

Meghan-Morgan Shannon
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October 13, 2009

Dr. Wanda Jones Subcommittee Chairman DHHS/OWH
Dr. James Oleske Subcommittee Chairman

RE: CFSAC October 30, 2009 public testimony for CFSAC

Dear Chairman Oleske and Chairwoman Jones and CFSAC panel and Leaders:

Thank you for giving me time to speak this morning via the telephone. I would like to take the time to thank you Dr. Jones for your leadership in your new role and especially for having my testimony from last May transcribed as I was too sick to recover from the May meeting.

I became ill when Adeno-Virus #2 continued to run through Children's Hospital, San Diego every fall, from 1980-1990. I became ill in the fall of 1982 and finally was told by the Hospital physician from Scripps La Jolla that I would have to leave my job as my Immune system was compromised. I left June 1983.

I would like to direct you to the page directly behind page one for a moment.

Dad's last letter to me.

1. It is a copy of the letter my father sent to me October 4, 1988. He was in Dallas Texas at the time, getting ready to fly back home to Stone Mt. Georgia.. Please read with me, "Dear Meg, I've had some strange vibes about your well-fare these past few days and feel that you might be short food money.

I scratched around and came up with a little which is enclosed.

I've had a nice visit with you Uncle Willis here in Dallas. He says hello

Nothing else is new.

Love Dad"

I copied the letter dated October 4, 1988 and the check my father sent to me for 2 hundred dollars.

I received his letter three days after he died on October 10th.

My Dad lost his battle with Non Hodgkin's Lymphoma on October 6th.

I want those of you who have known me for over 20 years as an activist for CFS, ME, PPS and Auto immune diseases, to see that;

I am someone's daughter,

I am someone's sister

I am someone's Aunt

I am someone's Friend

I am a HUMAN being and yes I may appear well most of the time

I am sick

There is such a high degree of dislike for people now named CFS that people who see ME/Myalgic Encephalomyelitis say, "gee what people will do to get their disease made real, give it a big name". Even a mother who testified before you last May, made a comment about Myalgic Encephalomyelitis. So let's not give it a larger name "neuroendocrinimmuno (18 letter)..." name.

10-4-88

Dear Meg,
 I've had some strange
 vibes about your well-
 fare these past few
 days and feel that
 you might be a hot
 food source.
 I am not around
 and some eggs with
 a little water is
 enclosed.
 I've had a real
 visit with your
 uncle Willis when
 in Dallas. He says
 hello.
 Nothing else is new
 Love-Dad.

H. W. SHANNON 2264

10/4 1988 64-5
610

PAY TO THE ORDER OF MEGHAN SHANNON \$ 200.00

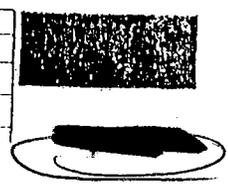
Two hundred and 00/100 DOLLARS

C&S The Citizens and Southern National Bank
Atlanta, Georgia

FOR H. W. Shannon

FOR DEPOSIT TO THE ACCOUNT OF
PEGGY ANN SHANNON

CASH	CURR. & COIN		
DATE CHECK DEPOSITED	6-1-88	200.00	



I gave you the codes used in my last testimony.

Now we have XMRV, this seems to answer most of the questions regarding the different DNA and RNA viruses associated with ME and USA's CFS. It also seems to address the muscles, cardiac and all of the other body systems that seem to be out of wack.

I am very grateful for Dr. Daniel Peterson and his team, and for my friend Pat Fero who continues to lead the way even when she is so sick.

I have three Points:

1.) *Please direct all information to the DHHS/OWH and CFSAC Committee regarding any inquiry about ME-CFS. The CDC is in the business of tracking diseases, they are not in the business of treating the disease.*

I would like to direct you to the May min. and your hand outs from May. You have one hand out that was sent to the "Obama Transition Team on health Committee", by Our bodies Our Selves/OBOS and Women's Health Network/WHNW, regarding the points that were needed to be met on CFS. If you look closely you will see that there were at least 4 re-write in answering this letter.

