

THE HEART OF THE MATTER: CFS & CARDIAC ISSUES

PART 1A

(current as of 04/02/05)

by [Carol Sieverling](#)



PREFACE

The following is my interpretation of transcripts and tapes of conversations that took place between Dr. Paul Cheney and two different patients (including myself) during September and November of 2004. Any treatments mentioned are highly individualized and should not be generalized to all CFS patients. Dr. Cheney's treatment approach is rapidly evolving as new information and insights unfold.

Certain broad concepts central to Dr. Cheney's understanding of this illness are generally much more constant (such as decreased cardiac output, HPA axis involvement, the role of glutathione, etc.). It's essential to note that a set "Cheney protocol" applicable to most patients does not exist, given that his treatment protocol is extremely individualized and constantly evolving.

Quotes are from Dr. Cheney or, where noted, from a patient. Statements in brackets were added by me to provide clarification or context. All other comments are statements from Dr. Cheney that have been slightly paraphrased, but, to the best of my knowledge, maintain his original meaning.

The focus of this article and much of Dr. Cheney's current work is based on the following publication: "*Abnormal Impedance Cardiography Predicts Symptom Severity in Chronic Fatigue Syndrome.*" Peckerman, et al; *The American Journal of the Medical Sciences.* 2003; 326(2):55-60.

A synopsis of this article and an interview with Dr. Peckerman was published in the Fall 2003 issue of *The CFS Research Review* by the CFIDS Association of America [cfids.org ==> archives ==> Research Review ==> 2003 ==> Fall (www.cfids.org/archives/2003rr/2003-rr2-article01.asp)]. The article can be found online at: www.cfids-cab.org/cfs-inform/Coicfs/peckerman.etal.03.pdf. You can also [Google](#) "Peckerman" and find another article on WebMD and elsewhere.

PECKERMAN'S ARTICLE

Dr. Cheney stated, "This is the best, most important publication in 20 years." [regarding CFS.] "This was published the year I left practice, 2003. The senior author is Benjamin Natelson, and the principal author is Arnold Peckerman. What this very impressive article says is that, without exception, every disabled CFS patient is in heart failure."

CFS COMPENSATES FOR IDIOPATHIC CARDIOMYOPATHY

"Let me first of all define heart failure. There are two kinds of heart failure. There's the kind that any cardiologist can diagnose in about a minute. That you do NOT have. Which is why cardiologists missed this. What you have is Compensated Idiopathic Cardiomyopathy." [Idiopathic: cause unknown; Cardiomyopathy: structural or functional disease of heart

[CONTINUE TO PART 1B](#)

[GO TO PART 2A](#)

[GO TO PART 2B](#)

[BACK TO CHENEY TOPICS](#)

[USEFUL DEFINITIONS](#)

MedlinePlus[®]
Trusted Health Information for You

Search [MedlinePlus](#):

muscle] "And your primary means of compensation—now this is the big twist—are you ready? Have you got your seat belt on? The primary methodology for compensation for this disorder is in fact CFS itself."

Patient responds: "I see. So, this is the body's way of saving us from dying of cardiomyopathy."

Dr. Cheney: Yes. From dying of cardiomyopathy. What is ironic about this, is that I had Idiopathic Cardiomyopathy (ICM). "But I never had CFIDS."

In the medical literature, at least 35% of those with a diagnosis of ICM will die within 5 years unless they receive a transplant. [That was Dr. Cheney's experience—a heart transplant.] I've been following CFS patients for 20 years and never seen one case of CFIDS go on to transplant or ever even heard of one going on to transplant.

Now if your diagnosis is ICM, why aren't you dead? Why hasn't one patient in 20 years needed a transplant? It's because you had CFIDS, and I didn't. "I even suspect the mechanism, and that has been published too."

"The disease [CFS] itself is protecting you from a deeper problem that has been totally missed, including by me. I missed it, too. Because it's so well-hidden."

THE RESEARCH

[Let's take a closer look at the study, beginning with the researchers.] This group is at the New Jersey Medical Center, a major medical school. Dr. Natelson, a neurologist and professor of neurology, is a very good researcher; quite a bright and accomplished scientist. Dr. Peckerman, the lead author, is a cardiac physiologist or cardiopulmonary physiologist. About five years ago, the NJ Medical Center received a multi-million dollar grant from the NIH (National Institutes of Health). To get the grant, Dr. Natelson wrote a proposal to find a physiological parameter that could be objectively measured and would correlate with disability.

