

Public comment on the P2P Draft Statement by Katharina Voss, Dec 2014:

(Corresponding line numbers of the report are shown here in parentheses, reference numbers are shown here in brackets)

What does the NIH leadership really think about our disease?

„They hate you!“

This was the answer of a retired NIH scientist to a patient at a medical conference in New York City, Dec 2013. [1] And his answer was the first and only honest answer patients with ME ever got from NIH. This NIH scientist frankly expressed what patients with ME undergo every single day: they face a wall of hatred and scorn.

The NIH P2P Draft Statement clearly shows that he was right.

As many of ME activists predicted we got just the same bad recommendations given to Gulf war veterans (whose disease was “redefined” into the belittling “CMI”) and fibromyalgia patients. [2] NIH wants to put us off with ineffective harmful treatments like GET, CBT, antidepressants, and self-management. (Lines 113-116, 135-138, 344-350, 370-371)

Self-management – have we read correctly? What else are we doing now for decades in the absence of proper medical care? Self-management! And the NIH spends millions of taxpayers` dollars to recommend **self-management**? Are you kidding us?

These treatments like GET, CBT, antidepressants, and self-management (“multimodal therapy”) could possibly be effective for some psychological disorders, but they do harm to patients with organic diseases like ME, a fact that is proven by true science but which is rejected by the P2P “experts“! [3]

Why does NIH neglect patients with ME?

Although men are also affected the majority of ME patients are women. Hence this neglect is clearly a case of misogyny! I want to compare the situation with the early AIDS epidemic when mainly gay men fell ill and were discriminated against as homosexuals and AIDS was called “gay plague”, “Gay Related Immune Deficiency“ (GRID), “Gay People’s Immuno Deficiency Syndrome“ (GIDS), the CDC’s creation “the 4H disease” (Haitians, homosexuals, hemophiliacs, heroin users)]. [4] Racism, homophobia and misogyny impeded research much too long.

Today there is a big problem with the so-called “medically unexplained syndromes“, a term created by psychiatrists in order to cover and falsely include a lot of physical diseases. These psychiatrists - mostly the same psychiatrists who recommend CBT, GET and antidepressants for patients with “ME/CFS” - try to “prove” that exposure to childhood trauma is associated with significantly increased risk of “ME/CFS”. They try

to “prove” that sexual abuse, emotional abuse and emotional neglect cause “ME/CFS”, and that these factors were most effective in distinguishing “ME/CFS” cases from healthy controls. [5] They try to “prove” this unscientific nonsense in spite of the very well-known results of biomedical research.

Their unscientific work results in falsely accusing mothers of children with ME of having a Munchausen by proxy syndrome. Parents, falsely accused of sexual abuse, emotional abuse and emotional neglect or of Munchausen by proxy syndrome lose custody and many children with ME have been separated from their families. They were mistreated with GET in psychiatric wards and their parents were wrongly criminalized. This is an ongoing praxis and this happens all due to the disregard of an organic disease. [6]

All these so-called “medically unexplained syndromes” which are in reality physical diseases affect more women than men. Women are probably genetically more susceptible for these diseases. Actually these diseases are not psychological disorders and many biomedical abnormalities can be measured for diseases like ME, fibromyalgia and so on, falsely labeled as “medically unexplained syndromes”.

We must not assume that these psychiatrists who assert that all these diseases are medically unexplained and caused by sexual abuse, emotional abuse and emotional neglect are stupid. We have to assume that they are well familiar with the results of biomedical research. Therefore, it is a deliberate misrepresentation by these psychiatrists, driven by misogyny.

This intentional misrepresentation is a violation of the AMERICAN DECLARATION OF THE RIGHTS AND DUTIES OF MAN, a violation of article I (Right to life, liberty and personal security), article VII (Right to protection for mothers and children), article XI (Right to the preservation of health and to well-being).

NIH consistently denies the fact that ME is an infectious disease. The report encourages more biopsychosocial studies. (Lines 275-276) Is that really what we need? More of these biopsychosocial studies from Wessely School and their worldwide followers which will “prove” that ME is a mental illness perpetuated by our “false illness beliefs”? No, we don’t need any single further study of this kind!

