualified" medical professionals. Others are subjected to endless expensive referrals, tests, and re-referrals with no answers, to be told eventually that "you have chronic fatigue and there is nothing I can do for it" (how untrue!). It seems from my experience that there are subsets of people who have varying etiologies (or at least descriptions of the course of illness) and these people all seem to move toward a syndrome that resembles the descriptions of CFS as we try to diagnose it by various criteria. (So far I feel the International Consensus criteria have come closest to the best description of CFS/ME). I have seen patients whose onset was post viral or bacterial illness, post partum, post encephalitis/meningitis, post repetitive sports injuries, post numerous surgeries, post repetitive concussions, post period of sustained physical or emotional stress, sometimes for no identifiable reason that we can tease out... many differences but a very similar syndrome. Maybe once we have identified biomarkers and more physiologic definition we may find one single entity or a cluster of similar looking syndromes. Obviously, a clear and well informed decision about who to study will be needed.
150	I'd have to say I didn't really blame the doctors, they just have a hard time admitting they 'don't know'. But if they do, they usually say that it may be psychological. I lucked out in '09. I was going to the VA because I lost my job at the University of Michigan after 20 years in. My primary there also happened to have ME/CFS. that's when I got my diagnosis.
151	Overall, difficulty getting the initial diagnosis, now that I am 70, treatment for pain and the rest is pretty much ignored.
152	I had a severe onset for well over 6 months. I was referred out by my PCP to Neurologists, Rheumatologists, 5 Sleep Studies. All at various intervals. Everything was symptom management. Nothing solved the severity of the overwhelming signs and symptoms. Had multiple CAT Scans, MRI's, and unending "basic blood tests"; never would they consider in-depth blood work to get to the core. One doctor diagnosed one illness, and 3 others would call them a fool! Finally, after 4 1/2 yrs a BCBS Nurse Case Mgr told me to go to a teaching Hospital, pay for ALL my medical records and that Nuerologist did diagnose CFS in 10 minutes. When I applied for SSDI I read the original PCP's notes. Not only did he have the same Diagnosis in his notes, so did the first 2 specialists he sent me to. No doctor would do any more than Palliative Care. It took years to finally get an Endocrinologist who does not recognize the ME. Too many drugs that did not solve the problems.
153	My doctor believed me when I told him something was wrong, since he knew me for years and respected me as an ex-medical professional. It took a year to run all the tests to rule everything else out. He was extremely thorough.
154	Terrible. No one knows what to do to help you except to throw all kinds of pills to try. Had reaction to many and you feel because they really do not understand how you feel you give up.
155	Road to diagnosis has been painful. There is a lot of stigma and specialists do not want to care for patients with ME. It's like playing 'hot potato'.
156	I contracted CFS/ME in 1980 there was very little knowledge of this syndrome.
157	Doctors didn't believe in it. Doctors didn't listen to what I was saying. Doctors thought if I would just go and get exercise, I would feel better. I think three years of that treatment only made my condition worse.

158	I had acute onset following a flu-like virus at age 46. Prior to then, I was in excellent health. My internist was worried I had cancer and prescribed a large battery of tests. I have a strong background in science and knew my internist was wrong. Another doctor at the same practice believed I had might have MS or Parkinson's, which I also knew was wrong. So I turned to a MD colleague and close friend who spent several days doing research. He hit upon the Carruthers (Canadian, 2003) study and knew instantly it fit my symptoms. Since then, I have essentially acted as my own medical management expert. No physician I have seen has known anything about ME. My symptoms correlate nearly precisely with the Carruthers 2003 and Carruthers 2011 Consensus Criteria.
159	Medical professionals have NO knowledge of this illness (unless one of the few specialists who have devoted their lives and careers to it). They are unable to diagnose it and do not have a clue how to treat or help. If you are very lucky (which I am) you at least have a doctor who cares and tries to help. Although my doctor will not give me a diagnosis, he acknowledges that I am sick and have many issues. Most patients, besides being very sick, have to deal with disbelief and disrespect.
160	I first became ill in 1957. I was diagnosed in 1988. That should tell you what hurdles I had to overcome. The illness wasn't "invented" yet. I also was diagnosed with psychosomatic problems including a misdiagnosed case of whooping cough because I got it 30 years before doctors noticed a vaccinated teen could get it. Lucky me. Always 30 years ahead of the medical establishment in my illnesses.
161	It was a lengthy and very expensive process of elimination of all other known causes. The medical professionals knowledge of CFS was almost non-existent. Once the diagnosis was made, they simple said there is nothing we can do for you.
162	I was diagnosed after I had guests at which time we swam and played a lot in a pool and after as few days I was so tired that I could hardly do anything. Ever since then I function well as long as I don't exercise too much [re: walking 3 miles an hour on a treadmill for 30 minutes]. My activities have to be prolonged and more strenuous than I do on a regular basis. Like today, I just returned from a walk at the Desert Botanical Garden and will be OK but when I over do, it takes me weeks to recover. Unbelievable !
163	Told over and over by health professionals (especially at Kaiser) that it was just depression in spite of: 1--I am a psychotherapist and know what depression is. Although occasionally mildly depressed, that is not what is primarily going on by a long shot. 2--I have many symptoms that have nothing to do with depression and are even contrary to depression such as extreme fatigue and chills if I try to exercise, multiple inflammation issues, brain fog and not able to think clearly 1/2 of the time (only associated with severe depression), poor ability to regulate temperature and strong alcohol intolerance.
164	Some doctors were kind but said they didn't know the cause of my symptoms. Others insisted it was all depression.
165	When I first became ill with ME/CFS, I experienced prolonged and severe flu-like symptoms, which caused me bewilderment and distress. Despite numerous doctor appointments over a period of months (before a diagnosis), and despite my symptoms persisting for months (before a diagnosis), and despite me usually being too exhausted to leave my house, my doctors persistently dismissed my symptoms as being caused by only a 'mild' respiratory tract infection. After a number of months, without a diagnosis from a doctor, I finally diagnosed myself with ME/CFS, and my doctor passively accepted my conclusion. The diagnosis was confirmed years later by a secondary-care specialist. Medical professionals are nearly always either under-educated or mis-educated re ME/CFS/CF. Doctors usually treat ME/CFS/CF as a single (homogeneous) fatiguing illness, dismissing all symptoms as being functional in nature, rather than biomedical symptoms of unknown biomedical cause. So ME/CFS/CF is treated as a single functional (psychosomatic) illness rather than a heterogeneous cohort of under-defined and little-understood illnesses. Doctors are nearly always at a total loss as how to treat patients, so patients are invariably dismissed, ill-treated and under-treated. In a number of research studies, roughly fifty percent of primary-care patients (diagnosed with CFS) were subsequently given an alternative diagnosis when investigated by a specialist secondary-care team. (The patients had other defined illnesses that were causing fatigue.) This underlines the importance of having expert teams investigate CFS patients for missed and alternative diagnoses.
166	Better than average
167	Found most doctors know nothing and can be very dismissive. At best, PCP is polite but clearly skeptical.

168	I worked as a medical professional and I knew it was what I had but the doctors I met with always denied it was a real disease. I traveled to Miami and got diagnosed by Dr. Klimas after having the disease 24 years
169	I felt helpless and then hopeless. 98% of medical professionals have a preconceived but highly misinformed opinion of what CFS is and the related conditions leading to mistreatment. Better to read the research going on through Health Rising web site. No who the CFS specialists are ,then decide if you can afford to see one. Proper blood tests are important but only a few people in the US or world know what those are. Try to get checked for Lyme infections and co-infections. My local Internal Specialist has a son with autism which makes him very understanding and he knows more about my condition than any other regular doc I have seen. Nonetheless you will be highly frustrated since there are no known standardized set of tests to diagnose condition, treatment is trial and error in even the best of circumstances and expensive. If you have done your homework you will be able to identify doctors quickly who really have no understanding of the condition -that can save you a lot of time,anguish and money. Understand the treatment of Lyme disease and the controversy surrounding it. The medical community in general place a low priority on this illness, precisely because there are no definitive test like in the case of Parkinson's disease of cancer. A patient with CFS will look much better than they feel but over time self care and weight issues are likely to surface to some degree. CFS patient feel demeaned often either because a doctor does not know much about CFS or he thinks it may be a mental disorder or because he/she is unable to speak honestly about it. The CFS research that I understand today is slowly inching toward possible tests. There are numerous autoimmune diseases where the causes remains unknown and no cure - but for many there are some tests to determine. It appears to me that finding a set of tests, genetic links, and a set of medications to help manage CFS in more than 10-15% of the population are still in the distant future, meaning 10-30 yrs away. As money gets tighter in economy I expect to see less research going on and less concern for CFS community. If there were a genetic or DNA breakthrough found it could turn the effort to find treatments in the other direction.
170	general medicine, rheumatology, gastroenterology, neurology, infection diseases, orthopedics, physical therapy.....some doctors even never listening about cfs.
171	I can trace CFS symptoms back to when my mother put me in foster care (1951) and I gained 1/2 my weight in three months. I was exceptionally bright but something always held me back. To avoid being considered a hypochondriac, I learned in my 20's not to tell the doctor "everything". In my 50's I wrote a one page Chronological History which works much better. Even good doctors seem to be able to take in and process only just so much, so it took until about 2001 to get a diagnosis of both Fibromyalgia (1979) and Chronic Fatigue (1951). Right now I am fighting three specific infections: mycoplasma (1979), an enterovirus (2010), and ??? (2013), which make the Cellular Hypoxia worse each time one of these rises to the surface. This is what will most likely kill this body so I have started looking for a good infectious diseases doctor. Pain, that which I could notice and describe, has been with me since about 1985. Its effect on me, both specific and body wide, grows year by year. Thank God for Savella!
172	There was a lot of confusion, with most doctors not knowing what to do with me. Even the CFS specialist said don't use this as your diagnosis because then people will stop looking for other things.
173	I went to a psychiatrist in 1984 because I did not know if I was sick and tired because I was depressed or depressed because I was sick and tired. What I then called depression is actually the mental and physical drainedness that this disease causes. As I became physically worse over time he said he was so confused he did not know what to think. I was diagnosed by an allergist 8 years later. I have been to countless doctors all over the country, and done a considerable amount of my own research, without which I do not think I would be alive today.
174	I never expected to be openly mocked by a physician and her staff.
175	My biggest hurdle was (and still is) convincing medical providers that I am not merely a "hysterical female" in need of mental health treatment. They have no idea -and most don't care to learn- just how debilitating this disease is.

176	I was fortunate in that Primary Care Physician was able to diagnose fairly soon, however he did not know how to treat me, so I then sought out Dr. Paul Cheney. I had good insurance back in 1991 and was able to see him for treatment. The problem is that there are so few good doctors who a) acknowledge the disease, and b) know how to treat it. It would take 20 pages to describe the pitfalls I've encountered dealing with doctors who are ignorant or purposely against the disease existing and those who may be sympathetic but are ill-equipped to do anything
177	All but two of the doctors I've seen so far were frighteningly ignorant -- for someone watching her life disappear that is not an exaggeration. Following my doctors' advice, I got at least five times worse, so I have learned to ignore my doctor's advice and follow the advice I find on websites like SolveCFS.org.
178	In the beginning, the overcoming consensus was other illnesses, hormones, menopause, depression, etc. Once the tests came back "normal", the only answer was depression, anxiety, "nervous", "worried", and on and on. No one, including me, realized, that the tests being done, were not the right tests. No one, realized that of course I was anxious, worried and nervous. I was visibly and seriously ill, and doctors could not help me, much less name my condition. Being so ill, it was and is, very difficult to advocate for myself through the judgments and power of the medical community. To this day, I must fight for any kind of even palliative care from so called traditional medicine, and those "outside the box", (though sometimes effective in giving even slight blessed relief) treatments, are not generally covered by insurance because they are not recognized by the FDA as treatments for this disease. we have lost our health and our lives have been devastated, and in addition we are betrayed by the doctors that most of us have been taught to revere and trust. It is a very helpless and alone feeling.
179	most medical people were condescending and disbelieving. i felt insulted and marginalized: heard repeatedly that it was probably psychological, and that it was probably bc i'm a woman.
180	Saw 17 different practitioners, each one not knowing what was wrong. Had at least 100 tests, all negative except hypothyroidism 2 years into illness.
181	I first became ill, but still functioning, 35 years ago. Physicians had no idea what was wrong with me and I don't think had even heard of CFS nor had I. I saw many specialists and alternative providers. 13 years ago I became bedridden. I had some very unpleasant experiences with doctors (2 at UCSF) who dismissed even the idea that I was sick. I saw others that were sympathetic but could not identify the illness. Eventually I was diagnosed with CFS and when I tell doctors that I see about other medical problems and tell them that I have CFS they seem to accept that it is a real illness.
182	It began in 1988 when diagnosis was very difficult and the disorder was dramatically discounted. I had consults with many, many different medical specialist including an endocrinologist, a neuropsychiatrist, an accupuncturist/MD and two different neurologists. Most if not all of them were seriously interested in finding the source of my symptoms. I met with virtually no one who doubted that I had a significant illness. Eventually, I worked with a distinguished neurologist from a hospital in San Francisco who diagnosed me based on symptomology and CFS diagnostic protocols.
183	Internist-Neurologist-Infectious Disease-Endocrinologist-Specialist at Stanford-6+ Months of 4+ signs of CFS for Diagnosis
184	My daughter is a physician and spotted ME immediately. My current PCP never heard if it until I sent him a batch of info.
185	It is 25 years that I was diagnosed with Fibromyalgia. In 1989, I began reading about CFS and saw that these symptoms were my condition... Doctors would say that it was in my head.
186	No one doctor or otherwise had any idea what I had. It was a diagnosis of exclusion. Finally after seeing neurologists, endocrinologist, cardiologist, and G.I. doctors it became apparent.
187	Over the years I've dealt with several doctors ignorant of the illness or reluctant to consider or treat it. I had to insist on getting the tests to rule out other illnesses. One insisted on diagnosing it as fibromyalgia that she wanted to treat with tricyclics which exacerbate ME/CFS - fighting that was terribly distressing, and at the end of the conversation she refused to treat me at all. I finally found a doctor who accepts my advice on treatment, but he doesn't really know much about it and hasn't educated himself yet though he's seen me 3 times now.