The first 2 re-writes were from DHHS acting Secretary.

The 2nd re-writes to this letter were from the CDC.

So the response from the CDC to this carefully written letter by two very well known Health Organizations got thrown to CDC (waste basket)

The Acting Secretary of Health for Obama's Transition Team probably never saw this letter.

The response from the CDC was an institutional response and it is the WRONG response.

It seems that all inquiries regarding CFS/CFIDS/ME no matter where they are sent (i.e. Senator, HHS..) are sent to the CDC.

*******I am requesting that all money that goes to both NIH and CDC go directly to DHHS/OWH and CFSAC committee so that they may take over the duties of the CDC regarding education and research. *******

The CDC and NIH should be out of the loop as they clearly do not feel that CFS, CFIDS or ME are real diseases. Dr. Fauci/NIH, Dr. Reeves and Dr. James Jones/CDC have no understanding of this disease.

In fact as I said in 1996 regarding a congressional hearing on the mis appropriations of funds, it was clear that the lack of understanding this disease has gone way beyond ignorance. It was then as it is now, clearly a display of severe discrimination against a patient population who are very ill.

2.)Name: *Let us not make the same mistake again.*

CFS focuses one of the Symptoms people have who are diagnosed in the USA with CFS.

So don't make the mistake of calling it a name by the BODY SYSTEMS, like Neuro, Endocrinology and immunological (NEIDS). It leaves out Cardiac system which is a huge problems with this disease.

Dr. Philip R. Lee said in 1998, "...It is time for a name change" "Chronic Fatigue Syndrome, Wedner tells us, is neither a disease no a syndrome. It is a committee definition."

3.0) TESTIMONIES: *by patients*

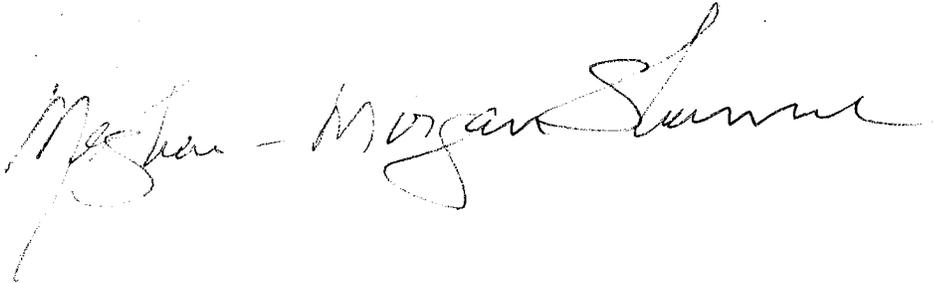
Dr. Oleske asked if there might be a better way to stop the testimonies as it seemed to be very abrupt for both Mary Schweitzer and myself. Dr. Lee was not so rigid on the time and the microphones were never turned off from 1993 to 2000, when Dr. Donna Dean was running these meetings. They would let the person who was speaking finish their sentence and give them a few min to wrap up even if it went past five min. allotment. Those who come in to speak before the panel are sick. Last May you saw not only Mary really go down hard after her testimony, but I did as well..

I would like to end by again saying thank you for letting me speak. And thank you for having Dr. Dan Peterson as a guest speaker. Ten years ago Dr. Peterson attended the Belgium Congress on CFS and Gulf War, he is quoted as saying, "in response to the conference Dr. Dan Peterson said, " this was the best conference on CFS he hd ever attended. At one conference, 99% of the presenters were psychiatrists-HERE there were almost NONE".

"Dr. Peterson finished by saying, "that 10 years ago (that would make it 1989) he believed CFS could be resolved by science; now he had changed his mind: It could only be resolved by 'politics'". I wonder what Dr. Peterson would say now.

Thank You

Meghan- Morgan Shannon

A handwritten signature in cursive script that reads "Meghan - Morgan Shannon". The signature is written in dark ink and is positioned below the typed name.