



FOR IMMEDIATE RELEASE

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### ***P.A.N.D.O.R.A. Urges Swift Action by U.S. Health Agencies to Improve Quality of Life for CFS Patients***

Coral Gables, FL (August 25, 2010)— Patients with chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME) in other countries, have endured too many years of misinformation, neglect, and mistreatment. “With a retrovirus infection now demonstrated to be present in the majority of CFS patients, now is the time to fix what is wrong with this illness, to stop the suffering of millions,” said Marly Silverman, founder of P.A.N.D.O.R.A. The nation’s public health is at stake as scientists report that 7% of samples taken from the blood supply in the United States shows positive for a family of murine leukemia viruses. (*Source: Proceedings of the National Academy of Sciences, August 24, 2010.*)

P.A.N.D.O.R.A. is encouraged by the National Institutes of Health (NIH) and Federal Drug Administration (FDA) study that confirms the strong association (87%) between a family of XMRV-related viruses and chronic fatigue syndrome. The years of misinformation and low priority research into NeuroEndocrineImmune Disorders can no longer be tolerated. There is no excuse for the continued disregard of the impoverished quality of life CFS patients endure. **We call for the following actions now:**

- Provide substantial research funding allocations for CFS and related NeuroEndocrineImmune diseases in order to close the scientific gap in this field.
- Start expedited, clinical trials of antiretrovirals for humanitarian reasons with volunteer patients who have CFS and are severely debilitated because of it.
- Establish centers for clinical training of primary care physicians for the proper diagnosis and treatment of CFS and institute medical school curricula accordingly.
- Adopt the diagnostic CFS criteria of the IACFS/ME Association, the only worldwide professional organization dedicated to the treatment of and research on CFS.
- Develop an FDA-approved test for the presence of murine-related viruses in patients with CFS to be distributed as robustly as the standardized test used for the diagnosis of AIDS.
- Conduct Congressional hearings as to why the U.S. government health agencies have consistently ignored the urgency of an aggressive public health agenda to tackle the substandard quality of life issues experienced by patients with CFS and their families.
- Screen all blood donors for retroviral infection. The presence of retroviral components in donated blood represents a potential threat to the nation’s blood supply.

The recent NIH/FDA study shows that crucial scientific advancements in the knowledge and etiology of CFS can be made. Given the current findings, it is unacceptable to wait another 25 years for the government's research effort to confirm the next significant finding stimulated by the private sector. CFS is a serious, legitimate illness that not only affects the afflicted patients but also represents a potential threat to the health of the general population. The time to act is now.

**About P.A.N.D.O.R.A. - Patient Alliance for NeuroEndocrineImmune Disorders Org. for Research and Advocacy, Inc.** Based in Coral Gables, Florida, P.A.N.D.O.R.A. was founded on July 1, 2002, by Marly C. Silverman, a Chronic Fatigue Syndrome and Fibromyalgia patient. Its mission is to raise awareness of the plight of

persons with Chronic Fatigue Syndrome, Fibromyalgia, Chronic Lyme disease, Multiple Chemical Sensitivities/Environmental and Gulf War Illnesses. P.A.N.D.O.R.A. advocates for an increased quality of life for persons who are chronically ill. P.A.N.D.O.R.A. is Built on Hope, is Strong on Advocacy, and champions cures for NeuroEndocrineImmune Disorders through Research. For more information, visit [www.pandoranet.info](http://www.pandoranet.info).

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