188	I felt fortunate to find a doctor who knew anything about CFS but he first tested me for HIV which was rather humiliating, since there was no cause. I live with CFS, knowing that there is very little I can do to overcome it. It hits me hard, plagues me, and then leaves me unexpectedly. I never know when I will be down for the count again and that severely affects my ability to work steadily.
189	My first dx was Epstein-Barr Virus.I was referred to . Marc Sencer, MD(who had CFIDS himself),who dx me first with post viral syndrome after 6 mos of testing. Through him I met the brilliant Nancy Klimas, MD who reconfirmed the dx and ran many tests for research purposes. One of the tests was the tilt table test during which my heart rate when up very high.It was determined I had a.fib with rapid ventricular responce. I had an AV ablation/pacemaker. Since then I've developed chronic bronchitis, and today am recovering from acute bronchitis.I've had NTM requiring intravenous antibiotics, and MRSA lung infections. It was 52 when dx and was on SS Disability for 13 years. I am now 73.Local doctors don't show any interest in my dx of CFIDS perhaps because they are busy dealing with my related symptoms and there is no Rx they can prescribe for CFIDS.
190	My GP knew something was organically wrong with me, but had no idea what it was or how to treat it. The doctor that actually diagnosed me made me feel like a cure was just around the corner, which prompted me to spend money on all kinds of tests---that I really couldn't afford.
191	Had been diagnosed with profound refractory depression. Put myself in psych hospital for ECT. Doctor there told me I didn't have any depression at all. He suggested I find specialist for CFIDS. I did and immediately started Ampligen trial.
192	Many medical Professionals dismissed my increasing myriad of frightening symptoms with comments like "we all get tired" or by simply saying "your blood work is normal, just relax." I finally traveled 1400 miles to a CFS/FMS specialist to get a diagnosis. However, now that I have that diagnosis that is no real help for me. And I recently discovered that having that diagnosis on your chart if you go to ER means that your concerns (new acute pain) will be dismissed as "probably just part of your condition" with no tests, scans or anything else before you are sent home. ( I have also been diagnosed with POTS, Multiple Chemical Sensitivities and maybe Fibromyalgia. )
193	Medical Ignorance about this disease is rampant; frequently told "it's stress" or "it's depression"
194	I found diagnosis to be actively unhelpful, as it served to justify the medicalisation of my cognitions and behaviours without informed consent, meaning that I was then manipulated with misleading 'positive' claims about my control over symptoms, the efficacy of CBT/GET and the likelihood of recovery. After falling ill, I was treated gradually worse and worse as I failed to recover, until eventually I had an ME/CFS diagnosis.
195	GP knew nothing about ME/CFS, rheumatologist did a good investigation for rheumatological disorders but knew nothing about ME/CFS, hematologist said I had low white blood cells, though not low enough to constitute immune deficiency - knew nothing about ME/CFS - and so on. I finally found the diagnosis myself via a radio interview with an ME/CFS patient and information sites on internet (patient orgs) and could make my way to a private ME/CFS expert.
196	I was working as an RN in a hospital setting with doctors and nurses who had treated others with ME. My private doctor also treated another with it.
197	Too long with no help
198	initially self diagnosed from the Internet. Consultant unwilling to agree as he said I was 'too old' (I was 73 at the start) but a buspirone test he prescribed has aparantly confirmed it.
199	The doctors initially couldn't find an explanation for my clinically documented symptoms. Several seemed content to tell me there weren't any answers and leave it at that. It took several years of increasing symptoms for me to push to find the real answers, during which I pushed myself very hard and made the illness far, far worse, doing irreparable damage along the way. Eventually a doctor made the connection between a virus I'd struggled with for a long time and ME.
200	It was suggested I see a Psychiatrist, exercise and take anti-depressant. The exercise made me the fatigue worse! After 2 1/2 years of telling Drs. I was not depressed, crazy or lazy I finally received a dx of CFS.

201	<p>I was very fortunate. While ill for only a few months I saw a documentary about M.E. that listed Dr. Nancy Klimas, who happened to work nearby. I made an appt. immediately for 5 months later (the soonest available). Had I not seen her, I would never have been diagnosed. The many other doctors I saw before her gave me multiple wrong diagnoses (flu, Mono, Lyme, sinus infection, etc.) or were extremely cruel and dismissive. I was shamed for seeking medical help, and told I was a hypochondriac seeking attention, or mentally ill (with not more than 5 minutes talking to me and no mental health treatment offered). I would never have given up my athletic lifestyle and my Ph.D. program to be bedridden for what now is 4.5 years if I had any other choice. In part, I believe I was dismissed because I am a woman, as most of the worst treatment I received was from male doctors. Other doctors tried in earnest to diagnose me, but did not believe either Fibromyalgia or M.E. were real illnesses, and did not have the unusual tests to give me that would have been required (such as ability to measure Natural Killer cell function or presence of active Coxsackie, Parvo, and HHV-6 infection) or tilt table testing. They did not have the knowledge, or the equipment, and because they never found abnormal tests, I was treated like I was crazy (the default diagnosis to preserve a doctor's ego when they can't help you). Now that I have a doctor who believes me and hundreds of pages of abnormal lab proof, I get somewhat better treatment from new doctors - but many still act like my doctor is also crazy. I am treated most seriously when I use my wheelchair or walker, despite having the same test results, even when the office is too small for that to be practical and so is really just so I won't be demeaned by a stranger who has pledged their professional life to help the ill.</p>
202	<p>I became ill suddenly after taking a medication called warfarin. The dysautonomic symptoms were severe and visible to everyone. Over the next 10 months I went round the various specialties in the hospital. The first time someone mentioned something like ME/CFS was a pain specialist who said "this looks like post viral fatigue", 3 other doctors made the same assessment over the following months. I didn't believe it, I thought I had celiac disease or mental health issues from the traumatic treatment at the beginning of my illness. Celiac disease was ruled out definitively and tracking my moods showed me that I was always at my best on Monday mornings and mood issues were fatigue/disorientation related.</p>
203	<p>Nightmare of callous indifference and hoop jumping that made me worse. Wrong advise ie to exercise more means I'm severely ill and unable to participate in society in any way short of keeping myself alive.</p>
204	<p>I was a physician prior to becoming ill. After having the flu, I waited approx 6 months while trying various supplements, acupuncture, rest, etc, before seeing my primary care physician for blood work and evaluation for continued flu-like symptoms, debilitating/bone-crushing exhaustion causing me to sleep 14-20 hours per day, etc. Blood work normal except slightly elevated TSH, started on low-dose levothyroxine, no improvement. Told likely diagnosis Post Viral Syndrome. Referred to statewide "expert" in PVS an infectious disease doctor, who barely examined me, did no lab work, and told me (a married woman in her late 30s) to "move home" several times, meaning to move back home for my parents to take care of me. Meanwhile, I my parents had been divorced since I was a child, and moving in with either of them was not even an option. He then told me that I would eventually get better and be fine, and told me about a patient he had who was sick for three years and now goes on ski trips. He ended by saying, "the only people who don't get better are the ones who don't want to work and just want disability." I was then sent back to my primary care physician, who was appalled by the encounter with the ID specialist and recommend I apply for disability. I resisted doing so as I was determined to recover and stupidly believed the ID specialist and I could do so with healthy diet, rest, pacing, supplements, positive attitude, etc. Almost 5 years later, and I am worse than ever, having gone from mostly housebound to almost completely bed bound. I also seen 2 neurologists for severe/intractable migraines, and both stated they knew nothing about the condition and dismissed it. One said, "if you ever decide you want to try to get better, let me know and maybe I can refer you." Completely insulting when all I do when I am awake is research the latest studies, potential treatments, diets, supplements, specialists, etc...ANYTHING I can possibly try to get better! When I had to move and started with a new primary care physician, I told her my diagnosis, she said "I don't know anything about that, what medications do you need refilled?" and quickly ended the visit. Doctors are not informed about this condition, don't believe it exists or believe it is psychosomatic, don't have time to deal with the complex medical issues of ME/CFS patients, and can't be bothered.</p>

205	Most medical professionals were of the opinion that it was 'all in my head'. It wasn't until I saw Dr. Riina Bray at the Women's College Hospital in Toronto, that I was treated with dignity and respect for this condition that is indeed *very* real and not imaginary in the least
206	It started with CMV in one day, I have a main symptom, R ear pain, to this day. So I saw an ENT, Internist, & 5 more Drs after my initial 6 wks of fever & rash. Finally an Infectious disease dr ran a lot of tests, even treated me for Lyme, but found active CMV. LUCKILY in Tulsa we had Dr Stanley Schwartz was was the regional specialist for CFS. He Dx me in 1995. He saved my life. I thought I was either dying or losing my mind. To be VERIFIED by a very respected Dr meant a lot. But he's since retired from practice and I'm back to trying to find Drs that know ANYTHING about ME/CFS. My own family doesn't even believe in it. I've become worse, bedridden, & alone in the last year. 19 yrs. and no one knows what this feels like! Very depressing. I have thoughts of ending my life every day.
207	i had mycomplasma pneumonia beginning on 2/24/2011 and never got better. i got over the pneumonia, but never regained full health. i live in NH. In the weeks and early months following the pneumonia, i saw my own PCP, an infectious disease doc, a rheumatologist, endocrinologist, two neurologists, a lyme specialist and finally, in January 2012, a specialist in NYC who diagnosed me w/CFS. Along the way the doctors attitudes ranged from dismissive, conciliatory and concerned but not especially helpful (as in - "sorry, it's not my specialty"), to concerned, interested and involved (luckily my own PCP). But i had to travel 250 miles to find a doctor who made a diagnosis. There are not enough docs who know about CFS and have the skills to help treat it.
208	Saw a psychologist at the direction of my Internist who, to this day, does not believe in ME/CFS. Finally stumbled onto an allergist who sent me to Dr. Klimas. I became ill with a virus in January 1986 and didn't find Dr. Klimas until 1992 so too many hurdles to list. I honestly believe I would be well today if I had received proper treatment and diagnosis early in my illness.
209	I was ill long before the CDC came up with the name CFS for a set of symptoms people were suffering from. Doctors I visited would only focus on a symptom that interested them rather than a group of symptoms that seemed to me to go together. Many doctors saw me as just a tired woman who must be depressed and prescribed one anti-depressant after another and were unmoved by my complaints that these medicines made me feel worse. Then when in 1990 I saw a doctor who knew about CFS and was interested in treating patients, I finally got a diagnosis, but he was overconfident in his ability and demanding. I stopped seeing him because I was too ill to get to his office once a month as he required and I was fed up with being a guinea pig. At present I haven't seen a doctor for seven or eight years because I lost medical coverage with divorce.
210	A primary physician could not diagnose what was wrong, and so sent me to a hematologist (due to some borderline anemia). The hematologist coordinated my visits with multiple specialists to rule out other causes: Neurologist/Sleep Specialist, Psychiatrist, Endocrinologist, Rheumatologist, Gastroenterologist. With nothing found, the Hematologist diagnosed CFS. It has since been confirmed by an MD who is a CFS specialist as well as a Naturopath.
211	I was going to doctor symptom by symptom, I keep getting bounced and forth from specialist to specialist, The GP sent me to Endocrinologist, the endo would say no it is not your thyroid go back and so forth for 5 years, they all agree there was something wrong (My MRI showed lesions, abnormal sleep study where I couldn't reach stage 4 sleep, the neuro psychiatrist found no depression but problems processing information....)
212	1st - general practitioner, 2nd - Clinic for diagnostics, Wiesbaden/Germany, 3rd - Charité, Berlin The only knowledgeable (and sympathetic) doctors were those from ghe Charité! We are desperate!
213	lengthy period of unacceptance by medical community and lack of understanding, and no known markers or testing. Long and established history of fatigue, myalgia, and malaise. Finally diagnosed by infectious disease specialist after years of seeing various other medical specialists. Family financial support had to be provided for most of adult life. Onset in teens and now 62. Still dependent on others to assist with anything other than basic life skills.

214	I had cycles of tiredness and had weird symptoms through out my whole life at least since from when I was 12 years of age had asthma also till I was 15 years old .I started working when I was 18 and was then I that i notice the I was always tired because ,at work , I needed to complete the usual 40 hour a week like any one else , to make the story short now I am 42 years old constant tired dont leave the house for much long most of the time, cant work at all ,can eat dairy food ,gluten , some fruits ,sugar without consequences .I am very skinny with a lot of pain , this last one I only developed in the last 3 years only 2years ago this one doc , hematologist , he is almost sure I have CFS ,and fibro no to mention IBS .
215	was lead to believe i had depression and my hectic active lifestyle was causing symptoms so i ignored the signs of ME and carried on with difficulty in the earlier stages until i was so ill i could no longer work From suspecting ME it took me over two years to get a diagnosis i gradually got worse being encouraged to exercise more on top of an already exhausting debilitating illness I believe the encouragement of increasing my exercise made me worse for longer which took me years to realise and ask to see a consultant who diagnosed me post viral fatigue syndrome over 7 years ago
216	I live in Australia, & there are no specialists who treat CFS. My GP has been the only Dr on my side. I find most Dr's and people think its in our mind/head & not a real illness. It's very hard to explain to others what my life is like now & the struggle everyday brings since getting CFS. I actually ended up getting officially diagnosed by a rheumatologist, for insurance purposes. Prior to that my GP believed I had it, but didn't know how to treat it. I've tried multiple things, but take daily multiple vitamins, & D.Ribose which has given me a 70% improvement in quality of life. Prior to getting CFS,i was constantly sick with recurring sinus infections & eventually my body was resistant to antibiotics & that's when I couldn't function anymore, & had to stop working for 1 year. I believe the recurring infections & hectic lifestyle led to my complete burnout & CFS. Would love a complete & lasting cure!!!!
217	Luckily sympathetic Primary Care Physician, took on board data supplied by Patient organisation followed by (eventual) referral to and diagnosis (Postviral Syndrome/M.E) by an Attending Physician
218	Doc said it was ME but that they had to call it CFS now. This was in 1997. He was sympathetic thank goodness - had known me for years and how reluctant I was to take time off because I taught blind students so specialised and replacement teacher would not know the equipment and Braille
219	My road to a diagnosis was probably smoother than most as my parents were able to find a specialist who could diagnose and treat me within a few years of my initially falling ill. This doctor was tremendously supportive and because of his specialist position, I was able to receive a diagnosis that was viewed as having some credibility by government officials. Despite this, and after more than 20 years with this condition, I still encounter numerous medical professionals who either refuse to believe CFS/ME exists, or that it has any significant impact on my health. It seems that most doctors are choosing to be ignorant of this condition. This is not only disheartening, it has a serious impact on the quality of medical care that I receive. How am I supposed to receive adequate medical care if doctors will not even take into consideration my most serious medical need?
220	I told the doctor my symptoms, he had me take a number of tests, concluded I had CFS.
221	My NHS GP (I am a US citizen living in Norfolk, England), who believed I had CFS/ME, organised blood-tests and sent me to a CFS/ME clinic in a neighbouring town, where I was diagnosed with a majority of the symptoms. No doctor since (mine has retired) in Norwich, UK, has questioned the diagnosis. I have blood-tests every one to two years, which to date have shown nothing wrong. My current doctor suffers from lupus and is most sympathetic about my condition.
222	In order of diagnosis IBS Secondary Hypocortisolism Mitochondrial damage / dysfunction - tested by Dr Sarah Myhill Medical professionals are out of their depth and ill-educated with regards to virology and the more detailed aspects of the immune system which are absolutely at the root of the problem in M.E. CFIDS Assn are too self serving.