Why is NIH consistently denying the fact that ME is an infectious disease? There are so many clusters in families and among fellow workers and pupils proving that ME is indeed infectious. [7] Why is NIH hiding this very well-known fact? No actions have been taken to stop this epidemic. Why? A disease which was “[not] numerically important on a national scale” in the fifties has now evolved into the “most common chronic disease of young and middle-aged adults” because NIH failed to recognize its epidemic character. [8]

Everyone who is able to read can read that Mikovits and Ruscetti found **uncontaminated** retroviral variants **other** than XMRV. Those variants were not XMRV. [9]

Only figure 1 of the Science paper was wrong. Figure 1 was the XMRV PCR sequencing/naming done by Silverman. Silverman was the one who sequenced

XMRV in his lab, and these are the PCR data shown in figure 1 in the Science paper. [10]

All the other data on the Science paper still stand. [11] The serology information is well documented. The research also showed the dysfunctional immune profile, the cytokine signature, and microarray co-pathogens associated with those who were antibody positive in several studies. This data is all published. [12]

The prostate cancer paper by Silverman falsely claimed XMRV to be a human infection and was later retracted. However, no research came to a halt for prostate cancer because of Silverman's error. Contrary to Dr. Judy Mikovits Silverman still has his career and the prostate cancer patients are still provided with research and treatment.

However, because of the original mistake made in XMRV prostate cancer research the ME patient population has been denied further research on Mikovits/Ruscettis **original results** and effective treatment. Silverman was wrong yet ME patients and Dr. Judy Mikovits are paying the price for his mistake.

And by the way, what about Maureen Hansons findings, her detection of MLV-like gag sequences in blood samples from a patient cohort? [13]

What about Sidney Grossberg's isolation of the JHK retrovirus in ME patients? [14]

And what about Elaine De Freitas' HTLV II-like retroviral sequences found in ME patients? [15] Why had the CDC never tried to follow her protocol? [16]

Why did the NIH continue refusing unbiased and true science? Why did the NIH destroy future research for our disease because of the XMRV mistake made in prostate cancer? Why is NIH not pursuing the research for the variants and serology found in Ruscetti's lab? Why did the NIH destroy the hope of millions ME sufferers for effective antiretroviral, antiviral and anti-inflammatory treatments?

Shall my beloved daughters never have a life? Both developed mild ME, at least at the age of three. The elder one lost 2 years of education due to her disease before she got completely bedbound, the younger one lost nearly a whole year of education before she got bedbound. In 2009 my elder daughter received a Boostrix shot (polio, tetanus, diphtheria) followed by a very severe relapse which continues to date. (100% bedbound, spoonfed, unable to wash, to brush her teeth without help, touch-sensitive, sensitive to the slightest noise and often unable to bear the presence of their beloved family members even for only a few minutes) In January 2011 my younger daughter relapsed after a series of viral infections. Being 90% bedbound, suffering from severe neurological and neurocognitive problems she is too severely affected to participate in any form of education, even at home. (My daughters are just the most severely affected members of our family! Many have/had other neuroimmunological diseases or/and cancer.)

My daughters clearly don't suffer from a syndrome "characterized by extreme fatigue" as "ME/CFS" is described in the P2P draft. (Lines 2-4) My daughters suffer from a disease characterized by postexertional neuroimmune exhaustion (PENE). And PENE "is part of the body's global protection response" in a disease named Myalgic Encephalomyelitis in the fifties, recognized as a neurological disease from WHO in 1969. [17]

PENE, the cardinal symptom of ME, is an objectively measurable (i.e. Two-day Cardiopulmonary Exercise Test) abnormal biological response to exertion. [18] ME is not characterized by a subjective feeling of fatigue. Fatigue **can** be an accompanying symptom but many ME sufferers never experience fatigue. But **every** real ME sufferer experiences PENE. ***Without PENE – no ME!***

My elder daughter is now 21 years old and spent 5 ½ years in a darkened room with no hope to ever get out of there. When will NIH research release her from prison? The younger one is now 14 years old, being severely ill nearly one third of her young life!

