My CFSAC Testimony

Kati Debelic

This will be my third testimony. Comes October will mark the first year anniversary of the publication of the Science paper. What has changed?

On the number of studies presented, a few controversial studies trickled in, than 1 that rocked the world of XMRV. Unfortunately the CDC slowed the PNAS publication despite them having found no XMRV at all.

I am afraid that not too much has changed since the last meeting, other than the trickling of the XMRV studies, and the first XMRV Workshop, which was strongly prostate related and left behind Judy Mikovits as a keynote speaker.

Why are the recommendations to the Secretary of Health not being followed? Why can't we seem to get any answers from up high? Why is it that we need to repeat the same old thing over and over and over? Do the governments really want to help us? Is the government really worried about XMRV?

Since I have previously talked about my own experience, I will go on to my recommendations, for what it's worth.

1. **Change the name**

The name CFS is harmful to patients. It is a social construct aimed at minimizing the severity of the disease. It is demeaning and discriminatory. I have experienced discrimination because doctors don't know about the disease and just attempt to make sense of the name, and figure this must not be important.

2. **Investigate the CDC**

Despite the recommendations of Dr Leonard Jason that the CDC criteria is not specific for CFS patients, the CDC continues to use the Wichita cohort in their studies

and publishing papers on their website about history of sexual abuse as a child in CFS patients. Garbage! In which way is it going to change the status and heath of the patients even if these studies are valid?

There is decades long history of lying, hiding facts, misuse of government money (which has been recognized in the mid 1990's), and labelling our community of patients as hysterical and making fun of us.

This needs to stop. (and it hasn't stopped). We need an agency that will recognize us as being sick and has being denied care for decades. Who can look after our interests as a group of sick patients?

3. **Remove the CDC website from the web**

The CDC is propagating the wrong information to all of our doctors and scientists that don't know any better. First page reads that CFS has a strong link with having had sexual abuse as a child. They also promote their study which didn't find any XMRV neither in their poorly defined cohort or controls.

On another page, the CDC is discouraging doctors to test CFS patients for viral testing immunological tests or tilt table tests, SPECT scans, unless it's to rule out other diseases. These are the tests that Dr Cheney, Peterson, Klimas, to name a few use in their practice to diagnose and to treat CFS.

On their treatment page, cognitive behavioral therapy and graduated exercise therapy are listed as what helps the most. Professional counselling, support groups and antidepressants are also listed. This information is wrong and supports the idea that the CDC thinks of CFS patients as having a psychiatric disorder.

The worst part of it all is this information goes to all the doctors of the world and suddenly there is no access to care at all.

On a personal note, when I got sicker last year and didn't know what was going on, the best information I got was from my peers, who recommended me many things to prevent complications, a crash or worsening of the disease.

The patients have a lot of knowledge and experience (they had to figure it out themselves) and I feel that this should be used into teaching our doctors about what CFS is. (Not all of them would listen, of course). A lot of us get applauded for our scientific knowledge. Some of the patients are nurses, doctors, scientists and we share and talk about the latest (and some of the oldest) papers and try to make sense of it all, because there is only a small amount of scientists doing the work, and because all the

research money that goes to the CDC is used for their depressed cohort, for another psychiatric study.

In conclusion please remove the CDC website from the web and provide up to date information to the doctors that have to deal with CFS patients.

4. **Fund research grants for WPI and other serious scientists that genuinly want to help the patients with CFS get better.**

The WPI has survived with private money, from the Whittemore family supporting and from private donors giving a part of their social security funds to support Dr Mikovits to continue her most excellent work. Dr Mikovits needs to be viewed as the authority in terms of XMRV and how it relates to CFS and other neuro-immune diseases. She (and her group) needs to be recognized and granted some most needed funds for her to pursue her researches.

5. **In regards to funding...**

NIH is funding **billions** to the HIV aids program. CFS got a mere 4 millions. In the light of finding key information like how does the virus is transmitted, for instance, it is critical that money needs to be allocated NOW. I would go as far as suggesting to fund XMRV in the same way that the NIH is funding the HIV program.

In conclusion:

Patients are watching, from their beds or from their couches. Patients also watch through windows and hoping that one day they will be able to take a holiday, return to their old job or start a new job. Unfortunately some have tried only to crash and return to their bed sicker than before. **It is time to pass to action, CFSAC, and put pressure on our secretary Mrs Sebelius to DO something.**

Thank you,

Kati Debelic.