223	Most doctors did not know much at all about ME/CFS in the 80's and 90's. I took info to them. Some doctors felt the science behind M.E. was weak and didn't feel comfortable in making a diagnosis. One rheumatologist gave me a simple blood test, which showed no abnormalities, and concluded the illness must be in my head. My oncologist and endocrinologist both knew that ME/CFS was a real physiological illness and offered emotional support. I finally found my current PCP, who keeps abreast of ME/CFS research and diagnosed my ME/CFS in the late 1990's. She is a blessing and is the only one in this community of about 120,000 who is known for treating ME/CFS patients. Overall, the biggest hurdle in getting a diagnosis was physicians' lack of knowledge about ME/CFS.
224	I HAD A SEVERE URVI , IN 1986, .... BEFORE CFS WAS WIDELY KNOWN . AFTER SEE A VARIETY OF DR'S , IT WAS RECOMMENDED THAT I SEE A INFECTIOUS DISEASE DR. I HAD BEEN WORKING IN A HOSPITAL LAB AS A MED TECH/MICROBIOLOGIST . INFO HAD BEEN CIRCULATED ABOUT CHRONIC EBV ACTIVATION. I HAD VERY HIGH RE-ACTIVATED TITERS .
225	Most doctors just did endless testing - they refused to treat any symptoms until they had some kind of concrete test results, which means I got zero treatment until I finally found my current doctor.
226	Hurdles to overcome- no effective treatment, no clear diagnostic testing. Wide range of people given the same label yet have different things. Many docs especially in holistic field who promise answers and help, none of which has worked. Hurdles to overcome- coping with being this sick every day while trying to be productive at all. Insensitivity, dismissive comments and attitudes of the public that can be cruel at times from family, doctors. Extremely debilitating symptoms. All treatments that have temporarily helped have been out of pocket.
227	First suggested as a Dx by pulmonologist. Several were disbelieving. Rheum. Said I had FM but not ME/CFS. It was easy to see he did not believe in it. Endo. Was obnoxious. Sleep dr very concerned About the seriousness of sleep study results but not much knowledge of ME/CFS. I was fortunate that the psych. Said it did NOT have depression. He was familiar with ME/CFS
228	I basically diagnosed myself early on by doing i-net research. I have yet to be diagnosed by a medical professional. However, after 5 years of seeing specialists of every kind and being told that my results are normal (with the exception of sleep apnea....another story altogether..ugh!), I asked to be referred to Dr. Jose Montoya at Stanford Medical Center. I was 4 years out for an appointment with him when referred in May 2012, and am not 12-18 months out. I have researched and tried supplements on my own, discarded some kept a few, but otherwise have had no treatment or guidance of any kind. My PCP told me he did not believe in ME/CFS, but did agree to refer me to Dr. Montoya. No good for me to change docs...same attitude prevails in this area. I live in southern WV....and willing to travel across country for any kind of help. Sad that I have to.
229	I have been to general practitioners, neurologists, 3 rhumatologists, 2 infectious disease specialists, physiatrists, sleep specialist and an endocrinologist. None of those doctors had knowledge or input on how to diagnose or treat my Chronic Farigue.
230	My primary physician was the first to suggest it but admitted his limited knowledge of the condition. I saw specialists in neurology, rheumatology, infectious disease, naturopathy, endocrinology, hematology and my treatment was abdominal. Fourteen months of trying to get someone who had a clue. Finally I was seen and diagnosed by Dr Charles Lapp, whose treatment and advice keep me functional enough to work for 14 years.
231	It has been a very frustrating road to diagnosis, when trying to describe symptoms, doctors tend to look at you as if your crazy, the most often thing they asked was "are you anxious or depressed". I had numerous false diagnosis, which resulted in me being on wrong medications, which made me feel worse.
232	Obnoxious doctors who scoffed at the inability to walk. Finally found an expert on CFS who understood.
233	I was a nurse in California, came down with flu like syptoms, extreme fatigue, fever, chills, body aches, swollen lymph nodes, swore throat. In bed for 3 weeks, went back to work. Over the next 6 months had strep 3 times, missed quite a bit of work. was sleeping anytime I was not working. My PHP did a multitude of tests and came up with CFS. I had to quit practicing nursing. And went on disability. I was 25 at the time. I have been ill for 23 years. I live from bed. I just want my life back.

234	I have seen my primary care physician, rheumatologist, infectious disease specialist, neurophysiologist, and had CT scans, MRI, x-rays, and tons of bloodwork to diagnosis it, though it was mostly diagnosed on symptoms and a process of eliminating conditions with similar symptoms. I feel like I am bounced around and never get a firm answer on anything.
235	Illness began in 1976. Over the next 20 years neither my family physician nor any of the 19 specialists I went to knew what was wrong. My family physician was convinced it was a physical problem, he knew me personally and knew it was not a mental illness. Most other physicians said it might be psychological since all tests came back in normal range. A few insisted it was so. So I went to three different Psychiatrists hoping they could help me. All three, after several months working with me, said it was definitely a physical illness NOT psychological, they were convinced doctors just hadn't found the cause yet. VERY frustrating time. It took until the late 1990s to get the DX of CFS by an infectious disease specialist in Tulsa, Ok. where I lived. By that time over \$80,000 (money we had been trying to set aside for our children's college fund) had been spent out-of-pocket on specialists, tests, vitamins, supplements, recommended protocols that would "cure" me, etc, etc. The only thing that resulted was a beginning of "gut" issues. Nothing was of any help, the CFS continued to worsen. I stopped all the supplements and protocols and the gut issues went away after a few months, but the CFS continued to gradually worsen. I have been ill 38 years now. I am bedridden. I STILL hope for answers and a cure!
236	Gradual onset until it was sudden and I could no longer function. History of thyroid dysfunction, endometriosis, some abnormal labs, high EBV, herpes simplex I, tick bite, suffer from low body temp, OI, POTS, migraines, pain, cognition problems, GI issues, dx'd with IBS, PEM is a huge issue. Previous competitive athlete, very physically fit, strong, educated (Master's), professional in health care industry, now unable to work for nearly 10 years on SSDI. No diagnosis of mental illness!
237	The first dr. I saw (a GP) ran lots of tests but waited a month or so between each batch--frustrating, as I was functioning at about 20% at that time. When the tests yielded nothing definite, he literally said, "Good luck" and sent me away with no further guidance. I was also seeing a nutritionist at that time for low weight and vitamin B12 deficiency. She suggested a GP who was fresh out of medical school. He was very up to date, looked at all the previous test results, tested me for fibromyalgia tender points, and gave me an immediate diagnosis of CFS/FM. (Don't know whether he used Fukuda or CCC criteria, but it was one of the two.) He suggested a muscle relaxer to help me sleep more deeply at night and I quickly regained about 30% functionality. He suggested mild exercise, too, and I overdid it on that, but I still credit much of my current relatively high functioning to this MD. He gave me basic research to read and various helpful suggestions for good self-care. Unfortunately, he and I both moved out of state, or I would still be attending him!
238	I was very frustrated as I became ill in the 80's, so there were not many Dr. Who knew or believed Cfs, existed. Finally after many ugly tests and skeptical Dr. I was finally diagnosed by a neurologist.
239	Most professionals were clueless and I live in a large metro city and attitude dismissive.

7. What else would you like IOM committee members to know about ME/CFS diagnosis?

1	ME is a neuro immune illness, it is rubricated as such by the World Health organization. There are specific tests and biomarkers that can help doctors in the diagnosis, asks the real experts and they will tell you all about the immune dysregulation the white matter lesions, the high IGg titers to many (if not all) herpes viruses, enteroviruses, Chlamydia Pneumoniae, Parvovirus 19, Mycoplasma, Toxoplasma etc
2	A way to find a qualified doctor in my area who could diagnose/treat someone with ME/CFS. So far, asking for referrals and google searches has been unsuccessful. Is there a central registry someplace?
3	ME research has progressed greatly and better diagnosis criteria are now available. There are new aspects like PEM to take into account. I believe that the CCC is a much better criteria for diagnosis and should be adopted by the HHS.

4	<p>Most providers don't understand ME/CFS -- don't know how to diagnose or treat it, don't understand how debilitating it is -- but I sense they desperately want to understand it and be able to help their patients who suffer from it. The hardest thing to understand is the post-exertional exacerbation of symptoms. It is so difficult for providers (and even patients!) to grasp how trivial the exertion has to be to cause an exacerbation of the entire global symptom complex. This post-exertional exacerbation is the key to diagnosing this disease but providers only see the patient during exertion, not after it. Moreover they have no basic lab and imaging results to help them "see" this disease. In lieu of clinically validated biomarkers, the advice of those who have significant clinic experience with this disease should be paramount in developing diagnostic criteria. I would also ask committee members to remember that while Evidence-based Medicine is the best we've got, it's not without weaknesses. How does bias affect the disbursement of research money? How does the peer review system encourage as well mitigate bias? How does systemic sexism affect how seriously a disease is treated where patients are overwhelmingly female? What happens when the frequently used phrase "there is no evidence to suggest..." too often means "absence of evidence is evidence of absence?" What happens when the disease in question does not fit neatly into disciplinary boundaries (i.e. neurological, immunological, etc.)? Along with all of the other weaknesses in EBM that medicine is dealing with at the moment I would plead with the committee to honor the concerns of patients with regard to a systemic review of the literature regarding ME/CFS. Listen to the concerns of patients. Listen past the 30 years of anger to hear and understand the pain and desperation for help.</p>
5	<p>There are abnormal blood test findings that can help support a diagnosis. Contact the Institute for Neuro Immune Medicine in Davie, Florida. Also, how can we educate the public that a diagnosis of ME/CFS denotes a real disease not laziness?</p>
6	<p>1. CFS is definitely a physical, not a mental, disease. 2. It makes continuing with one's life impossible. People who have MS and cancer can continue to pursue their education, work, exercise, and get out to pursue a fairly normal range of activities. The patient's whole family is affected by CFS.</p>
7	<p>It is incredibly demeaning to try to get medical help for a debilitating disease that is not understood, nor recognized by local doctors. I know before technology was able to show holes in myelin sheaths, people with MS were diagnosed with "faker's disease." Polio was thought to be hysterical paralysis. That's how it feels today to enter a doctor's office and tell her or him how I feel. Will I be believed? It's hugely important for doctors to be educated about lab tests that show aberrations indicating problems with a patient's immune system, neurological and endocrine systems, digestive system and others affected by ME. It's also important that ME is legitimized and that insurance companies are expected to pay for tests and treatment that may help people like me. I've been in bed 22 of every 24 hours for the past 7 years. I want a life, I just don't have one. I had to spend more than \$10,000 of my own money on myriad tests before I could be diagnosed, but it is not impossible to diagnose this disease.</p>

8	<p>Fibro/Cfs/Me are all 'Related', Co-existing conditions that the primary source of is the Immune system. Naturalists, or alternative sources of treatment are effective however not covered by insurance. So patients suffer for years with non effective testing, diagnosis and treatments from the mainstream medical field. MORE RESEARCH IS CRUCIAL.</p>
9	<p>I am curious as to whether anyone else was exposed to 3 Mile Island meltdown and how it affected their health. I was diagnosed with CFS after my exposure and later was diagnosed with Celiac and breast cancer stage 2.</p>
10	<p>Thank you for conducting this survey. I think subgrouping is very important. As far as I can tell, subgrouping determined at this time will only be approximate because the data have not been collected, let alone analyzed, to identify the subgroups. Any definition set up now should be revisited in a few years; with the very limited research currently available, defining this disease and subgroups can not be accurate at this time. I have a more nuanced opinion of PEM than your questions allow. PEM status is extremely important in selecting safe treatments for patients. The testing of PEM with two-day VOMax exercise testing is harmful to many patients with ME. A safer method of determining PEM status needs to be used, especially for more disabled patients. Personally, I would never agree to undergo such a test. I know it would harm me based upon years of experience. For clinical use, what is the problem with determining PEM by questioning the patient? In science, observation informs theory and theory informs observations. When the two are incongruent, both need to be examined for science to progress. From my viewpoint as a person who came down with ME after a viral infection in 2004 and has read about 200 papers on CFS/ME, very little science has taken place because most of 30 years of observations have been disregarded and thrown away. The papers reference the Fakuda criteria which does not require PEM dysfunction</p>
11	<p>My case goes up through the NIH, CDC, White House, WHO, to the UN. I testified federally in Washington-DC, and am published 22 times on 4 continents (including PEOPLE’S VOICE, FROM THE TRENCHES WORLD REPORT, PFLAG, &amp; FUSE MAGAZINE). E.g., <a href="http://www.ukprogressive.co.uk/the-aids-like-disease-seldom-mentioned/article20891.html">www.ukprogressive.co.uk/the-aids-like-disease-seldom-mentioned/article20891.html</a> or simply google "NON HIV AIDS"</p>
12	<p>Dental amalgam mercury toxicity for genetically susceptible children and adults (20%+) is a common cause of chronic diseases, with synergistic impacts from other toxins and heavy metals, biotoxins like lyme and low-grade anaerobic bacterial infections associated with teeth and roots, and molds for genetically susceptible people. We need a much broader name for all of the autoimmune, cognitive, immune and neurological diseases caused by mercury toxicity. Options: Chronic Mercury Immune &amp; Nerve Dysfunction Syndrome (CMINDS), Mercury Acquired Cognitive Metabolic Immune &amp; Nerve Dysfunction Syndrome (MACMINDS), Mercury Autonomic Dysfunction Metabolic Immune &amp; Nerve Deficiency Syndrome (MADMINDS) Acquired Nerve Deficiency Syndrome (ANDS), Acquired Dental Amalgam (ADA) Disease.</p>

