

## **Testimony – Angie Croix**

### **Letter to CFSAC for the May 10, 2010 meeting:**

Dear CFSAC and Wanda,

First I would like to Thank YOU personally for existing (CFSAC) and Wanda for ALL that you have done to help us ... it is REALLY appreciated. Words can NOT really express HOW Grateful we all are for your work and efforts on our behalf.

AND HOW especially last Oct's meeting was SO IMPORTANT and brought us all HOPE and the WILL TO LIVE and sense of COMMUNITY back to many of us.. that have been living like a prisoner in the 4 walls of our bedrooms in solitary confinement.

Many Many of us were all on Facebook at the same time watching the webcast and for the folks that have been made poor by this illness that can only afford dialup (AND there ARE Many !!! ) we had to attempt to give them like a sports caster~ a blow by blow accounting of what was happening and being said..

However, because of the TERRIBLE QUALITY of "Real Player" Many of us have started calling it "Real NOT Player" and we WISH you could use something LIVE like either USTREAM or VIMEO ~ AND~ eventually contact Google and GET PERMISSION to upload the "Entire thing" to "you tube" which is SOOOO much easier to watch and we can comments on it also... I mean "really" if the White House has a "youtube site" WHY can't the HHS give the CFSAC one.? THEY ARE FREE !!! This IS not only a USA but a WORLD issue and we have MANY folks trying to watch from ALL OVER THE WORLD....and for the poor dialup folks PLEASE see if you can find an "audiocast" that will work for Dialup... I for one can speak to the issue of HOW much of a financial drain this illness has had on my life.

I have not written "before" because the PUBLICITY about ME/CFS is SO POOR I had NOT even HEARD of you and didn't KNOW about any Support Groups and had been suffering a dwindling life of this illness for 23 years now... ONLY to learn about many places after your webcast last Oct and the Science

publication of the WPI XMRV study. ... I find this history especially disgraceful because I, like many others I am finding out,

WERE Healthcare workers when we got sick and were treated with the attitude of "Kick them when they are down" by the hospital's lawyers so I could not even get any disability.

So here I sit 23 years later, after working in the hospital for 17 years, being shunned and stigmatized by ALL of my Friends and Family because the HHS has NOT done the appropriate amount of PR to make the WORLD take this disease SERIOUSLY...

I have no income, no medical insurance, am alone with NO help, am NOT old enough for Medicare yet, have had to cut back on OH SO Many things in my life JUST to s-t-r-e-t-c-h- money for the Basics of FOOD and Utilities and property tax and car insurance and a HUGE Amount of Supplements that I HOPE are serving to even keep me from deteriorating more until a cure can be found...

But, until the WPI we had NO HOPE and even SO ~ I REFUSED to Surrender or get depressed I was simply FRUSTRATED as I had already lived thru the 80's and had 5 close friends die from AIDS..and I got sick during that period. Is THIS the kind of treatment that the BEST Country in the World should be providing to their citizens that WANT to work again and Have a life..?

My body maybe sick.. and I am unable to even GO to any "job fairs" cuz I could ONLY do things from home in bed on my laptop... when I am NOT asleep from a Relapse...so keeping ANY kind of schedule is EXTREMELY HARD and for 2 years I ONLY had Dr's appts "By Phone" and it took much arm twisting to even get those which were eventually cut off by one of the Dr's....

Many of us ARE Slipping thru the cracks and this MUST STOP NOW.

**I respectfully request that the CFSAC:**

**1.~ Meet 4 times a year so we can have more timely info and input allowed AND that each meeting be 2 days in length to allow adequate time for Quality Reports from Researchers and public input and feedback.**

Waiting 6 months in bed for a one day meeting that cuts public comment time and does NOT even allow official Updates on previous reports or feedback just does NOT cut it.

**2.~ It Must be ACKNOWLEDGED that Many of us DO have PTSD that**

**"has been caused by the Government's lack of REQUIRING the needed Research and PR for us, for it to be taught in Medical schools and thus NO Dr's know HOW to treat us and ONLY say we are depressed" ..NOT TRUE...not even Close..**

Until THEY get this illness...THEN a "Light Bulb" goes on.....

**3.- I respectfully REQUEST THAT We ALL Deserve "IMMEDIATE Health Care" even for the basics of life and our PTSD.**

My last BIG Relapse was caused by a VERY Painful Medical Procedure caused last Dec that made me SCREAM LOUDLY at the time.. That was my First "in office appt" in over 2 years.. and I get a Relapse from it.. ?? HELP US PLEASE.. Is anybody listening ??? Who is tying your hands ??? We are helping everyone "all over the world " but NOT helping our own Citizens ???

Because I and the Dr's didn't know what I had long ago they would NOT write a letter for me to get disability and now that it is longer than 10 years since I have worked they tell me that even IF I get a letter ...it has been TOO Long and I am NOT Eligible for disability.