Both girls lost half of their childhood due to mild ME and her whole youth due to very severe ME. But all the NIH has to offer is ***self-management?*** Will NIH not allow them to have a future?

Oh yes, all the tests, medications and medical care we ***really*** need (and some of us probably lifelong) would be costly if the NIH would actually recognize ME as an infectious and transmissible disease.

But what is the alternative? The alternative is that we will further spread this disease. And many of our beloved ones will contract this disease, our friends and carers and physicians. And this disease will not stop in front of the doors of NIH.

Wake up, NIH! Break down the wall of hatred and scorn!

Wake up, America!

Thank you for your attention!

References

- [1] Heckenlively, Kent, Mikovits, Judy "Plague: One Scientist's Intrepid Search for the Truth about Human Retroviruses and Chronic Fatigue Syndrome, Autism, and Other Diseases". Foreword by Hillary Johnson, p. xxi, Skyhorse Publishing 2014
- [2] "Gulf War and Health Volume 9 Treatment for Chronic Multisymptom Illness", Institute of Medicine
- [3] Snell, Christopher R., Stevens, Staci R., Davenport, Todd E., and Van Ness, J. Mark "Discriminative Validity of Metabolic and Workload Measurements to Identify Individuals With Chronic Fatigue Syndrome", published online before print 27 June 2013 doi: 10.2522/ptj.20110368
- VanNess JM, Stevens SR, Bateman L, Stiles TL, Snell CR "Postexertional malaise in women with chronic fatigue syndrome." J Womens Health (Larchmt). 2010;19:239-44
- VanNess JM, Snell CR, Stevens S "Diminished Cardiopulmonary Capacity During Post- Exertional Malaise." J Chronic Fatigue Syndr. 2008;14(2):77-85

Nijs J1, Almond F, De Becker P, Truijten S, Paul L "Can exercise limits prevent post-exertional malaise in chronic fatigue syndrome? An uncontrolled clinical trial." *Clin Rehabil.* 2008 May; 22(5):426-35. doi: 10.1177/0269215507084410

LaManca JJ, Sisto SA, DeLuca J, Johnson SK, Lange G, Pareja J, Cook S, Natelson BH. "Influence of exhaustive treadmill exercise on cognitive functioning in chronic fatigue syndrome." *Am J Med.* 1998 Sep 28;105(3A):59S-65S

VanNess JM, Snell CR, Stevens SR, Stiles TL "Metabolic and neurocognitive responses to an exercise challenge in chronic fatigue syndrome/(CFS)", *Med Sci Sports Exerc.* 2007

White AT, Light AR, Hughen RW, Bateman L, Martins TB, Hill HR, Light KC. "Severity of symptom flare after moderate exercise is linked to cytokine activity in chronic fatigue syndrome." *Psychophysiology.* 2010 Jul 1;47(4):615-24. doi: 10.1111/j.1469-8986.2010.00978.x.

Twisk FNM, Maes M "A review on Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET) in Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS): CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS." *Neuro Endocrinol Lett.* 2009;30:284-299

Cooper DM, Radom-Aizik S, Schwindt CD, Zaldivar F. "Dangerous exercise: lessons learned from dysregulated inflammatory responses to physical activity." *J Appl Physiol.* 2007;103:700–709.

Vermeulen, Ruud CW and Vermeulen van Eck, Ineke WG "Decreased oxygen extraction during cardiopulmonary exercise test in patients with chronic fatigue syndrome", *Journal of Translationa Medicine* 2014, 12:20 doi:10.1186/1479-5876-12-20

Light AR, White AT, Hughen RW, Light KC "Moderate exercise increases expression for sensory, adrenergic, and immune genes in chronic fatigue syndrome patients but not in normal subjects." *J Pain.* 2009;10:1099-112

Kindlon, Tom "Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome", *Bulletin of the IACFS/ME.* 2011;19(2): 59-111. <http://www.iacfsme.org/LinkClick.aspx?fileticket=Rd2tJ0oHqk%3D&> (12/25/2014)