13	<p>I was diagnosed with CFIDS as a sophomore in high school, I was top of my class, in every organization, club, and chapter you could think of, in a matter of a year everything in my life changed. I was unable to graduate, I was forced into a GED program by my school counselor because my absences interfered with a normal school schedule. I've lost job after job after job, it's taken me 12 years to get a 4 year degree and I still haven't graduated yet. I have a child, and I've buried a child. Not a day of my life passes that I don't realize how much harder every aspect of my life is because of the CFS. I've lived for 10 years with virtually no prescribed treatment for this disease and I have coped efficiently but it has been an exhausting overwhelming struggle to do so that didn't have to be that way. There has got to be some type of treatment out there with all our knowledge that would make people like me better able to cope in a comfortable manner with our disease. It does not have to be as miserable and filled with a feeling of NO ONE understanding or caring as it has been. It's a horrible, terrifying feeling to beg for help and have the door shut in your face time and time again. When my doctor asks do you have any chronic illnesses it would be nice if the doctor would ask how does this illness affect your day to day life, and what are you struggling with so we can give you some solutions or options, something. I try to research but these quacks on the internet and Dr. Oz they will tell you anything and virtually none of it works. Pain, sleep, diet, and immune function are my biggest issues in that order. I shake a lot like a shiver but I'm not cold, it's usually the pain. Ibuprofen and other pain relievers will help temporarily however my stomach is very sensitive to medication and the pain relief is short lived. I have periods in which I cannot wake up by alarm clock, or even being shaken or yelled at, I have periods when I am so exhausted I cannot go to sleep and I lay awake in tears trying to sleep. There are times I cannot stay asleep I can doze off for a few minutes or even an hour but wake up repeatedly unrefreshed. My diet is frustrating, I have unexplained weight loss, however since my last pregnancy this has not been as big an issue. My stomach is volatile at best, I'm nauseous throughout the day, I vomit at least once a week from an upset stomach. I get extreme cravings for protein and carbs particularly red (bloody) meat and breads, crackers, rice, or potatoes. I have bouts where I can't eat anything because I'm so nauseated, and then bouts where I feel like I'm starving no matter how much I eat. My immune system is clearly still extremely weak as I catch everything I come in contact with so much so I had to place my son in home school because him going to school was bringing home so many germs I stayed sick for 7 months straight and lost my job.</p>
14	<p>Its real and people are suffering with pain nerologic problems and extreme exhaustion . Its causing finance problems relationship problems work problems family problems.. DR can't figure it out so they push you off as if you nuts! Get people the help they need and deserve ..</p>
15	<p>I implore the IOM Committee to explore in depth oral Cortisol therapy for CFS. I know it's controversial, but here's the conundrum: Why do doctors want their patients to take multiple medications, whose long-term side effects are unknown, instead of considering a cheap medication like oral Cortisol, which the body produces naturally?</p>
16	<p>Trust your gut. Jump all over it because it has cost me EVERYTHING</p>
17	<p>Get rid of the Chronic Fatigue Syndrome name! Educate doctors and medical professionals, push for research into finding biomarker(s) for this illness. At Clinicaltrials.gov, [as of today] there are 358 trials for erectile dysfunction, 192 studies for alopecia and 6,487 studies for depression. There are already many drugs on the market for these conditions. I found only 6 studies in the U.S. for drugs being tested specifically for CFS. What is wrong with this picture?</p>

18	<p>2 issues, both related to the changes in symptoms over time.... 1) The current CDC criteria are problematic for those of us who have recovered to a significant degree. After I learned to recognize warning symptoms and adjust my work/exercise/ rest patterns accordingly on a daily basis, I reduced my symptoms and did not meet all the criteria. However, if I tried to return to a pre-illness work schedule, I would relapse. This is significant in relation to long-term disability coverage and Social Security disability income qualification. 2) If you review the work of Hans Selye, it becomes apparent that there are different phases of CFS characterized by differing symptoms and daily cortisol patterns. I am sure this complicates diagnosis efforts, and I suspect it causes problems in many research studies that do not differentiate between the stages or phases of their participants.</p>
19	<p>While my wife’s disability insurance acknowledged CFIDS as a disabling condition, it placed a maximum 2 year limit on benefits – similar to that placed on mental health conditions. In addition, since there is no medically recognized treatment, my wife’s management of her symptoms has come in large part from nutritional supplements, naturopathic treatment, additional massage and bodywork – none of which are covered by our medical insurance. The result is that my wife’s CFIDS has placed a huge financial burden on our household – to say nothing of the costs to my wife in terms of her career and her quality of life. Oh, BTW, for those that think CFIDS is possibly related to “chronic Lyme”, I believe we can dispel that. After 3 years with ME/CFS, my wife came down with the classic Lyme rash and had new symptoms on top of her ME/CFS. Not a good combination!</p>
20	<p>This illness is very debilitating, we need some answers, people's lives are falling apart.</p>
21	<p>Still hopeful</p>
22	<p>I strongly suspect that although I was diagnosed within the first year of severe illness, I may have actually been sick for 18 years. In the late 90's I suffered a series of back injuries and was unusually slow to heal. Along with that came the beginnings of some food intolerances. Over the following decade the digestive issues slowly progressed along with bouts of unusual fatigue and no diagnoses --not for lack of trying! Eventually 2 years before I became seriously ill, I was prescribed OTC antacids long term. By the time I got the "flu" so severely, I had a seriously depleted metabolism - likely due to the antacids blocking vital nutrients/vitamins. Bottom line: We desperately need research! Research on accident/injury related to CFIDS, research on digestive dysfunction as a precursor or co-condition, research on food intolerances related to CFIDS, research on the relationship of long term antacids and CFIDS, research on mitochondria dysfunction..... and the list could go on and on!!!!</p>
23	<p>Destroys lives</p>
24	<p>How depressing it is to live with a chronic condition that has no cure. How I look okay but truly house bound and have little energy for life itself.</p>

25	This disease has taken away my ability to be a nurse. That was devastating to me. The older I get the worse my disease is progressing. I never see anyone talk about that. My husband and I know that I will probably end up in a wheelchair soon. Why isn't there more discussion about progressive CFS?
26	Please consider the plight of the sickest patients. I was lucky to have enough energy to go around from doctor to doctor when I fell ill and had good health coverage. If I was sicker or had less health coverage it would have been very hard to get a proper diagnosis. I'd bet that the sickest / poorest people are not getting any help at all - if they ended up homeless and then died no one would realize what had happened because no one is looking for this. In general this problem is still way off the radar screen of the medical system. We still don't take profound disability from chronic illness all that seriously compared to acute illnesses and death.
27	Stress the impact on your life and the lack of support in the medical community.
28	Encouraging insurance companies to allow the use of a naturopath as a primary care or even as a specialist might be the best thing the IOM can do for us. We are people with sensitive systems and western medicine is all too often too harsh for us, leaving our docs scratching their heads. NDs do not scratch their heads, they provide answers!
29	It takes years and most doctors do not think it exists. My granddaughter needs help badly but I think she may be on track at this point after two years of sleep studies, too much blood work to count, tests, tests, tests, tests with no bad results. She has every symptom of CFS.....needs help!
30	There need to be more CFS Drs. I have Dr. Montoya at Stanford. I'm lucky.
31	Doctors need to be alerted to the fact that is multidimensional and leads to mental health problems, no one wants to be unable to rely on themselves, especially with an invisible disease. Personally I developed bipolar symptoms from being constantly bombarded with unexplainable symptoms
32	Plain and simple: stop the endless self serving talk shops and use the money instead to get on finding a medically accepted diagnostic test. Then a cure would be a good step!
33	I have been abandoned by most of my friends and family because ME/CFS is not treated or looked upon as a "real disease". My family even had me forcibly removed from my home and committed to a mental facility because they were convinced my only problem was severe depression. After being locked up for 5 days and having every drug test, MRI and blood work test done, they could find nothing wrong with me and therefore had to release me. The trauma of that event haunts me to this day.
34	I dont want to be patronized with a phony diagnosis i want research into what is the real cause & how to diagnose and treat & prevent the condition.
35	Doctors should allow patients to speak and should listen.
36	That Fibromyalgia and CFS are not the same disease!

37	We all have symptoms of the same nature we all have been on opiod meds and we all never find a medical doctor with the true compassion to really see this IS A MEDICAL ILLNESS, We need the testing and symptoms to be recorded on every person suffering this dibilitating illness and to move forward with a medical diagnoses and some treatments that will begin to relieve our suffering WE NEED A CURE NOT JUST PAIN MEDS AND A OK I WILL SEE YOU next month to repeat the same or add a complaint of worsening symptoms and to add more symptoms
38	Too many medical professionals still believe that ME/CFS is not a real disease, and probably not even a real "syndrome". Medical professionals need to be instructed in what to look for to be able to give a diagnosis earlier. Also, the general public needs to know that this is a real disease. Many of my (former) friends and even some of my family, do not really think I have an illness. And I have heard way too many jokes on TV about ME/CFS, including two separate episodes of "House". Please help us. Thank you.
39	Most doctors seem ignorant of the disease and treat the patient like it is all in their head or worse. Is very disheartening for the individual suffering with the disease not to mention depressing.
40	It is very frustrating trying to get help.
41	The attitude of nearly the entire medical community is demeaning toward patients; the name of the illness does not help. Frankly, I'm so disgusted with doctors on the whole that I have suffered through my illness for years without any help because I'm tired of being belittled by those who swore an oath to help me.
42	Patients are people. They have feelings and intelligence. We are not to be dismissed because doctors don't know all the answers. The world is full of unknowns. Because a doctor doesn't know something doesn't mean an illness doesn't exist. We deserve respect.
43	Please consider the input of professionals who have been involved in the care, treatment, and research of this illness. Be careful not to assume mental illness just because medicine can not yet explain the symptoms, remembering at one time MS was known as "hysterical paralysis."
44	If I would have been taken seriously sooner maybe I could have managed the illness better. I had a hard time believing the diagnosis due to MD's not acknowledging it. Even now, trying to find MD they reluctantly diagnose FM but can't find MD just to support symptom treatment.
45	To fully understand the post-exertional malaise.
46	there are a multitude of illnesses that come with the disease of ME/CFS, in my case, diabetes, polycythemia, Costochondritis, fibromyalgia, degenerative disc disease, and others
47	A lot of people struggle greatly.
48	This is real. We are not hypochondriacs. We need research to find the cause, so we can find a cure. We are suffering in silence. HELP US..... PLEASE.
49	Ceases to take this disease for a psychiatric case and considers Burning Out the slightest effort and consider all the symptoms that accompany this disease

50	I was told I should exercise, that I was depressed, and that I should get a life!
51	<p>I think the term CFS should be dropped. This harrowing illness deserves a proper name but even more we need appropriate research. I have lost so much of my life to this illness. Society has lost much from me because of this illness not being treated properly. I was a 20 year old college student with a 4.0 gpa and a part time job. I was very active in the community. I have not been able to work since. I am not on disability because I had only worked parttime for two years. Without family I would have has no place to live and no one to help care for me. Through God's grace I am better than I was. This is a serious illness and it deserves a serious and appropriate response from the government. Please do not disappoint a battle weary group of patients again.</p>
52	Dr.'s need to be more open and listen to their patients complaints!
53	<p>Most doctors today do not "believe" in CFS because it is a "controversial" diagnosis. So I WASTE countless visits to uncaring doctors that are ignorant to my needs. I'm tired of having to educate every doctor that comes into my life. I can't get any continuity of care even at so-called top facilities. Shame on doctors for blatant discrimination. Shame on the DSM's over-reach of neurological and immunological diseases and conditions. The Canadian definition is perfect for my virus-onset of CFS/ME. I prefer the name ME, and the use of the Canadian Consensus guidelines already established. Quit changing things, if you have nothing new to bring to the table.</p>
54	it's HELL .
55	<p>I got sick when I was seventeen. I am now sixty-five. I am getting old and I have never been young. I had to give up my career as an educator, my standards of taking care of myself, my home and my family and just recently a forty-two year marriage. Still, when I see a doctor that doesn't know or believe in this disease, I have to struggle to get the appropriate care. Most physicians in this area do not accept the diagnosis and I was diagnosed at the Cleveland Clinic. I am severely ill and have spent many years in bed for the most part. I don't think change will come in my lifetime. I was hugely disappointed with the FDA's denial of Ampligen. It was my only hope of getting my life back. I pray the answers can be found for those who follow.</p>
56	This is real. We. Suffer dialysis with just get tinge out of bed. Fighting the stigma of being lazy or even stupid for not being able to concentrate on a job. With more awareness, and support, maybe we can live more normal lives.