EXCUSE ME (sarcasm) for "Purposely NOT trying to be a drain on our society" as I was raised in a family where we took care of each other and my mother WAS helping me until she -passed away...10 years ago.. I relapsed again after helping take her and my step-father thru Hospice at home..

Now ~ I am going downhill... " I REALLY need the Help" and My Government where I was born tells me I am NOT eligible even if my Dr. says I am Disabled?

For goodness sakes.... I even have a Disabled Parking Placard because of the Cardiac OI and POTS issues that I am now having.. WHY can my CAR get a "Disabled Placard," BUT I CAN NOT GET Disability ????? Something is VERY WRONG with this picture... aka Denial by the HHS/NIH/CDC ???

There IS growing public disenchantment with other emerging health concerns that have been mishandled. That erodes the CDC/NIH's support base. For the CDC/NIH to turn a blind eye at this retroviral juncture in front of the public may be the "in" that can knock down their obstructionism.

**4.- I request that replacements for outgoing committee members be filled in a timely fashion and NOT at last minute....**

This type of action gives them NO time to get caught up to date with not only the history but all that is happening currently... ..and is just plain Disrespectful to THEM and US.  
Timing and Actions and Intentions DO count....and will be noted by ALL.

**5. ~ I respectfully request that the agendas be posted in a timely fashion so that the public can submit testimony with a little more time to respond...**

Hello? ..we are SICK and sleeping a LOT, many times  
12-18 hours a day and a month FLIES by..literally... paying bills or walking to the mailbox or kitchen is a HARD CHALLENGE at this point.

**6. ~ Please make video live-streaming of the meetings be embedded in the charter along with a dial-up audiocast.**

**7.~ I ask that the "status" of the CFSAC's recommendations be posted in a timely manner and let the HHS KNOW that WE WANT to KNOW WHY they have been ignoring us year after year.? This MUST STOP NOW.**

**8. ~ I "Sincerely Request" that comments by the public be allowed to remain 5 min segments PERMANENTLY.... we have been Silenced for TOO Long.**

**9. ~ I also Please am asking that there BE FOLLOW UP about XMRV by WPI or other Dr's or Researchers that testified at "ANY immediately Previous meeting" AND on EVERY Research that has been done....**

YOU are the ones WE NEED to HEAR this INFO FROM... PLEASE  
HOW can YOU NOT expect US to want to HEAR what is being done???  
MANY countries are NOW asking ME/CFS patients NOT to donate blood..  
..well then.. that MUST mean that "it is NOT ALL in our head's" is it?

Especially after the stunt and intentional fouling invalidation of the research material of an XMRV test by the experimental virologist Dr. Frank van Kuppeveld from UMC St. Radboud and internist doctor Jos van der Meer didn't find a trace of XMRV in the frozen blood of 32 Dutch CFS patients, taken in 1991 and 1992. Also, in the blood of 43 healthy control subjects they didn't find the retrovirus. They published their findings online in the British Medical Journal (3), late January. Annette Whittemore points out that the WPI, at the request of van Kuppeveld, has tested some blood samples from the Dutch research cohort before the study at

UMC St. Radboud was completed. The WPI found traces of XMRV in those blood samples. Whittemore claims she possesses over email correspondence, which proves that van Kuppeveld was informed about these WPI research results before he published his negative study. However, in his scientific publication, no word is spoken about the co-operation with WPI. The redaction at Ortho has requested a copy of the email correspondence with UMC St. Radboud from Annette Whittemore, but this request has not (yet) been honoured. Why did the UMC St. Radboud researchers keep silent about all of this in and around their research publication in the British Medical Journal?

**10. ~ I desperately request that the CFSAC requisition physical therapists that MUST give the CFSAC a list of exercises that those that are in the early stages of being bedbound can DO to PREVENT muscle de-conditioning and thus experience MORE loss of quality of life and then becoming MORE disabled... (isometric OR other) and then Make SURE ALL DR"s HAVE this INFO as they currently DO NOT and will not even advise if you ask.**

If you think they don't know anything about nutrition, wait until you find out HOW LITTLE they know about conditioning for people that are chronically ill and bedbound.

**11.~ I please also would like to ask for you to allow the public a chance to respond to ex officio testimony like they used to.**

**12. ~ Additionally, I would like to request that we have permission to ask a few questions after each presentation by an ex officio member (such as NIH, CDC, etc.)**

**13.~ I would also like to respectfully suggest that you also set up a system for email to notify those that Sign-up to receive notifications of any Updates, Info, or Upcoming meetings...**

Hearing about everything 4th party removed~ a week before the event is NOT proper communication with the citizens that you are set up to serve..

If other blogs and websites can do this ~ so can the CFSAC....

PLEASE come into the 21st Century and KEEP in Touch with us in a timely manner DIRECTLY.

**Thanks for listening...and for all you do.... hopefully a lot MORE ASAP ~ If things can NOT "Improve SOON " the Band WILL be playing ON... and the tune will be a dirge played by the World Court of Public Opinion**