Bringsli, Gunn J., Gilje, Anette and Getz Wold, Bjørn K. "THE NORWEGIAN ME ASSOCIATION NATIONAL SURVEY Abridged ENGLISH VERSION", <http://me-foreningen.com/meforeningen/innhold/div/2014/05/ME-Nat-Norwegian-Survey-Abr-Eng-Ver.pdf> (12/25/2014)

[4] "AIDS", <http://en.wikipedia.org/wiki/HIV/AIDS#Discovery> (12/25/2014)

"Making Headway Under Hellacious Circumstances"
<http://www.sciencemag.org/content/313/5786/470.2.full.pdf> (12/25/2014)

"Ronald Reagan Remembered: First Public Discussion of HIV/AIDS"
<http://www.thebody.com/content/art31696.html> (12/25/2014)

[5] Heim, Christine PhD; Nater, Urs M. PhD; Reeves, William C. MD, MSc, et al. "Childhood Trauma and Risk for Chronic Fatigue Syndrom – Association with neuroendocrine dysfunction", *Arch Gen Psychiatry.* 2009;66(1):72-80. doi:10.1001/archgenpsychiatry.2008.508

[6] Colby, Jane "False Allegations of Child Abuse in Cases of Childhood Myalgic Encephalomyelitis (ME)". http://www.argumentcritique.com/uploads/1/0/3/1/10317653/colby_j.pdf (12/25/2014)

[7] Dowsett EG, Colby J. "Longterm sickness absence due to ME/CFS in UK schools: an epidemiological study with medical and educational implications." *J CFS* 3(2):2942, 1997, <http://www.tymestrust.org/pdfs/dowsettcoby.pdf> (12/25/2014)

Underhill, Rosemary A., O'gorman, Ruth "Prevalence of Chronic Fatigue Syndrome and Chronic Fatigue Within Families of CFS Patients", *Journal of Chronic Fatigue Syndrome* 2006, Vol. 13, No. 1, Pages 3-13, http://informahealthcare.com/doi/abs/10.1300/J092v13n01_02 (12/25/2014)

[8] Henderson, Donald A., and Shelokov, Alexis "Epidemic Neuromyasthenia — Clinical Syndrome?" *N Engl J Med* 1959; 260:757-764 April 9, 1959 DOI: 10.1056/NEJM195904092601506

Johnson, Hillary "Osler's Web: Inside the Labyrinth of the Chronic Fatigue Syndrome Epidemic", p. 203, Penguin Books 1997

[9] Lombardi VC, Ruscetti FW, Das Gupta J, Pfof MA, Hagen KS, Peterson DL, Ruscetti SK, Bagni RK, Petrow-Sadowski C, Gold B, Dean M, Silverman RH, Mikovits JA "Detection of an infectious retrovirus, XMRV, in blood cells of patients with chronic fatigue syndrome", *Science.* 2009 Oct 23;326(5952):585-9. doi: 10.1126/science.1179052.

Goetz, Deborah L. S., Mikovits, Judy A., Deckoff-Jones, Jamie and Ruscetti, Francis W. "INNATE IMMUNE CHANGES IN THE PERIPHERAL BLOOD OF CHRONIC FATIGUE SYNDROME PATIENTS: RISK FACTORS FOR DISEASE PROGRESSION AND MANAGEMENT", Chapter VI (pp. 91-130) in "Chronic Fatigue Syndrome", Nova Science Publishers, Inc. 2014, ISBN: 978-1-63321-961-8

Mikovits, Judy "The Exotic Biology of Xenotropic Murine Leukemia Related Virus XMRVs – Pitfalls and New Concepts", Presentation from the Mount Sinai Conference Nov. 2013

<https://www.facebook.com/media/set/?set=a.244564049033185.1073741854.101589063330685&type=1>

Heckenlively, Kent, Mikovits, Judy "Plague: One Scientist's Intrepid Search for the Truth about Human Retroviruses and Chronic Fatigue Syndrome, Autism, and Other Diseases", p. 336, Skyhorse Publishing 2014