57	<p>I am not opposed to a more narrow definition of ME/CFS, am not angry at it being called CFS or anything for that matter. All I want to get out of this is for there to be more doctors who want to treat CFS and have a knowledge of what is involved, and for there to be a definitive test of some sort that would allow me to show that this is in fact a thing and that it's ruining my life when it's not treated properly. I would also like there to be a better way of finding doctors who treat CFS, a way to talk about any related mental health problems without people assuming that because I'm depressed about my life being in effect ruined by CFS does not mean that depression led to CFS. I would also like for more pediatricians to be aware that it can effect younger people, like I was when I first developed symptoms. I don't care who helps this happens or what it's called, as long as it's taken seriously and helps patients I see no need for petty pessimism and distrust. I understand why that exists in this community, but I don't believe that is what most of the people with CFS are obsessed with. We just want to live our lives and to be treated with respect.</p>
58	<p>This disease takes a toll on every biological system within a persons existence. It is a broadly damaging disease with multiple tragic losses. Medicine needs to take this seriously, now. It is already too late for thousands of American's afflicted for too many years with no medical care.</p>
59	<p>Education of primary care physicians, especially pediatricians (I have a daughter with ME) needs to be improved to minimize misdiagnosis and mistreatment</p>
60	<p>It's devastating. People in congestive heart failure I've been around are shocked that I am functioning at their level. Yet most people don't consider me to be REALLY sick.</p>
61	<p>Just please have doctors take this awful illness more seriously. It's a life altering illness in every way. It shouldn't take 10 years to get diagnosed (like myself).</p>
62	<p>The GPs need to be updated about the condition as they are the first point of contact. The GPs also has to have the possibility to refer the patient to a specialist for further investigation.</p>
63	<p>Please consider the two day exercise test like the one done at the Workwell Foundation as diagnostic criteria or a biomarker. It distinguishes people with CFS from people with depression and sedentary and obese people which is a crucial distinction for future all future CFS studies.</p>
64	<p>about my CFS : im sick since 5.5 years, iam 31.5 years old, women, living in South of France ( sorry for my English). I'm so tired, i can't work, and its very difficult to survive like this. I stay for my son, only. In France, Doctors arent interesting in CFS, they dont believe in this, exept some ones.I fight for having some medical investigations, 5.5 years after, i' have them. They find me on PET SCAN, 2 monthS ago, an inflammation of spinal cord. It prouve im an authentic EM/CFS, but ..in your countries ( America,Canada, Australia, Israel, and all around the word, but...not in France :( Please, help us.</p>
65	<p>All patients should be tested for MTHFR and heavy metals</p>

66	<p>This disease is not a psychological disease and CBT and GET only make patients worse. This is a very serious neuroimmune illness. Most of the people I came down with this disease suddenly and never recover. I have an existence not a life. I have a list of symptoms that would fill up a full page. The name Chronic Fatigue Syndrome needs to go. I have Myalgic Encephalomyelitis We need the Canadian Consensus Criteria adopted as the case definition. We need for the IOM Committee to listen to our fifty experts and researchers in M.E./CFS who say that adopting the CCC is the way to go. I couldn't agree more. When I got sick I was a vibrant hard working professional with many friends. I had a good life. This is a physical disease. This is not a psychological problem. The one million patients in the U.S. have been neglected for thirty years. We desperately need money for research, we desperately need this disease taught in the medical schools correctly. It is inhumane that most people who are ill with this disease go to multiple doctors and spend a lot of money before they finally get correctly diagnosed. Dr. Nancy Klimas has said that the doctors don't respect our disease because of the name, which leads to family members not respecting the disease and society as a whole. I am not tired. I am very very sick.</p>
67	<p>ME (NOT, repeat NOT, CFS) is real. The most important symptom is NOT fatigue, though fatigue is present. The most important symptom is post exertional malaise. This can be documented, see the work of Snell, Stevens and others. Proper diagnostic criteria that separates ME sufferers from patients who suffer from other diseases which have fatigue as a symptom, are extremely important. This is not only for the sake of ME sufferers. Today, a great many people who suffer from other diseases are given a CFS diagnosis. An English study showed that as many as 40% of patients referred by GPs actually suffered from other, treatable diseases. These are people who could get proper treatment if they got the correct diagnosis! If research into ME is going to make sense, good diagnostic criteria are alpha and omega. A separation between ME and CFS is to the benefit of all parties.</p>
68	<p>Even with an early diagnosis, after 21 years of illness, I still find most medical professionals are neither educated about it or interested in becoming educated.</p>
69	<p>me-cfs needs to be addressed and patients need medical support. I tend to over exert myself (because i have two young children) and get ill (pneumonia, percarditis, various virus reactivations). i would have to go to the emergency room often if i wasn't followed by my two amazing doctors.</p>
70	<p>There are tests out there that some of us have used to document disability (i.e. PEM at U of Pacific, blood volume, etc.). Perhaps, these tests can be more widely publicized.</p>
71	<p>It is an invisible disability. We need more medical people to take it seriously, who can then convince politicians to help us. I am a single mom who must support two daughters. It is overwhelming to try to work full time. I have no quality of life because I always ache or am exhausted. My employer has no idea what is wrong with me, so it appears that I'm not always at my best, yet feel like I am performing Herculean tasks just to get through the day. I am constantly afraid that I will not be able to continue to perform my duties (I am an RN, ironically) and will lose everything. In the mean time, I would probably not qualify for disability because I "look" healthy. So frustrating and scary.</p>

72	M.E. is a devastating neuro-immune disease, which is best defined and described by the Canadian Consensus Criteria. I urge you strongly to defer to experts in M.E.
73	It is extremely difficult to find doctors who will take patients that they don't have answers for. I have been told that if course of treatment is not AMA and FDA approved they will not treat me. I now have an osteopathic Dr who is willing to work with me.
74	There is information available through researchers and clinical practitioners that needs to be disseminated so that diagnoses can be made in a timely manner. This could prevent years of heartache and harmful treatments, and might be able to help some of us get back into the world.
75	Doctors need to become more informed about this condition. There needs to be more news reports about it so others believe that this invisible illness is debilitating.
76	Why is it so hard? Why do some Doctors yell, ignore, belittle you? Doctors are they to do no harm, but all they cause is stress. According to some chronic stress and chronic trauma damages an ME patient. We couldn't just one day wake up and because this illness is supposed to be in the mind, say to ourselves one day, well I feel depressed today so I think I inflate my spinal cord or brain. And of course it effects all the organs. It's been a tough road and you have to spend a lot of time out witting the doctors, doing your own research. And even then when you have the right information some Doctors Look at you like you have grown two heads or just completely ignore you. Why put a sick person through this?
77	More general practioners and family doctors should be aware of the symptoms. At least enough to refer to a specialist. Listen to patience when they come to you with suspicions. People know their bodies.
78	A thorough, acute understanding of, and strongest possible emphasis on, the pathological condition of post-exertional exhaustion.
79	The only reason my diagnosis was easy, if you can call 2 years of time easy, was because of amazingly thorough doctors that I previously strong relationships with AND because I had a specialist in my region. Most people with CFS do not have these situations.
80	ME/CFS is a debilitating, PHYSICAL illness. I truly believe that the only reason that researchers have not yet found the cause and treatment for this disease is due to lack of funding and appropriate research.
81	We need CFS to be taught in medical schools. I don't know. You know what we've gone through. We are just out here barely living and then dying. Do whatever you can to establish quick diagnosis and treatment. The longer the disease goes untreated the worse the patient gets.

82	<p>That there is still a big stigma about CFS. CFS is not ME. You can't combine these 2 diseases - they have to be classified by 2 separate diseases. ME is complex and has many subtypes. It is a must for doctors to find out if you have EBV, HHV-6, CMV - but you don't have to have viruses to have ME - it is one subtype with viruses. Check for toxins and mold. NTK. There are many biomarkers that our experts use and should know what they are. Depression is not primary and not all ME and CFS patients have depression. depression is common in chronic illnesses. This is a multi-system (CNS, endocrine, cardiovascular, etc). CBT doesn't work - we all who have this disease remain positive to fight this disease and stigma. Pacing is necessary but pacing is individualized. For instance, my pacing consists of many days of bed rest, each day afterwards, I will have to define what I can and can't do. If my body is ready, I will go to doctors appointments, shopping for necessities, or visit a friend. But it takes many days of bed rest before and after. Make sure, they understand severe ME - bedridden patients and pediatric patients. Don't rely on past studies to determine case definition, reach out to all of our main EXPERTS who treat all types of ME patients. They are the only ones that will understand and comprehend the disease. No doctor that doesn't treat this disease will understand - the literature will not tell the full story! Only patients and their doctors truly know ME. That is what frightens me about the IOM case definition. They don't have enough experts to understand ME. ME is very individualized in many aspects - just like pediatric brain cancer. That is why they have a Children's oncology Group that leading experts and hospitals that treat pediatric brain cancer use to confirm diagnosis and treatment. That is what we need and this is how the case definition should be derived. Not by non-experts.</p>
83	<p>Without a biomarker I have no idea if I have CFS, fibro, or if this is the result of the Hashimoto's I also have or some other combo of autoimmune disease. There is no help through the maze and most doctors don't "believe" in CFS.</p>
84	<p>This illness is so devastating and so misunderstood. There needs to be much more research. Also, medical professionals need to be trained to recognize and understand this illness. Not only medical professionals but the public needs to be aware that this illness is much more than simple fatigue.</p>
85	<p>Many people with ME can be provisionally diagnosed before 6 months. With a provisional diagnosis, they can be given advice about rest and pacing that may help them prevent the illness from becoming more severe.</p>
86	<p>Can be totally disabling. I'm not as bad now after taking Valcyte, but there were times when I could not scratch my nose or roll over in bed, much less take care of my children.</p>
87	<p>That most people with ME/CFS go undiagnosed, how severe this illness is, and how important it is to have a clear set of diagnostic criteria for researchers and clinicians. That the trend toward GET/CBT has been a disaster and better criteria and treatment protocols have to be distributed to the medical community at large.</p>
88	<p>Cure, cure, cure. Nothing else really matters.</p>
89	<p>If it can't be possible to find a cure right now, please at least give us a treatment. Thanks!</p>
90	<p>Accept the CCC. The IOM is not qualified. It does not have the expertise to judge the many difficulties that surround this disease.</p>

91	See above.
92	The Canadian Consensus Criteria should be immediately adopted as the sole case definition for ME. The name "CFS" should be dropped.
93	More research needs to be done to find the cause of CFS and its related conditions such as fibromyalgia. We also need more awareness of CFS to the general public so they can better understand our illness and our limitations.
94	They MUST be made aware of all the biomedical evidence showing ME is an organic disease , evidence which completely invalidates the view that it is psychiatric, with no physical evidence, due to patients wrongly thinking they are physically ill. The evidence clearly shows it to be a neuroimmune disease with post exertional malaise as a pathognomonic symptom. They MUST be made aware and acknowledge all the biomedical evidence and specifically the research showing PEM is an organic phenomenon. What is going on in the medical profession, with doctors either actively choosing to ignore the biomedical evidence or ignorant of its existence is completely unscientific and unethical. They also need to be made aware of the serious statistical and scientific errors in the PACE trial, where someone could score 65, be deemed to be seriously ill and enter into the trial, yet subsequently be classified as "recovered" due to the authors changing the criteria for recovery post hoc, then promoting the use of CBT/GET on the basis of this and several other post hoc changes in the statistical analysis of the trial.
95	I don't use it on my chart any more. BUT, it's 27 yrs of active living that I have lost.
96	It's not "every symptom under the sun" -- they're all neurological. And it shouldn't be a wastebasket diagnosis - doctors need to be educated that not every case of fatigue is CFS.
97	Our country needs to invest more in medical research, period. More research, less bickering and turf wars. In essence medicine has had little to offer folks like me for more than 3 decades and this is a travesty.
98	Extensive, multi-faceted diagnosis is critical to identify which interventions might be most appropriate and effective
99	Post exertional fatigue. Wanting to work out to be healthy but learning when to stop because of the exacerbated symptoms of exhaustion after work-out.
100	I was a dental hygienist and it ended my career. I feel like I have spent 20 years in bed and i still cannot lift my arm without help.
101	I am broke, completely alone and dying. I need help from someone and don't know where to turn.
102	That drs need to listen to their patients in order to dx and not think it is all in their heads

103	<p>We desperately need to educate doctors about the realities and potential severity of this illness. When I was less severely ill, doctors brushed me off. When I became outstandingly severely ill, they assumed I had too many symptoms for this to be the cause. The lack of doctor awareness about this illness is hurting patients in so many ways. Lack of diagnosis also often leads to worsening of the condition in ways that could have been prevented with more knowledge. It costs patients their health, but it costs the country countless dollars as well. It is imperative that doctors become informed about -Recognizing the common group of secondary symptoms that people tend to manifest with this illness (sweating, temperature control issues, blood pressure problems, etc.) -The legitimate physical nature of the illness, and how to distinguish it from depression or anxiety -How severe it can get at its worst -That early diagnosis can prevent it from getting so severe -That avoiding over-exertions is key to recovery</p>
104	<p>Diagnosed by neurologist in 1993 I have had EVERY CONCEIVABLE, symptom but the predominant Two are: Fatigue and pain They never go away. Even tho I take morphine sr which is important ...narcotics are the only thing that works I try\tried everything</p>
105	<p>That they need to get it right this time. The US and medical bodies throughout Europe have used too many interchangeable names for this disease for nearly thirty years. Clarity is needed both for the medial professions and for sufferers.</p>
106	<p>Despite what some medical professionals have said over the years, and some more yet today, ME/CFS is not and never been a psychological condition. It's a physical condition or abnormality. Don't waste everyone's time trying to prove CFS is psychological in nature. It's a total insult to all patients to do so.</p>
107	<p>Please listen to Dr.Klimas!</p>
108	<p>It's real.</p>
109	<p>There must be an antibiotic treatment for this condition as I've always felt better and much more energy on antibiotics and antifungals. Do more to raise awareness of it being of pathogenic nature!!!! I was a corporate executive now in the gutter, SICKENING TO BE SO UNSUPPORTED!!!</p>
110	<p>Please find a way to educate more physicians about this. I should not have to beg for care. I should not go bankrupt trying to feel halfway human. Thank you.</p>
111	<p>ME/CFS is so complex that diagnosing, necessarily, cannot be simplistic. One example: normal range hemoglobin-related tests were usurped by a near- zero value of Fe in my son's liver. His physician had the good sense and experience to have the tests run from the same blood draw--and to listen carefully to his narrative of red-meat cravings every other day and the need for oxygen-rich air in the open, high-school athletic field in the late evening and early morning hours. All of this makes sense, but only if clinicians follow the admonishment of Sir William Osler--listen to the patient. Fe tablets were immediately prescribed, but--here's the dilemma--Fe fed the virus. (See research on liver defensin.)</p>

112	its a hard diagnose to live with because you are not sure and sometimes you here from people who get after a time of surching an other diagnosis and you are unsure again, please begin with making subgroups, also male and female and duration different, help the bedridden ones with a diagnosis, give more money for really hard diagnosis to be found
113	It needs to be diagnosed immediately so that it does not get worse. I suffered through it while getting my degree and then while working full time. If I had been properly diagnosed, it would never have gotten as bad as it did. I was housebound for years and though I am well enough now to run occasional errands and do a little bit of housework, I cannot return to work or lead a normal, active life.
114	I would like for the non experts to review this post by Cort Johnson, <a href="http://www.cortjohnson.org/blog/2013/12/22/unfulfilled-commitments-broken-promises-nih-chronic-fatigue-syndrome-twenty-five-years/">http://www.cortjohnson.org/blog/2013/12/22/unfulfilled-commitments-broken-promises-nih-chronic-fatigue-syndrome-twenty-five-years/</a> It's despicable that NIH and other government agencies (CDC, FDA) have ignored this disease so long. If they hadn't diverted money allocated to the disease to other diseases and actually put it towards ME/CFS research we would probably have better information about cause and possibly some effective treatments. This has to end, there has to be a much more concerted effort to SOLVE CFS.
115	I think the name CFS trivializes the illness and adds to the perception, especially as a woman, that we are just lazy and don't really have any reason to complain about how horrific things can be.
116	Please limit the definition to ME, not just chronic fatigue. Fatigue whilst a big problem, is superseded by all the other debilitating symptoms.
117	This diagnosis is FAR over the heads of the IOM organization. They have no business defining a disease as complex as ME when they are so woefully ignorant of this disease, its biomedical signs, and the many flaws of loosely defined "CFS" criteria. There are reams of research papers using these uselessly loose criteria which should be flushed down the toilet. Yet the IOM committee threatens to uncritically factor this horrible research into their "definition" of ME. The IOM's prior pronouncements on ME and CBT/GET put them in a position of rank conflict of interest. Simply voting on existing literature without any understanding of the difference between ME and idiopathic fatigue (or fatigue of other diseases such as MS, which are frequently mis-diagnosed as ME) and without any understanding of which literature is irrelevant - is an exercise in more punishment of ME patients who desperately and urgently need biomedical treatments. This contract is a human rights scandal, directly in opposition to experts who have endorsed the Canadian Criteria for ME as a much more credible and humane starting point. PLEASE LET OUR EXPERTS - NOT THE BUREAUCRATS - DEFINE THIS DISEASE!
118	That Dr.s who treat patients with CFS , and we have very few in Canada, need not be afraid to be advocates for their patients with Disability insurance companies. That family physician's as they are the ones expected to diagnose and treat CFS patients need to have more time to work with them, and that resources to support physicians and these patients need to be accessible and funded.

