



PATIENT ALLIANCE FOR NEUROENDOCRINEIMMUNE DISORDERS
P-A-N-D-O-R-A
ORGANIZATION FOR RESEARCH AND ADVOCACY *inc.*

• 501 c 3 • ID # 550795076

255 Alhambra Circle, Suite 715, Coral Gables, Florida 33134
Phone: 305-441-1591 • Volunteer Help line: 954-783-6771 • Fax: 954-783-1098
www.pandoranet.info

November 14, 2010

American Red Cross
President and CEO

Gail J. McGovern

Via e-mail to: Ms. Stephanie Millian millianst@usa.redcross.org

Office: (202) 303-4488

Dear Ms. McGovern,

As a patient organization, we are concerned that the American Red Cross website does not show that your organization is explicitly refusing to accept blood donations from the 1 million Americans with chronic fatigue syndrome (CFS), known in other countries as myalgic encephalomyelitis (ME).

Recent discoveries show 67-87% of ME/CFS patients have murine leukemia virus-like viruses (MLV) and / or xenotropic murine leukemia virus-related virus (XMRV).[1-2]. We notice that the American Red Cross website encourages blood donations because it “gives life.” Allowing anyone positive for these viruses and / or ME/CFS patients to donate blood may result in their giving a NeuroEndocrineImmune disease instead of giving life. The higher rate of XMRV in prostate cancer patients adds to the threat this policy may pose to the public.

Your website also says that people with chronic illnesses may donate blood as long as they “feel well, the condition is under control, and you meet all other eligibility requirements.” A review of all the exclusionary chronic conditions listed on your website indicates someone who is feeling well at the time, even if they have ME/CFS or have tested positive for XMRV, may donate blood. A retrovirus does not disappear from the blood when someone “feels well.” We ask, would someone who is HIV positive be allowed to donate blood if they feel well that day? With XMRV being the third infectious human retrovirus discovered, prudence and moral responsibility should move the American Red Cross to ban all ME/CFS and XMRV positive patients from donating blood.

We urge you to take the same steps that the federally-appointed Chronic Fatigue Syndrome Advisory Committee (CFSAC) recommended in their May 2010 meeting. We urge you to follow the example of the Canadian, Australian, New Zealand and British governments of banning ME/CFS patients from donating blood.

Dr. Nancy Klimas, ME/CFS researcher and clinician at the University of Miami, said in the May CFSAC 2010 meeting: “Many of my patients are very civically conscious and want to do the right thing... And if they felt well enough to donate blood they would—and they do donate blood. I can tell you, they do donate blood.” She pointed out that other infections commonly seen as more active in ME/ CFS patients have been shown to be oncogenic (tumor viruses). Yet, Jerry Holmberg, Senior Advisor for Blood Policy in the U.S. Department of Health and Human Services, said concerning XMRV, “It would be foolish to think it is not transmitted by blood...”

While science takes time, sometimes years, to prove cause and effect, the spread of disease happens every day. By banning ME/CFS patients and people who are XMRV positive today, you will send a message that the American Red Cross can be trusted to protect the public health with the safest blood products possible. In contrast, a “wait and see” attitude may end up undermining the trust the public has because your organization failed to act earlier to protect the public health.

This situation is very reminiscent of the scandal of the 1980s when a lack of aggressive protective measures led to many blood recipients becoming infected with a deadly retrovirus. We cannot afford to have this happen again. We should be proactive with a view to caution and public safety.

We hope you will give this urgent matter your attention. We look forward to hearing from you soon.

Sincerely yours,

Marly C. Silverman

Marly C. Silverman

Founder

Patient Alliance for NeuroEndocrineImmune Disorders Organization for Research and Advocacy, Inc. (P.A.N.D.O.R.A.)

1. Lombardi VC, Ruscetti FW, DasGuptaJ, Pfof MA, HagenKS, 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 , 326:585-589.

2. Lo S ,Pripuzova N, Li B, Komaroff AL, Hung G,Wang R,Alter H:DetectionofMLV-related virusgene sequences in blood of patients with chronic fatigue syndrome and health blood donors, *Proc. of the National Academy of the USA*, August 23, 2010, doi:10.1073/pnas.1007944107