FIND AN ACCURATE MEASURE OF DISABILITY

Their job was not to find the etiology, pathophysiology, or treatment for this disorder. "Their job was to find a measurable number that could accurately demarcate those with [CFS] that are disabled vs. those that are not, so that we could resolve some of the disability adjudication problems [that affect so many CFS patients], where people don't believe you have a problem and it's hard for you to get objective proof that will satisfy critics as to your disability."

As clinicians, we know that not everyone with CFIDS is disabled; yet, there are many people with CFIDS that are disabled. "We know these extremes exist. What we know less about is where to draw the line, because that's a harder thing to do. And the government is just nuts about this, because some circles feel that too many people are getting access to SSDI that shouldn't, and on the other side there are people who feel that there are some who aren't getting it who deserve it. We need to resolve this in a compassionate and fair manner."

"That was [Natelson's] proposal and it was funded, fully. [The NJMC was named a "CFS Cooperative Research Center.] And you can guess why. The government has a vested interest in knowing we're not raiding the treasury unfairly, but they don't want to be accused of knocking people off [SSDI] who later turn out to be disabled."

A "Q" PROBLEM

So the NJ team looked at many things, and they found something: a "Q" problem. "Q" stands for cardiac output in liters per minute. "Q" in CFIDS patients correlated—with great precision—with the level of disability as judged by validated clinical questionnaires that asked about activities of daily living. What can you do (bathe, dress, cook, etc.) and how hard is it (no problem, little bit of a problem, moderate problem, lot of problem)?

"Question after question after question. Then they have a score, and those with the highest score were the most disabled, and those with the lowest score were the least disabled. And then they gave the same questionnaire to normal sedentary controls."

THE TEST: IMPEDANCE CARDIOGRAPHY

"Then they measured Q, using impedance cardiography. This technology allows one to accurately measure the cardiac output using the idea that the resistance a current has, passed through your chest, is a function of the blood flow through it. It's actually inversely proportional. The greater the blood flow, the lower the impedance. The less the blood flow, the greater the impedance [resistance]. Because blood is water, water passes current better. It's a simple idea. Put an electrode on your front and your back, and pass the current through. If it goes quickly through, there's a lot of blood going through the chest, and if there's resistance, there's less."

They used a thoracic algorithm, developed at the University of Minnesota some 30 years ago. This algorithm allows many factors to be part of determining Q, including chest and body size. Using it, you can compare the "Q" of big people to the "Q" of small people and still be comparing apples to apples.

The University of Minnesota algorithm has been approved by the FDA as a valid measurement of Q. The point is that Medicare pays for this. It's been clinically validated by a government agency and is not considered experimental or research—as long as you use this algorithm. That's important, because whenever this test result filters back to a cardiologist, the first thing many say is, well, but, you know, that's not accurate. And indeed, it may not be accurate, depending on the machine and the algorithm it uses.

"By the way, there's one other important detail. Unlike all other measures of cardiac output, this is the only one that can be done in the upright position. Which, as you'll find out in a second, was a critical step. Absolutely critical. All other cardiac output measurements are done in the supine position—laying down." [To detect the heart problem in CFS patients, it has to be done both lying down and standing up. If you can manage the whole test, it's preferred to take readings in four positions on a tilt table.]

Now, do CFIDS patients prefer to stand up or lie down? Of course, they prefer to lie down. Do you know why? "Do you know what your cardiac output does when you stand up? It drops 30%. In all humans, without exception. So very critical to this technology is that it's the only one that could be done upright [again, four positions on the tilt table are best; standing up and laying down at a minimum]. And what they found is absolutely astonishing, truly astonishing. When [disabled CFIDS patients] stand up, [they're] on the edge of organ failure due to low cardiac output."

The study involved 38 CFIDS patients and 27 matched sedentary controls—a reasonable sample to get convincing statistics. The CFIDS patients were subdivided into 18 severe cases, and 20 that were less severe. When they looked at the test result statistics, disability correlated with Q!

P VALUE: "Q" CORRELATES WITH DEGREE OF DISABILITY

"And this is the relevant number. The correlation coefficient of .46 with P value of 0.0002 suggests that the disability level of those that were disabled was exactly proportional to the severity of their "Q" defect—without exception, and with scientific precision by virtue of their most disabling symptom, post-exertional fatigue. **WOW. WOW!**"

[Dr. Cheney circles the P value on the copy of the article with great excitement. A little research on Google revealed that a P value less than 0.05 means there's a 5% likelihood that the association between the factor and the outcome is due to chance. A P value of 0.01 means there's a 1% likelihood that the association is due to coincidence. A P value of 0.03 means there's a 3% likelihood that the association is due to chance. So, the P value of 0.0002 in this study means there are only 2 chances in 10,000 that the factor and outcome are due to coincidence! The factor being severity of CFS (disability) and the outcome being lower cardiac output ("Q" problem).]