119	<p>ME/CFS is often misdiagnosed. The literature is full of studies looking at patients who have not been carefully diagnosed. It is customary to have people who live and work with a condition in question to define it because definition is complicated. Which puts half of you and the IOM process itself in an odd position for being out of good form. Nonetheless I trust everyone will do their best for the good of the patients and the integrity of science itself, not confusing any process such as rules of EBM with science. ME is a complex disease (or set of diseases; we don't have enough information to know which yet) which needs to be distinguished from idiopathic chronic fatigue (many CFS studies are actually of ICF), which is not a disease but a recognition of a symptom with the cause not determined (whether because the doctor/researcher got busy with other things, or because the proper test has not yet been invented, or distinguishing feature not yet noted, or the disease is not yet progressed in that patient so the distinguishing elements are not yet available). ME should be handled in a similar fashion to other complex diseases like Lupus and multiple sclerosis. For example, suspected cases should be referred to specialty for confirmation and treatment, and it should be noted that some prominent distinguishing features such as post-exertional collapse (PEM or PENE) may not be noticeable in all patients at onset, so some patients may need to be followed until it becomes clear what disease they have (e.g. do they develop Lupus antibodies, PEM and low NK cell function, or MS lesions?). In no case should patients be left to shrift for themselves. They should be given symptomatic treatment, and investigated for treatable conditions like orthostatic intolerance and asthma. It is not acceptable to say, "CFS causes shortness of breath, and your SpO2 is fine while sitting quietly in a chair, so, oh well. There is nothing we can do." To a person who cannot walk across her house due to short of breath. Or "we cannot find a disease so you are fine. Go be happy." If you would not put up with something for a patient with multiple sclerosis or cancer or Lupus, you should not stand for it in our case either (or in ICF, or anyone else). People with undersireable diagnoses (not just us) are left without basic care, needed aids, nursing care even in ER and hospitals, and social support. It has fallen to you to fix this for us. The literature is not strong, because funding has been dismal (and an amazing amount of it has gone to investigators who don't seem to know they should use a control group or blind their assessments, etc.). A strong recommendation for an intense, well-funded research program into biomarkers and treatments would be warranted. Whatever you come up with in this process will necessarily be temporary because so much more basic research into biopathology is needed. Do not be afraid to recommend CCC or ICC for now, then more research. It is not yet time for a research-based definition because we don't yet have a robust body of research.</p>
120	<p>Thorough investigations NEED to be made. Orthostatic intolerance, SIBO, gluten intolerance, fructose malabsorption, lactose intolerance are all quite common when I talk to other patients.</p>
121	<p>This illness is real, physical (not psychological) &amp; devastating to those who have it. Research &amp; medical support is vitally needed to make a real difference in the lives of those who have it.</p>

122	<p>I am no longer the person I was before this illness. I have no social life because I don't dare make plans to do anything because I don't know if I will be well enough to leave the house at that time. I always feel ill, much as though I always have the flu, it is just a question of how ill I am at any given day, or moment, really. This disease affects your entire body as well as mentally. I developed many allergies, I am ultra sensitive to sounds, light, and scents. I smell chemicals in products that no one else smells, and they make me sick. I have major insomnia. Without sleeping pills, I sleep a maximum of two hours per night, if I sleep at all. When I first became ill before I started using sleeping pills, I would go as long as 72 hrs. without sleeping at all. I can be up during the day for two or three hrs. at a time then I must lie down and stretch out and rest because of pain and fatigue. The worst part, perhaps, is that most people don't even believe I am sick. Only those who have it seem to be able to understand it. Another interesting symptom of this illness I noticed in myself and others is that we have trouble finding the words we are trying to say. I think I sound like an idiot because I can't find even the most simple everyday words. There have been periods when I feel like I am getting better, but if I get a cold or virus, I hit bottom again and can barely function. I can take care of my personal needs, but little else. Sad. Very sad.</p>
123	<p>CFS has devastated my life and the life of my family.</p>
124	<p>I would like them to know that the National CFIDS Foundation has found the true cause of the illness. This is chronic radiation sickness.</p>
125	<p>Im a type A personality who needs to accept the disease without quitting on everything</p>
126	<p>When someone with ME/CFS talks to another patient it is pretty obvious they have ME/CFS when one compares symptoms. Though some specific symptoms and secondary diagnosis may vary basically unrelenting fatigue, exercise intolerance, GI symptoms, malaise, environmental sensitivities (sounds, smells, light) and delayed symptoms to exercise pretty much sum it up along with partial to total disability. And of course most patients look perfectly healthy (when they are actually able to go out in public).</p>
127	<p>Exhaustion is post-exertional. No exceptions. POTS is terribly hard to live with. Cognitive difficulties can be profoundly troublesome.</p>
128	<p>So much work has already been done e.g. the CCC. Please build on that. Please focus on biomarkers, especially PEM and the 2-day exercise test. I personally am 100% convinced this is not a psychological illness, so please don't be distracted by that line of thought. It's not that I don't want to have a "psychological" illness, but I do not believe effective treatments or cures will be found in that domain.</p>
129	<p>This debilitating illness has no specialist physicians to treat this illness. It falls upon the PCP who don't have the time to become a specialist for handful CFS patients that they might have. I lived in the Pittsburgh area and there is not one specialist in the area. Because of this, we are not being diagnosis or treated for our illness,</p>
130	<p>If it's a virus, any medicament or naturel product is essential. Just prevention until now. And something very thin for insomnia.</p>

131	I am completely debilitated at this time. Bedbound. I am on extended medical leave from work. My disability company agrees that I have CFS but are refusing to pay as they say the treatment is not congruent with a high level of disability and they also want a letter from a psychiatrist. For one there is no agreed upon treatment regimen for CFS and the disability company wants to make this a psychiatric issue so they only have to pay for 24 months max.
132	Diagnosis is not difficult if only one looks for it. Firstly the medical community must be educated about the complex syndrome, only then they will acknowledge the same. ME must be given the seriousness it deserves in all medical textbooks given the extremely debilitating, life altering and incapacitating symptoms. ME must not be falsified as it is done now. Regulatory authorities and federal agencies must encourage research and generously fund the same proactively and in all earnest, which can make a vast difference between living as against existing as in ME.
133	Meeting Dr Klimas and being tested and diagnosed helped me immensely to feel acknowledged and understand that this is a real illness!
134	The Canadian criteria are what should be used. They identify true ME/CFS patients. It is that simple. Don't reinvent the wheel to fit some other agenda.
135	I was told by several of the initial doctors that I had post-viral syndrome and I "just have to fight through it." It seems most GP's don't know how to diagnose it.
136	I was diagnosed in 1990. No other doctor seems have heard of ME since and a number have been very irritated by my mentioning it.
137	The definition of Myalgic Encephalomyelitis by Byron Hyde MD, of Ottawa, describes my condition & should be used to define Myalgic Encephalomyelitis (which is not "CFS", "ME/CFS" etc etc); see - <a href="http://www.nightingale.ca/documents/Nightingale_ME_Definition_en.pdf">http://www.nightingale.ca/documents/Nightingale_ME_Definition_en.pdf</a>
138	Just because you look relatively ok on the outside, it is like a living hell. Pain, fatigue, brain fog, etc + frustration! loss of hope! despair, hopelessness of situation. I used to race bicycles and never felt as bad even after a 100 mile ride, I would feel ok again after 10 minutes.
139	I must admit, after 22 years, it feels pretty hopeless that there will ever be a cure or even knowledge about how this started. Biomarkers. Anything. At least get rid of the name CFS. Please.
140	Go to hell, don't need your meddling and muddying the waters!

141	<p>I am very very ill... and want doctors to understand that if this was all in my head, I would be over it by now! I can see NO secondary gain to loosing my practice/work, my health, my income, my home, many friends, colleagues, the ability to socialize and contribute, and to be able to do a hundred small things most people take for granted... until they get sick! Please CHANGE this trivializing name! It is insulting and leads to confusion and suspicion that it could still be psychiatric! And when I get so frustrated trying to educate doctors and having to defend myself and break down in tears... and misunderstood - of course I would be depressed - anyone would be who have experienced what those of us who are terribly ill have! It is overwhelming having to figure out what is wrong, then finding doctors who are willing to do the research and provide medical treatment needed or often even the dignity that I deserve, all because they don't understand the illness... is cruel! If getting sick, and experiencing accumulated losses isn't enough, we have to endure ignorance, indifference or suspicion. I want to get well! I want to work! I want to contribute! I want to hike and bike and play tennis, ski double black diamond (advanced runs), host a dinner party again, Attend seminars and lectures, Practice what I have been trained to do as a master level clinician. I want to get well. And if I can't have that, well, then at lease give me the dignity of taking my illness seriously!</p>
142	<p>Much of the research done using a variety of criteria for defining the disease is worthless. We need a definition that requires actual biomarkers and provable symptoms. CCC, please.</p>
143	<p>Given that the international consensus criteria were published in 2011 and most expert researchers in the field already have a consensus about the diagnosis, I hope that this group can speedily come to an agreement about diagnosis so that 'next steps' can be taken. I think that energy needs to be put into public and doctor education about ME/CFS. Most individuals don't have an accurate understanding of what this disease is really like. Additionally, it may be helpful to eliminate the name CFS. Unfortunately, it seems to promote an inaccurate stereotype that all this disease involves is having some fatigue.</p>
144	<p>After diagnosis, many drs. still only give lip service to taking CFS seriously. After a TIA (generated by a CFS symptom), a cardiologist tried mightily to persuade me to take a treadmill test even though I explained several times to her how devastating it would be to my health &amp; a neurologist had the same attitude about an MRI. I refused both (&amp; there were less severe alternatives) &amp; still required over a year to return to the same level I'd been at before the many TIA-related dr. &amp; lab app'ts. I kept.</p>

145	<p>CFS/ME/CFIDS is a life changing illness and more common than most people realize. Our patients' lives are often devastated by their debilitating symptoms and they are usually very limited in their ability or are unable to work, attend school, have a satisfying social life, or care for their families. They experience more marital separations and suicides because there is very little support or treatment available. This group of people has been maligned over and over again. I have attended medical meetings where lecturers have made casual and denigrating remarks about the very patients I care for every day. As an experienced clinician, I feel infuriated by this. Can you imagine how a patient feels under these conditions? Our system has failed them and resigned the majority of them to substandard care, disregard, or even genuine neglect because we do not yet have the knowledge to define the illness, and in our medical world, if we do not have it defined yet, it does not exist. With nearly all my new patient intakes, I hear about repetitive dismissals from providers who simply do not have the time, tools, or interest to care for these patients. Imagine doing that to patients with congestive heart failure or cancer. Those are complex patients too, but we do the research, work on definition, and provide care strategies that at least reassure them, make them more comfortable, and sometime even cure them. In this society we have developed compassion for patients who have AIDS, so why can we not do this for CFS\ME patients? I urge this IOM committee to listen to and benefit from the community of experienced scientists, clinicians, and patients who work or live with CFS/ME. We need to provide the best definition and guidelines for diagnosis so we can more on with more productive research and treatment. I sincerely thank you for allowing me this opportunity to express my opinions.</p>
146	It would be easier if people knew how much ME/CFS wrecks a person's life. a little empathy goes a long way.
147	Diagnosis needs to be taught to medical professionals.
148	This is a serious debilitating disease that mandates in-depth testing in the early stages of onset. Doctors should be mandated to respect. Understand every aspect of the disease. NO PHYSICIAN SHOULD LOSE THEIR PROFESSIONAL STANDING FOR TREATING people with this gravely debilitating disease.
149	<a href="http://thetenthparadigm.org/index.html">http://thetenthparadigm.org/index.html</a> Downregulating the NO/ONOO- cycle really works.
150	This needs to be taught in medical schools so the future patients do not have to go to doctors who do not believe it is even a disorder, dis-ease, etc.
151	Please stay away from 'making it easy' to diagnose, and please stay away from CBT and GET trap. Patients are very sick and expect to be taken VERY, very seriously. We need a 'Manatthan' project and leadership.
152	I understand that CFS/ME is difficult to diagnose and there may be some crossover with psychiatric conditions however to be told that you are suffering a psychiatric condition when you are not is extremely upsetting.
153	Please help us!

