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There are many people in this room today that are true hero's and I am honored to be in your presence. My name is Rik Carlson and I live in Burlington VT with my wife Barbara. We have a son who is a United States Marine currently serving his second tour of duty in Iraq.

No talk about Chronic Fatigue Syndrome is complete without the personal story, but I am not going to dwell on mine and that's because I don't think I have to try to convince you that this is a very real, debilitating and long term disease. At least I hope not. I have to assume you've heard or read the stories. I have to assume that you're familiar with the morbidity studies that show that CFIDS patients experience a level of suffering that exceeds that of some heart attack victims, patients with rheumatoid arthritis, cancer and even those in their final days of Aids. I have to assume that you understand that the word "fatigue" doesn't even come close to explaining the degree of debility that goes on for weeks, months, years and decades. For what became years on end, I was bedridden, and unable to move except for when I had to pee, the great equalizer. My body was made of lead and my brain, sludge. My visit here today and my focus on these 15 minutes, is the most substantial activity I've taken on my own in eleven years. But let me make one thing perfectly clear, and that is that I'm not here to whine. No one wants to talk about being sick and I can't imagine anyone who wants to listen to someone talk about being sick.

I am President of the VT CFIDS Association, almost ten years now, and I have been at the receiving end of an 800 number. Patients form support groups when conventional medicine fails. There's no where else to turn, but to find others. No one wants to do this and to even imagine a group of CFIDS patients as "activists" is absurd. I have taken hundreds of calls and over and over again I hear the same thing. "Do you know a good doctor? My doctor doesn't believe this to be real." To the one, these callers are desperate and confused. I am charged with the duty to speak for them here today and for that I am humbled and burdened with responsibility and in just a minute I will share some of their words.

You can't imagine what it's like to be so ill that you can barely stand, filling out a new-patient form in a doctor's office, and when you get to the part about Chronic Fatigue Syndrome, watching the eyes roll at the other end. When that scene is repeated to exhaustion, there becomes no where to go, no one to turn to, no one who understands. And they find me. I refer them to our “Buddy List” and our newsletters on the web page which is the most I can do. I talk.

Many doctors revert to a psychiatric profile first, encouraged by the awkward CDC definition and CFIDS here has been mostly treated as illegitimate. When that comes from a physician, and then from a series of physicians, it leads to broken marriages, bankruptcy, and public housing. I’ve seen it, and I’ve heard it, over and over. And then people just disappear. Then, of course, because our estimated patient population is 70% women, it’s discarded as a woman’s thing. They do this. The way many women are treated by the medical community is abhorrent. There it is. Nobody ever said it would be easy and nobody ever said it would be fair.

Certainly our primary issue is seeking an approach to a cure for this complex and multi -systemic disorder, but before we can do that, we have to address the repeated misunderstandings and misdiagnoses that destroy so many lives and families across our land. When CFIDS is treated as a psychiatric disorder and when the viral illness is ignored or denied, every time and I mean every time, no exceptions, the patient worsens. There is not a higher percentage of psychiatric disorders among the CFIDS population before they got sick than there is the general population. These problems arise when they drag themselves into a doctors office only to be given the boot and told “It’s all in your head.” We can deal with being sick, millions do, just don’t tell us it’s not real. Don’t tell us we’re lying. Don’t paint us into a corner.

You’re not sick if it’s only a syndrome. It’s not officially a disease, and it’s been given that foolish, foolish name. Chronic means you’re a whiner, fatigue means you’re tired and a syndrome means it’s not real. I hate that name because so many of the traditional Vermont medical community have determined that it’s an unwarranted claim, making the search for a treating physician in my neighborhood, fruitless. Insurance companies are having a field day. From the first day that there is any indication of the need for a psychiatric profile, the patient has lost. A doctor is going to believe another doctor before he believes the patient and then these distorted reports build on each other. They cast suspicion of secondary gain. They judge what they don’t know. As a result, the road to recovery is booby-trapped with red-flags and road blocks and terribly ill people are made far worse and that stinks.

Let me give you some examples.

I was given an Independent Medical Exam by the insurance company’s physician, and I arrived with a three year history of debility, supporting letters from 2 M.D.’s, an extensive history of sophisticated blood work from the naturopath and depression test results that showed me overflowing with self-worth. When we first met, he tossed all the paperwork aside and said, “Margin of error” and then he said, “Let me make something clear, I’m a hit man for the insurance company.” Barbara and I were dumbfounded. I couldn’t function without Barbara.

In his report, he said.

"The record does not document adequate trials of antidepressant therapy in terms of either dose or duration. (His) alternative medicines have not been shown to provide any benefit. (his) belief system constitutes a barrier to attempts at rehabilitation. I think that he should be evaluated by a competent psychiatrist and that appropriate psychotherapy and drug therapy for diagnoses be instituted."

To defend myself, I went to a psychiatrist that I chose and he countered:

"It may be that (he) has a tendency towards organizing in an aggressive manner and in this instance, developing a recovery plan for himself and a support group for the community. This I believe is a strength, rather than a self-defeating pattern, nor is it a pattern that is destructive in any way that I can ascertain. I do not see him as presently in need of a psychiatrist, but encouraged him to continue his significant efforts at recovery."

And I saved myself.

But the next IME was a cold call, in that the doctor had not reviewed any material before the 90 minute mostly interrupted interview. His report was grossly inaccurate and actual fabrication. It was boiler-plate. He did everything the insurance company asked him to do, with total disregard to either my testimony or my medical records.

We were forced to settle and did.