Statin drugs are given to people with high cholesterol due to only a $P < 0.05$. [They're given—based on a much weaker P value.]

Dr. Cheney continued, "And I'll tell you, it's profound because no other paper that I know of has been published in 20 years that can give a number which so precisely correlates with the level of disability. There's nothing out there. Believe me—nothing exists. Not RNase L, not immune-activation levels, not SED rates. NOTHING has this sort of correlation with

disability that I know of."

POST-EXERTIONAL FATIGUE INDICATES A "Q" PROBLEM

Next, the NJ team looked to see if there were any symptoms that were 100% observable in the group of disabled cases, but not in the others. They found that there was only one symptom (among the loooong list of CFIDS symptoms) that was seen in 100% of the patients with the Q problem. Only one. Post-exertional fatigue. That is, when you push yourself physically, you get worse.

What distinguishes CFIDS from FM? Post-exertional fatigue. Patients who have FM, but not CFIDS, can exercise—it helps them. FM patients do not have a Q problem. MCS patients do not have a Q problem. [Unless they also have CFIDS.] They do have other issues that overlap with CFIDS. Martin Pall's conceptual framework allows us to lump these people all together (FM, MCS, GWS, CFIDS). However, Q is what separates them. CFIDS patients have a big Q problem, and post-exertional fatigue is the one symptom that correlates with Q.

Post-exertional fatigue is the number one symptom reported by people with ICM. Among the disabled CFS patients [the severe group], 80% had muscle pain, 75% had joint pain, 72% memory & concentration problems, 70% unrefreshing sleep, 62% generalized weakness, 60% headaches, 60% lymph node swelling, 68% fever and chills, and, 50% had sore throat. Though some symptoms were certainly more common among the disabled patients, the symptoms varied—with the exception of post-exertional fatigue. They all had that.

This suggests that it is not so much the symptoms that are disabling. Rather, "the symptoms are reflecting an interaction (or a nexus) between Q, and how you compensate for Q. Depending on the nature of the compensation, which is individually distinct, you will get an array of symptoms that is individually determined. Just like this: ten patients with MS will not have identical symptoms. Any more than ten AIDS patients, or ten cancer patients, or ten of anything." Why? Because the disease process—which they all have—will manifest differently in each person. The specific symptoms will arise out of factors unique to each person; those factors will determine how the disease plays out in each.

"Within the non-disabled [CFS] group they saw pretty much the same thing—it's just that the percentages were a lot lower. For example, fever and chills were found in only 5% of the non-disabled. The highest percent was post-exertional fatigue seen in 60%. But 40% of the CFIDS patients who were not disabled did not have post-exertional fatigue, but did have CFIDS."

"The reason for that is, of course, if you look at the original case definition, post-exertional fatigue—that is exercise worsens the syndrome, effort-related exacerbation, push-crash phenomenon—is not a major criteria, it's one of the eight minor criteria. It's possible not to have that and still meet the case definition. But all disabled patients have that, and 60% of non-disabled have that." [It's possible to not even have post-exertional fatigue and still have CFS. However, all disabled CFS patients have post-exertional fatigue, as do 60% of the non-disabled.]

"More importantly, all disabled CFIDS patients, all of whom have post-exertional fatigue, have low "Q" and are in heart failure."

[CONTINUE TO PART 1 B](#)


[GO TO PART 2A](#)

[GO TO PART 2B](#)

[BACK TO TOP OF PAGE](#)

[BACK TO MAIN RESEARCH PAGE](#)

[BACK TO DR. CHENEY TOPICS](#)

Search: Books	Enter keywords...
	enter search term <input type="button" value="Search"/>

Easy search for the Amazon.com site. Check out their books and music.



[BACK TO TOP OF PAGE](#)

[Home](#) • [Meeting Information](#) • [Resources](#) • [Medical Information](#) • [Newsletter Archives](#) • [Who Are We?](#) • [Board of Directors & Staff Information](#) • [Help & Email](#) • [Legal Disclaimer](#) • [Fair Use Notice](#) • Copyright © 2005 CFS/FM Support Group of DFW. All rights reserved.
• Update: 04/10/05