154	<p>The chronic fatigue syndrome name is grotesquely inapt. The CFS Fukuda criteria are outdated and misleading. My symptoms fit the Carruthers 2003 and 2011 criteria almost verbatim. Thus in my case ME is a clear diagnosis. However the CFS criteria are so vague there is no way to know whether they describe the same condition as ME (albeit poorly), a broader spectrum disorder, or an entirely different illness.</p>
155	<p>ME/CFS destroys and takes everything from you - hopes, dreams, careers, friends, even family. Ability to pursue your interests and contribute/help the causes you believe in, your community and other people. Even the ability to do normal everyday things people do to live - grocery shopping, cleaning house, preparing meals; even personal care suffers. It is essential to have a valid set of criteria for diagnosis. Otherwise there is no hope. Having a diagnosis that is accepted and known by the medical community and public in general would be a first step. Most very sick people get help and assistance from medical providers, friends and family. We get disbelief and loss of relationships. Research absolutely depends on a good diagnosis to be valid. And hopefully this research could lead to treatments some day and relief of an illness that is life-destroying and never goes away. This is such a complex illness, certainly not simple to define and no one definitive marker. I am not sure how people who have not really dealt with this illness, can understand it. I hope the results of this will be helpful. But my big fear is that if this is used by government agencies to make decisions on research and treatment, then if not done correctly - There is no hope.</p>
156	<p>Even as late as 5 years ago, I had trouble with a new specialist because of the diagnosis. While it isn't 1957 or even 1970 anymore, we still have a long way to go. Even though I had definitive lab tests showing mitochondrial problems as well as neurological problems, he insisted I "MUST" have a psychosomatic disorder, because he didn't "believe" in ME/CFS. This was like my experiences when I had ME from whooping cough--doctors insisted I had a psychosomatic disorder even though I had the traditional unique cough and fever, etc. since they "knew" it was "impossible" for vaccinated teens to have whooping cough. I've had cancer three times. At least that is not an illness of "belief".</p>
157	<p>There are treatments and supplements that are available that help alleviate some of the symptoms. Identify these and make sure the entire medical community is aware of these so that patients do not have to suffer without any help.</p>
158	<p>I had Infectious Mononucleosis when I was 20 years old and from what I have read, my CFS might stem from that episode. I do take 2000 mcg of Folic Acid and well as 1000 mcg Sublingual Vit-B12 every day. I do believe that the B-12 does help. I also have had Polymyalgia Rheumatica and I am recovering from that and will probably be completely off the Prednisone by next week. I have been on Prednisone since 2005 and have been on 1 mg every other day for a year and my blood work, Sed Rate and CRP have been normal for 2 years.</p>
159	<p>Validating the diagnosis is very important to feeling understood and respected for one's suffering, even if there are not good treatments at this point.</p>
160	<p>Exercise intolerance or post-exertion malaise and a subtle form of dizziness are two symptoms that seem most characteristic of the disease for me, and the most debilitating.</p>

161	<p>In my opinion, if the IOM committee fails to define and distinguish 'ME' as a separate and distinct cohort (either a separate subgroup or a separate illness) then the whole IOM process will have been a waste of time and resources. When using the term 'ME' I refer to the cohort of patients who have a specific type of 'post-exertional malaise' as a symptom. I will define post-exertional malaise below. (Post-exertional malaise is considered to be a defining symptom of 'ME' as opposed to 'CFS' or chronic fatigue.) The committee needs to understand that Fukuda CFS defines a heterogeneous cohort. For example, some patients with a Fukuda CFS diagnosis will have the symptom of post-exertional malaise (PEM) and some will not. The best outcome of the committee for patients will be to sub-divide the current heterogeneous CFS cohort into subsets that include a subset of ME. The committee could also define and distinguish other subsets, for example: ME, atypical ME, CFS and chronic fatigue etc. To define 'ME' (i.e. an illness that includes post-exertional malaise as a cardinal symptom) as a separate cohort or distinct illness must be an outcome for the committee, otherwise many patients will consider the whole process to have been a complete waste of time and resources. A good place for the committee to start would be to understand and define the nature of post-exertional malaise, which many patients consider to be the 'cardinal' symptom of 'ME'. The nature of PEM must be understood, in order for the nature of ME to be understood. PEM (in ME) is not simply (ordinary) tiredness and fatigue after exercise. But it is a delayed and prolonged exacerbation of all symptoms (of ME) after exertion, which is not relieved by ordinary rest. This must be understood by the committee. Post-exertional malaise is not the same as post-exertional fatigue, but it has a distinct nature, and involves possible exacerbation of the whole range of symptoms that define ME. For many patients, using PEM to distinguish a cohort named 'ME' would be a satisfactory starting point for the committee. It must be understood by the committee that ME, as opposed to chronic fatigue and Fukuda CFS has a distinct set of symptoms and a definite and definable nature. ME is not simply 'fatigue' in the absence of alternative diagnoses. ('Chronic fatigue' may be defined as 'fatigue' in the absence of alternative diagnoses, and Fukuda CFS includes patients defined by 'fatigue' in the absence of alternative diagnoses.) Also, unlike chronic fatigue, ME cannot simply be defined as pathological 'fatigue' on a scale of fatigue that includes ordinary fatigue. Instead, ME has a distinct nature and distinct set of symptoms which define the illness. ME has distinct and definite features and symptoms that distinguishes it as either a distinct condition or distinct subset. Unlike chronic fatigue, and CFS, fatigue does not have to be the primary symptom of ME. ME patients can, for example, experience the following primary symptoms: malaise, post-exertional malaise, cognitive dysfunction, exhaustion, endocrine dysfunction, dysautonomia.</p>
162	<p>CFS specialists don't accept insurance ---are we left with few options for medical care? Yes! Primary care physicians don't have the knowledge or experience to care for us.</p>
163	<p>So many patients are desperate for recognition, understanding, validation and a "reasonable" treatment plan. That alone would go a long way, even without hope of a cure.</p>
164	<p>It is a life destroyer. Even if you don't die from it you also can never really live. Every decision you make is colored by having this disability. I have lost close relationships from having this disabling problem. Now I live alone and have a hard time caring for myself. Children try to understand but can't quite grasp it. Like many severe and chronic diseases it is very isolating from feeling quite human, it's a sad life. Depression? Who me?</p>

165	<p>I would like to see a set of blood tests that researchers in field could agree upon are indicators of CFS and combine this with a set of physical and daily functioning reports by patient that are widely reported by CFS community to become part of standardized diagnosis. There is a certain ruling out of other diseases that should occur - like MS, etc. but I don't think that list should be extremely long. There should be a concerted effort by the Medical community to become more educated on CFS as a matter of required education, however we have seen great harm caused when so many practitioners were educated to believe that depression was the primary cause of CFS/FM as opposed to an outcome or one of the symptoms. There were two doctors who immediately upon hearing I was in their office to discuss FM told me they did not want me as a patient-not quite that directly but near to it. They did me a favor.</p>
166	<p>nobody pays attention to persons with this condition. the first thing you listen is "depression". we are not ill because of depression, we get depressed because of illness.</p>
167	<p>From all my research over the past 10 years, the diagnostic description that felt right was that of Neuro-Immune Fatigue and Cellular Hypoxia. There is so much more but those two terms seem to be an umbrella which describes almost every major aspect of the problems that I am currently experiencing at age 69. At ages 30, or 50, the problems were things which held me back, kept me from doing all the things that others my age were able to do. Now, even with an exceptionally strong body, one of these two will send me to my grave within the next five years.</p>
168	<p>Doctors need to know what ME/CFS is and that you can actually diagnose it (not just slap it on as a label when you run out of other options).</p>
169	<p>The incredible additional personal pain caused by the medical profession, including my M.D. brother and sister-in-law, who dismiss and deny the suffering. They, and the media, thus many friends, are pawns in the medical-Insurance-pharmaceutical-governmental complex who's financial interests lie in burying, failing to fund, ignoring, and manipulating data that gives legitimacy to this devastating illness.</p>
170	<p>My sister's physician recently told her that ME 'was something people got back in the 1990's.'</p>
171	<p>Drop the demeaning CFS, and refer to this illness as ME. Diagnostic criteria need to be based on symptoms unique to this disease (like PEM) and not general fatiguing or mental health conditions.</p>
172	<p>Many of us have suffered with this illness for more than 20 years. We have lost our best years while the government fiddled and did nothing. We are sick. We are not tired. We are not lazy. We are not "depressed." I have multiple ideas about things I'd like to do, but do not possess the ability to do them. To consider this as a psychiatric disease does a disservice to those of us in severe physical pain who have gone untreated or poorly treated for years and years.</p>
173	<p>Doctors who treat people with ME/CFS should be prepared to spend a few extra minutes with us -- doctors cannot expect to treat us satisfactorily if they do not understand all the challenges we face; and we desperately need our doctors help in prioritizing and planning our self care.</p>

174	I would like most of all, for the Committee to understand with extreme clarity, the devastation this disease wreaks on our lives as a whole. I have been sick in my life. This disease is beyond any suffering I have ever had to endure before. People ask me what exactly is wrong. The answer is that everything is wrong. I feel so ill, there are no words to explain it or to make a well person understand. The emotional and mental effects are so difficult as well. My life has been taken and in its place I have found profound illness, doctors whose main goal is to preserve their own ego, judgment and doubt from all, even those closest to you. It is lonely and sad and at times physical torture. It is real, it is not because we are depressed! We are depressed beyond belief because of where we find ourselves, watching this horrible disease steal everything from us.
175	i was a hard working and highly functional person prior to getting me/cfs. i lost the life i'd been living prior to being ill - i had to stop working, lost the income, the sense of accomplishment and the role of functioning adult that were connected to my work. i cannot adequately describe the depth and forever-ness of that loss. i hate being ill and not being able to accomplish things. there is no benefit to me, psychological or otherwise, in this illness and, in fact, the opposite is true: my life has been so reduced and limited by this illness. i fight it every day, and fail every day.
176	This illness has ripped my life away foe 8 years and they have to consider rating it at the top of the priority list, urgent attention. Although it isn't a death sentence, it might as well be as the life you have known is GONE. Sincerely, Anna Zapp
177	Very often the symptoms of CFS are invisible to the outside worlds so patients/sufferers are often met with the suspicion of others including co-workers and close friends. This tendency tends to isolate CFS sufferers and leave them with less access to the social support that can be so helpful.
178	This is not a psychological disease. I was an energetic doctor, the next day I'm disabled now considering strongly suicide daily.
179	Less focus on diagnosis, and more emphasis on cure.
180	It progresses to include other conditions.. I now have total body neuropathy, along with all the other symptoms that are common for persons with CFS
181	It is real, life altering and we desperately need treatments.It decimates lives and families in ways that are hard to imagine. I want to be able to work again!
182	1. Please define it using the 2011 Myalgic Encephalomyelitis: International Consensus Criteria. Please also use the Canadian Consensus documents to define it. Please ignore the U.K.'s NICE guidelines or anyone there whose connections to the insurance industry & for-profit clinics should disqualify them i.e. White, Sharpe, Wessley. 2. Please come up with a new name that reflects the science behind the disorder including the words neuro, endocrine, immune. 3. Please put a process in place to make sure that every medical practitioner receives the latest information regarding diagnoses & treatment. Require medical schools to teach it.

183	I was an exceptionally active, professionally successful, happy woman and mother until being struck down by CFS at age 52. It left me totally exhausted, mentally confused, with memory problems. It resulted in my contracting serious health issues such as COPD (I never smoked.),NTM and MRSA lung infections.It is also devastating to the US economy because so many of us go on SS Disability and are no longer in the workforce. Please help us discover the cause/s so there can be a cure. Thank you.
184	I still fear that there are thousands of people with the condition who don't have doctors in their area that even know of its existence. Making a solid, basic criteria part of each and every doctor's knowledge base would give patients hope and alleviate the fear of being all alone
185	MD's and psychiatrists need info on CFS/CFIDS
186	It is a horrible, life-altering disorder that took me almost overnight from being active and busy to house bound.
187	In order that suffering patients be treated with dignity and respect, it is vital that we adopt an appropriate name, require PEM (which also could use a better name), and define the disease based on biological symptoms, indicating clearly that this is NOT a psychological illness)
188	It is important that any constructed diagnosis is not allowed to remove patient's right to be spoken to honestly and clearly, and does not allow doctors to make claims to the patient which are not justified by the evidence. Given how little is currently understood about CFS, and the long history of bigotry and quackery, it is important that no claims are made to patients about the role of cognitions/behaviour - too much harm in this area has already been done, and no one will ever face disciplinary action for it. Exaggerated claims about the 'efficacy' of behavioural/cognitive interventions led to the stigmatisation and abuse of gay people for decades, and no-one faced accountability there either. We need to restrict the power doctors have over the lives of their patients.
189	The all-important thing is to have a narrow definition for ME/CFS. The broad definitions create so much trouble for me as a patient, since I get lumped in with people who do not have the same, rather distinct, post-infectious disorder that I have.
190	I was extraordinarily fortunate in the quick diagnosis as well as their willingness to research (what little) treatments were available for me.
191	because it IS multi-conditions including neurological, specialists can't/don't get beyond their part/system of the body; only one dr. asked me to tell him everything that was going on
192	Rightly described as 'the living death' - lack of knowledge and lack of support and help by the medical profession and the widespread ignorance of the general public makes everything more difficult