After the fact, and in my notes, I wrote about the insurance company:

I said:

This latest round paints a picture of business in America and shows how this disease is handled in particular. It's pretty simple. They hired a doctor to do their bidding and he did. They decided to cheat, not only as a deliberate course of action, but it was their first choice. If they treat me this way, I'll bet I'm not the only one.

Then I asked:

What does this malfeasance portend for the those who have been trashed by CFIDS, ravaged by the disease and forced into hermitage? It's not pretty and true optimism hovers in the distance, veiled by fog. That's the facts. The overwhelming power of the medical / pharmaceutical / insurance cartel, stomps and smothers, crashes and trashes, dominates and destroys. For those who struggle to raise an arm to wash a dish or to feed a child, turning the tides against this steamroller of greed and fraud is an unlikely event.

There is a doctor in Vermont currently fully debilitated by CFIDS.
These are his words:

"I just finished your book. Since I'm part of the Medical-Industrial Complex I was prepared to be more offended. I wasn't. Probably because my experiences with Drs. and insurance companies has been identical to yours. I am embarrassed to be a part of it at the same time I'm being victimized by it. When I revealed to my colleagues that I had CFS it was like telling some of them that I had seen a UFO. I immediately lost stature and respect. Many of these colleagues know very little about CFS and even less about caring for someone with it. These are the same doctors that pride themselves on their breadth and depth of knowledge of cancer, heart disease and diabetes. It's as if by remaining ignorant about this illness they are somehow preserving the dignified objectivity of the science of medicine by not giving in to the make believe symptoms of these difficult patients. Perhaps I knew that would happen and that's why I did not tell anyone for 6 years and just put up with the pain and limitations. I remember going out to San Diego to see an "expert" on CFS, Dr. Jay Goldstein. I sat in his waiting room for 8 hours a day with other patients while we were waiting our turns to try different drugs. We all talked, of course. When they found out that I was an MD, they crucified me. I tried to defend myself and point out that one is not guilty by association but I think it would be easier to defend a terrorist. I'm still in bed 18 hours per day and have 3 young children and a wife who gets stuck with everything who needs support. I am a 52 year old Family Practice M.D. who practiced for 17 years before I became disabled by CFS. I am well aware of the ignorance that my colleagues have regarding this illness. When I went through my 7 years of medical training at UVM in '80's, there was nothing even mentioned about CFS, except for a few derogatory remarks about "yuppie flu". No one knew anything about it and fewer cared. Even in the most prominent Medicine (Harrison's) and Family Practice (Rachel) textbooks of the mid '90's, 2000 plus page tomes, there is not even a reference to CFS in the index.

Only the pediatrics text(Nelson's) included a 2 page write-up. That means that most MD's practicing now were never formally educated on a devastating illness that affects up to one percent of the population. In addition to simply lacking the knowledge-base required to care for these patients, an even more sinister result occurs. There is a certain arrogance that develops in even the most conscientious medical school graduate who has just spent 7 years learning about illnesses, often 80 to 100 hours a week, who just doesn't believe that he could have missed studying an illness that was really that important. What results is a Dr. who just doesn't believe his patient or thinks his symptoms are the product of an over worked imagination. This causes unnecessary pain and suffering and a poor delivery of health care for these patients. Chronic Fatigue Syndrome patients are already undesirable in the eyes of health care providers. Nobody really wants us. We have lots of complaints about symptoms that don't make sense. We take a lot of valuable time. We require lots of paper work for disability, social security and referral forms. We don't get better. We appear normal yet can't go to work. I once heard a lecturer talk about the current state of understanding (lack of understanding) of CFS at Fletcher Allen Health Care grand rounds (in Burlington). He finished his talk by saying, "Don't send your patients to me!"

My friend Rachel tells me:

"I just want to impress on the powers-that-be that these autoimmune conditions, including MS and Parkinson's, are increasing to epidemic proportions in this country and that because there appears to be no easy fix, i.e., no drugs they can prescribe, their existence is being either ignored or discounted completely by the allopathic community.

My friend Cecelia says:

What I always wish for is that research dollars and efforts go into finding effective treatments for the symptoms of CFIDS instead of all this fruitless needle-in-a-haystack searching for The Original Cause, if anything as simple as that even exists. Instead of pursuing the question, “What causes it?”, I wish they were pursuing the questions, “What is it? and How best can it be treated?”

In Vermont we are about to pass the tiniest little piece of legislation designed to educate primary care physicians about CFIDS, using the Consensus Manual developed in New Jersey. It’s hard to imagine that we have to use the State Legislature to get the attention of the local medical community.

The Consensus Manual says:

“That physicians are reluctant to assume care of such challenging, distraught patients is understandable, yet, we know that competent management of these patients can be productive and rewarding for patient and physician alike. The Consensus Manual for Primary Care Physicians will facilitate and enhance the care of patients with CFIDS. The stigma associated with having CFIDS and also with caring for patients with CFIDS defies explanation. This manual starts to de stigmatize the primary care and outlines the range of therapies across medical disciplines that can improve the lives of these patients. The 13 chapters are intended so that the physician can appreciate the pathophysiology, differential diagnosis, and therapeutic opportunities. The extensive bibliography will also allow caregivers to further research CFIDS.”

In Conclusion:

Because of the repeated misdiagnoses, educating primary care physicians is imperative and this manual will give us a legitimate starting point. Furthermore, patients will be able to bring this manual to their caregiver and by focusing on the chapters that are relevant to their condition, experience a degree of empowerment which has been previously unthinkable.

Legitimacy and empowerment.

Imagine.

Robert Kennedy once said that the longest journey begins with a single step.
Let us hope, not necessarily for ourselves, but for those who follow in our wake, that today is the day we took that step.

Thank you.