

CFIDS awareness is the first step.

Grass roots organizations are the fundamental tool.

Here in Vermont we've been through the legislative process twice and last year were successful in getting an appropriation to train primary care physicians passed as part of the general budget and assigned to the Department of Health. They have since posted a resource page on their web site for Chronic Fatigue Syndrome. Their recognition and support is outstanding, and while we are appreciative, our root problem goes much deeper. To implement necessary change we need to address the medical bias.

There is a physician in Vermont with CFIDS, and he wrote the following:

"Rik, 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 The University of Vermont in the '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 and Family Practice 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 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, Vermont). He finished his talk by saying, "Don't send your patients to me!"

These words are from a doctor in Vermont and give us a glimpse of our other battle as we adjust to this hideous disease, and yes, I'll always call it a disease. I am sorry for how ill he is, yet grateful at the same time. We can deal with being sick, millions do, just don't tell us it's not real. We need CFIDS taught in medical school's, we need CFIDS brought to the hospital's in educational training programs and we need the respect and attention deserving of a debilitating long term disease. People with CFIDS in Vermont are dismissed. Many struggle to find understanding and support within the traditional medical community and repeatedly come up empty. Doctor's need to be taught. Recovery programs need to be developed. I hear stories of misdiagnoses and outright ridicule with regularity, events that fracture spirits and destroy families, and it breaks my heart. When we change that, we'll start to understand success.

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www.monkeyswithwings.com/vtcfids.html