193	<p>I feel it is extremely important to stop combining ME and CFS. ME has been a distinct neurological illness, similar to MS, recognized by the WHO since 1969, and should be diagnosed exclusively by the ICC criteria developed specifically and unanimously by many of the world's top experts on this illness. CFS, on the other hand, has become an umbrella term for any illness that causes fatigue that doctors have not yet diagnosed correctly. Multiple studies have shown that over 90% of CFS patients do not have true ME. Thus combining the terms in research and other ways is as harmful and unhelpful as combining ME and MS, AIDS, cancer, and every other fatigue producing illness. Until these two diagnoses are separated once and for all, absolutely zero progress or answers is possible. *Please* fix this and restore this illness its individuality by using the correct name and criteria, already in existence. Then, and only then, can we finally have hope. Thank you.</p>
194	<p>It is real, it is frustrating and a patient knows her body better than a Dr. Dr. Are PRATICING medicine therefore don't know everything and should not dismiss symptoms. ME/CFS is depressing not depression!</p>
195	<p>M.E. is a real biological disease that is separate from mental illness. I was not depressed at all when I became ill, and am still not depressed or psychotic. I want to work, and to exercise, and to have a normal life, but day after day, my body won't let me. I feel like I have the worst flu of my life, every single day without break, for well over a thousand days in a row now. Its onset was acute for me - one day I went to work, and by the end of the day I was crumpled on the floor in agonizing pain. I never got better. It is frequently misdiagnosed, but if the govt. were to give it an accurate name and work hard to spread awareness of the seriousness of the disease and its diagnostic criteria, that would end. For me it is genetic - my mother and her entire line had immune dysfunction and immune-related cancers, as well as symptoms that would likely qualify for a Fibromyalgia diagnosis today. I was very healthy and active though until one day when I was 30, out of absolutely nowhere. I had felt run-down for a month before that, because I was working hard on my doctoral program, but that was it. I thought I caught something from one of the students on campus. M.E. diagnosis requires very low Natural Killer cell function. It also should require a lack of autonomic function, which can be measured in changing temperature, and significant difference in blood pressure sitting up versus laying down for 5 minutes (tilt tables are cruel, they will cause patients to faint and be ill for a week or more afterwards). Abnormal heart rate can also be measured - sinus tachycardia is common (72-hr Holter monitor may be required to demonstrate), as well as unusual extreme response to chemical stress test despite all other evidence of a healthy heart. Using a VO2max test will produce results unique to M.E. and separate from Fibromyalgia alone, as the patient will have significantly decreased function/recovery after 24 hrs - which will be worse than the immediate results just after the exercise. One can also measure cognitive function with testing - short term memory and a number of distinct brain functions (computing, comprehension, etc.) will suffer significantly, especially when the patient is crashing (a day after exercise). Be cautioned, though, that these tests really are only a comparison to previous function, so of limited value without a reading while the patient was healthy. Ill, I score higher than most healthy controls, but my scores would have been significantly higher had a tested while healthy - cognitive ability is always an individual thing. Self-reported symptoms of flu and stomach virus/IBS should also be present, although without fever. A vision test before stress and after would show significant loss of ability to focus after exertion/while crashing, and thus light sensitivity will also become an issue. Both cognitive and physical exertion will cause the heart rate to increase significantly, and thinking too hard can cause the patient to faint. Fainting due to lack of sufficient blood volume is common, high sodium and electrolyte intake with fluids will cause significant improvement in functioning, as do compression stockings as blood tends to pool in the ankles although it did not while healthy. Presence of multiple active virus infections such as Coxsackie B1-6, HHV6, CMV, and Parvo are common due to the inability of the immune system to fight adequately. PLEASE speak to</p>

Dr. Klimas regarding successful diagnostic testing and what recent studies have shown for possible biomarkers. M.E. causes widespread multisystemic dysfunction.

196

Investing more resources in a clearly sick person at the beginning of their illness will probably save tonnes of money in the long run. If I had known to rest more and had actions to appropriate medications initially rather than pushing through I might be better by now.

197

I wish gps had listened and the info on me available been available to them. Maybe then I wouldn't think about killing myself each day because I can do so little. If I were an animal I'd have been put out of my misery years ago.

198	<p>The NIH and CDC have completely thrown "ME/CFS" patents under the bus, and I have great concerns the IOM is going to do the same. First, when the CDC ignored the proper name given to this illness, Myalgic Encephalomyelitis, by the WHO back in the 1950s, and decided to call it by the ridiculous, belittling, and dismissive name "Chronic Fatigue Syndrome," patients began to be treated like "lazies and crazies" and somatisizers, and be dismissed by their doctors and others as sick. This despite known evidence of outbreaks, NK cell dysfunction, mitochondrial dysfunction, etc. The NIH and CDC continue to downplay this seriously debilitating and disabling illness, only spending a few million a year on funding research, pretending to be concerned about patients while not truly seeking cures, legitimizing patients or the severity of the illness, not educating doctors about the severity and true physiologic origins of this disease; instead leaning towards the ridiculous and already disproven ideas that the disease is psychological and recommending treatments such as GET and CBT from horribly flawed studies. The IOM has done similarly. mentioning CFS in it's study on Gulf War Illness and making the same inferences and recommendations. In addition, given the fact that research for ME/CFS have been so under-funded, there are not as many studies as there should be on this subject, especially if the committee only or mostly pulls from US studies when gathering data, this another problem with the IOM trying to form a diagnosis based on the "available evidence/ scientific studies/ RCT." The greatest knowledge base on this topic is obviously the ME/CFS specialist physicians, who have seen and treated thousands of patients with ME/CFS over many years. These are the same physicians who devised the ICC for diagnosis, which is the best criteria to date, has been recommended by the specialists and patients, but ignored by the NIH/CDC, who have instead hired the IOM to come up with new criteria? To what end? To continue to disenfranchise and dismiss patients with diagnostic criteria for a " fatigue syndrome" so we can continue to be dismissed by doctors and insurance companies, and instead be plied with antidepressants and prescribed GET and CBT when we are so sick with a neuroimmune illness that we cannot even get out of our beds? Lastly, due to the extremely complex nature of this disease and the paucity of understanding by physicians who do not have extensive first-hand knowledge of this disease, ONLY physicians who could be considered specialists and advocates for ME patients should be conducting a study such as this, which is redundant, since this has already been done and how the recommendation for the Canadian Criteria made to the NIH. There is no reason this study with the IOM should have even been contracted (in secret, I might add) and it should be cancelled.</p>
199	<p>The financial blow has been crushing. I had to retire early from teaching High School, three years ago, and have been struggling to survive on 1/3 of my former salary and working part-time for a very low wage, ever since. I was denied long term disability from the pplan into which I paid for about 20 years - I'm very angry about that.</p>
200	<p>Change the damn name! Maybe I wouldn't be completely isolated if anyone believed I've declined so badly. I wake up feeling like I have HHV6 Meningitis&amp; Encephalitis again, every morning. I had Reactivation of it a few yrs ago. My quality of life is so poor , I don't know why I hang on. I want advertising of ME so my own family and old friends will finally believe me.</p>

201	<p>There needs to be an understanding and acceptance of a patients subjective descriptions of the symptoms, because, for me at least, they are like none other i've experienced (i'm 64) in my life. the headaches are not like other headaches - mine can be sharp and tingling and on the top of my head, other times dull and buzzing as if i had a bee hive inside my head. body sensations range from flu-like weakness to a deep fatigue that is like no other - it's like waking up after a good nights sleep and having no gas in the tank - and wondering if i have the strength and energy to get up and walk to the bathroom. i'm a lifelong athlete - long distance biker, marathon runner, college basketball player - and at a young 64 to be this incapacitated - with little to no hope of recovery - sucks. sorry, my vocabulary failed me - but it best describes the situation.</p>
202	<p>Early diagnosis and treatment are absolutely crucial to recovery. I have lived every single day of the last 28 years feeling like I'm coming down with the flu or have already come down with it. This illness creates a life that cannot be lived and a death that does not come. "The good news is 'You have Chronic Fatigue Syndrome.' The bad news is 'You have Chronic Fatigue Syndrome.'" There is relief in finally receiving a diagnosis, but utter horror when you realize it is a life sentence.</p>
203	<p>You are in a position, if you get the definition wrong, to cause a great deal of harm.</p>
204	<p>Proper management of symptoms is so crucial to increasing the quality of life for CFS patients, but access to the knowledge is scarce. If Doctors had education on the realities of CFS and tools to direct patients to self-help techniques, it would go a long way to helping patients and their families while we wait for science to find better solutions. Too many doctors are clueless, and it makes them appear careless.</p>
205	<p>I was bed bound and I see A CFS specialist, I went back to work and I am being managed, I am not cured but thanks to the access to a good specialist I have been treated for my NK cell dysfunction and coinfections (hh6,Parvo,Coasakie,EBV). I was am being treated Extremely succesfully for OI with midodrine and florinef and I lead a fairly normal productive live. I just want others to have access to treatment like I do. The amount of pain, lack of sleep, brain fog, Post exertional malaise and not being able to produce energy on demand is sooo devastating that we need to move forward.</p>
206	<p>Disease appears to be progressive with age. Need to properly diagnose early on and develop some type of treatment to prevent the ongoing suffering.</p>
207	<p>post exertional malaise is a prominant differEnce betwEen just being tired WITH OTHER CFS and feeling ill which is ME</p>
208	<p>IOM is in a unique position, it can commit itself (if it so chooses) to a pragmatic process, rather a mere academic exercise. That pragmatic process could produce a disease criteria set that recognises patient (not physician) need is the primary objective and that patient need requires a criteria set that is capable of response to dynamic changes in treatment and understading of the illness as research progresses.</p>
209	<p>The key feature of ME is post exertional malaise after minimal exertion, ie feeling ill not simply fatigued - if only!! Calling it cfs has muddied the waters and widened the diagnosis to include those who do not have ME, with the key symptom of PEM</p>

210	ME/CFS is a devastating condition. It needs to be taken seriously as a legitimate disease, so that those who suffer with it can receive treatment and live with dignity.
211	Recently I was given a 7-day course of Klaricid, Clarithromycin (I am now allergic to salicylates and penicillin), for an ear infection and within four days of starting it, felt like my old self. The remission did not last, however. My doctor also temporarily switched me from Amitriptyline (10 mg) to Nortriptyline for restless legs, which seems to give me a little more energy but causes severe sweating even in the lowest dose. I would like to see these, especially the Clarithromycin, investigated with regard to CFS/ME.
212	Adopt the Canadian Consensus Criteria as recommended by the experts in the field. The IOM's report on GWS was a disaster for Gulf War Veterans, resulting in the infamous new name - Multi-symptom Illness. It contained many statements and references to ME/cfs which are testament to the IOM's bias towards psychosomatic interpretations of unexplained illnesses and are clearly prejudicial to them delivering an objective assessment of ME/cfs. The secretive contracting process and the non-expert majority make-up of the IoM panel confirms to me that this process is a sham and a stitch-up.
213	A biomarker is desperately needed to speed up the diagnostic process. Diagnosing ME/CFS is a time-consuming process for physicians and stressful and tiring for patients. It can also be expensive. Until a biomarker is found, physicians need comprehensive education about the illness and training in how to diagnose. ME/CFS training should be a part of the curriculum at every medical school.
214	THE TOTAL DEVASTATION THAT THIS ILLNESS HAS BROUGHT TO MY LIFE. THE CRUEL "JOKE " THAT HAS BEEN PERPETUATED BY THAT LACK OF PROPER GOV'T BACK RESEARCH. THE SHOCKING AMOUNT OF "ARROGANCE & IGNORANCE " OF THE MEDICAL COMMUNITY. ESPECIALLY WHERE IT PERTAINS TO "SPECIALIST DR'S " . HOW IT AFFECTS EVERY ASPECT OF MY LIFE AND MEDICAL CARE.
215	We need more research into Epstein Barr. Even when it shows up in blood as a past infection, I strongly believe it can still be present in the brain and nervous system. I believe there is a misdiagnosis and over diagnosis of lyme when Epstein Barr in the brain and nervous system is likely a main cause for many people. Which can be aggravated by lyme and or mold among other things.
216	The biggest problem I see is the lack of knowledge by good docs. Mine is accepting but acknowledges his knowledge is minimal.

217	<p>Post-Exertional Malaise (PEM) seems to be one of the hallmark symptoms of ME/CFS. I get really aggravated when I see reports or articles claiming that things like B-12 'cures' CFS. I've tried B-12 in shot form, tablet, and sublingual drops...no improvement in energy. My B-12 is not low. B-12 helps a B-12 deficiency...don't categorize that fatigue as CFS. Different animals altogether. I'm praying that there will be some refining of the diagnostic criteria at the IACFSME in March, as well as some treatment options developed. Medical professionals...and INSURANCES...need to be made aware of this condition and what is required for diagnosis/treatment. I'd personally like to see some research directed toward cannabis as a treatment option and functional medical options covered by insurance. Since there are so many other illnesses that have to be ruled out for an exclusionary diagnosis of CFS/ME, there HAS to be some common element. A breakthrough in any of these diseases could/might mean a breakthrough in most, if not all, of them. Wouldn't that be wonderful????!! Perhaps a fresh eye needs to look at the data...someone like Jack Andraka. I feel there is a viral component to these diseases. I haven't functioned properly since I woke up on December 21, 2007 with Bell's Palsy...and an extremely high EBV count. I've always been a 'virus magnet'...chicken pox, roseola, rubella, herpes, EBV. This normally active 56-year-old forced-to-retire elementary education teacher needs some hope that life will resume...soon.</p>
218	<p>This condition needs a name change and doctors need to be educated on how to treat patients. Money needs to be allocated to research!!! Those of us who have it want to life life. I want to work!!! I want to be productive. Please do what ever you can to help is. We are bedridden and cannot do much ourselves.</p>
219	<p>It is not life threatening, but it destroys our lives, nonetheless. We desperately need more education, research and a diagnostic tool to assist PWC suffers.</p>
220	<p>Even though it has now been diagnosed I feel my doctor does not understand the illness and is not very helpful or sympathetic</p>
221	<p>Serious immune issues including idiopathic anaphylaxis with no relief without mega doses of prednisone</p>
222	<p>That we in the M.E. community want to be heard, we want to be believed, and we want to be whole again. Please help us.</p>
223	<p>Primary Care Physicans need to have a lot more training on how to deal with it!!!</p>
224	<p>This is a physical disease. It is NOT a psychological one!</p>
225	<p>It is my hope that this panel will embrace the struggles of this large patient population who struggle daily with very physical disabilities that prevent us from not only the joys of living, but from the fundamental events that bring us joy in life. I want to work and play as I did prior to being sick. We need you to create a valid and reliable diagnostic criteria that can identify THIS illness, and eliminates those with primary psychiatric illness, other treatable diseases, and idiopathic fatigue. We can no longer have those patients polluting the research necessary to find treatment and/or cure for our REAL physiological disease. Please throw out any and all studies that used the Oxford and/or Fukuda definitions.</p>

226	The contrast between those first two dr.'s I saw just stunned me: one completely ignorant, never heard of CFS, one completely on top of things and able to steer me toward things that actively and quickly improved my life. Without the diagnosing dr. I would probably have ended up on disability, because I was so minimally functional at the time.
227	There is very little to help with this condition and still run into many Dr. Who do not believe Cfs exists
228	THAT THIS DISEASE IS NO WAY RELATED TO PSYCHOLOGICAL ONSET!!
229	Over 50% of my daily life I face insurmountable crushing fatigue and pain! I feel like every cell in my body is dying and I don't know how I will make it to the next day - BELIEVE AND HELP US-change the name to a medical identity dr sand indri duals will take seriously. Veterinarians treat animals with more respect.