[10] Heckenlively, Kent, Mikovits, Judy "Plague: One Scientist's Intrepid Search for the Truth about Human Retroviruses and Chronic Fatigue Syndrome, Autism, and Other Diseases", p. 337, 342, Skyhorse Publishing 2014

[11] Heckenlively, Kent, Mikovits, Judy "Plague: One Scientist's Intrepid Search for the Truth about Human Retroviruses and Chronic Fatigue Syndrome, Autism, and Other Diseases", p. 341f., Skyhorse Publishing 2014

[12] Goetz, Deborah L. S., Mikovits, Judy A., Deckoff-Jones, Jamie and Ruscetti, Francis W. "INNATE IMMUNE CHANGES IN THE PERIPHERAL BLOOD OF CHRONIC FATIGUE SYNDROME PATIENTS: RISK FACTORS FOR DISEASE PROGRESSION AND MANAGEMENT", Chapter VI (pp. 91-130) in "Chronic Fatigue Syndrome", Nova Science Publishers, Inc. 2014, ISBN: 978-1-63321-961-8

[13] Hanson, Maureen R, Bell, David S et al "Detection of MLV-like gag sequences in blood samples from a New York state CFS cohort", *Retrovirology*. 2011; 8(Suppl 1): A234. Published online 2011 June 6. doi: 10.1186/1742-4690-8-S1-A234

[14] Halligan, Brian D, Sun, Hai-Yuan, Kushnaryov, Vladimir M & Grossberg, Sidney E "Partial molecular cloning of the JHK retrovirus using gammaretrovirus consensus PCR primers", *Future Virology*, May 2013, Vol. 8, No. 5, Pages 507-520, DOI 10.2217/fvl.13.25

[15] DEFREITAS, ELAINE, HILLIARD, BRENDAN, CHENEY, PAUL R., BELLS, DAVID S, KIGGUNDU, EDWARD, SANKEY, DIANE, WROBLEWSKA, ZOFIA, PALLADINO, MARIA, WOODWARD, JOHN P., AND KOPROWSKI, HILARY "Retroviral sequences related to human T-lymphotropic virus type II in patients with chronic fatigue immune dysfunction syndrome (Epstein-Barr virus syndrome/infectious mononucleosis/myalgic encephalomyelitis/polymerase chain reaction/in situ hybridization)", *Proc. Natl. Acad. Sci. USA* Vol. 88, pp. 2922-2926, April 1991, Medical Sciences, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC51352/>

[16] Heckenlively, Kent, Mikovits, Judy "Plague: One Scientist's Intrepid Search for the Truth about Human Retroviruses and Chronic Fatigue Syndrome, Autism, and Other Diseases", Skyhorse Publishing 2014, foreword by Johnson, Hillary „A Disease Able to Affect the Economies of Nations”, p. xviii

Hooper, Malcolm "ME/CFS (WHO ICD-10 G93.3) BIOMEDICAL EVIDENCE SUMMARIES", February 2010, <http://www.stonebird.co.uk/hooper.html> (12/25/2014)

[17] Carruthers, B M, van de Sande, M I [...], and Stevens, S "Myalgic Encephalomyelitis: International Consensus Criteria", p. 331, *Journal of INTERNAL MEDICINE* Oct 2011, Review. <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x/pdf>

[18] Snell, Christopher R., Stevens, Staci R., Davenport, Todd E., and Van Ness, J. Mark "Discriminative Validity of Metabolic and Workload Measurements to Identify Individuals With Chronic Fatigue Syndrome", published online before print 27 June 2013 doi: 10.2522/ptj.20110368

White AT, Light AR, Hughen RW, Vanhaitsma TA, Light KC. "Differences in metabolite-detecting, adrenergic, and immune gene expression after moderate exercise in patients with chronic fatigue syndrome, patients with multiple sclerosis, and healthy controls." *Psychosom Med*. 2012 Jan;74(1):46-54. doi: 10.1097/PSY.0b013e31824152ed