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**PATIENT ALLIANCE FOR NEUROENDOCRINEIMMUNE DISORDERS
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February 10, 2007

Honorable Michael Leavitt
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington DC 20201

Dear Secretary Leavitt,

On behalf of P.A.N.D.O.R.A., I would like to thank you and Dr. John Agwunobi for responding to our July 13, 2006 letter detailing P.A.N.D.O.R.A.'s concerns for the Chronic Fatigue Syndrome Advisory Committee (CFSAC).

Despite Dr. Agwunobi's welcome and expeditious response, P.A.N.D.O.R.A. believes that the outlook for the CFSAC and the adequate management of neuroendocrineimmune patients are *not* promising.

P.A.N.D.O.R.A. conservatively represents an estimated 60,000 – 75,000 patients in the State of Florida who suffer from chronic fatigue syndrome. Since Dr. William Reeves of the Centers for Disease Control and Prevention has publicly announced that the number of chronic fatigue syndrome patients in the United States is more accurately placed at 4 million patients rather than the previous estimate of 1 million patients, the estimated number of patients in the State of Florida may actually be fourfold multiple of the 75,000 patient estimate.

Clearly P.A.N.D.O.R.A. speaks for a large number of patients in the State of Florida and we wish to make our concerns known:

#1: Administrative Responsibility and Funding for CFS Research. It is our understanding that CFS is currently homeless within the CDC. It is our understanding that there is no department, or administrator within the CDC who has the direct responsibility of overseeing the CDC's research mission into CFS. We have been told

that funding for CFS research within the CDC has been cut. We find this unfortunate. CFS research is currently burgeoning as it was demonstrated during the 8th IACFS Conference from Jan 10-14, 2007, in Fort Lauderdale, Florida, sponsored by P.A.N.D.O.R.A. and by the CDC. CFS research impacts a number of other illnesses: fibromyalgia, Gulf War Syndrome, and chronic Lyme disease. It is reasonable to sustain this level of productivity.

P.A.N.D.O.R.A. calls to your attention to the number one recommendation of the CFSAC: *...In the opinion of the CFSAC, the greatest priority for the DHHS is to substantially increase research efforts and funding. Future research efforts must apply an integrative approach because CFS is characterized by dysregulation of a number of highly integrated body systems, particularly the immune and nervous systems. Forming multidisciplinary research teams would provide a platform to conduct well-controlled, methodologically sound, longitudinal studies to clarify the pathophysiology of this syndrome, and to develop effective treatment modalities. Serum and tissue banks for future investigations should be established.*

Despite the roadmap initiative, P.A.N.D.O.R.A. urges the DHHS to direct the NIH to ...establish a minimum of five Centers of Excellence (or Neuroendocrineimmune Institutes) within the United States that would effectively utilize state-of-the art knowledge concerning the diagnosis, clinical management, treatment and clinical research of persons with CFS. These Centers (or Neuroendocrineimmune Institutes) should be modeled after the previous Centers of Excellence program, with funding not to be less than \$1.5 million per center per year for a period not less than five years.”

Ongoing analysis by P.A.N.D.O.R.A. finds that \$1.5 million per center per year is a modest request. It is, however, a hopeful start. P.A.N.D.O.R.A. for the past two years has supported a “grassroots” initiative in the State of Florida for a Neuroendocrineimmune Institute or a Center of Excellence, and we also support other such centers in other parts of the United States.

#2: Inclusion of CFS in OPASI. In 2006, the NIH established the **Office of Portfolio Analysis and Strategic Initiatives, (OPASI)** to ... *”provide better information to support planning and priority-setting in areas of shared Institute and Center interests.”* (Excerpt from Dr. Elias A. Zerhouni, Director of the NIH, in his FY 2007 Budget Request to the House Subcommittee on Labor – HHS- Education Appropriations, April 6, 2006.) ***P.A.N.D.O.R.A. wishes to receive assurances that CFS and the funding of CFS research are vigorously included in OPASI planning and will continue to be an OPASI priority in the reasonable future.*** It is important that CFS and other related neuroendocrineimmune disorders are not left behind or forgotten, but rather included as NIH undergoes its internal structural changes. ***Patients in the United States die of the complications of untreated or poorly treated complications of CFS. These deaths are due in part to a lack of essential social services, quality of life issues and a lack of knowledgeable medical care and treatments.***

#3: Public Access to Advisory Committee Meetings. *P.A.N.D.O.R.A. requests that CFSAC Meetings be broadcast to the CFS community in “real time.”* Because most CFS patients are too sick to travel to Advisory Committee meetings, audio or audiovisual broadcasts of the Advisory Committee meetings should be made available.

P.A.N.D.O.R.A. believes that “real time” audio broadcast of Advisory Committee meetings should be possible for a fee of \$400/day. Video broadband broadcast through a website would be more expensive but possible. P.A.N.D.O.R.A. requests that D.H.H.S. investigate this possibility. One company providing such service is C3 Conferencing of Montgomery, AL. Their website is www.c3conferencing.com. P.A.N.D.O.R.A. urges D.H.H.S. to provide such broadcasts so citizens/patients in the U.S. can be given the same opportunities granted by health congressional committees. *P.A.N.D.O.R.A. has found a benefactor willing to donate the necessary fund for broadcasts. P.A.N.D.O.R.A. requests D.H.H.S. to pursue this partnership as it is extremely beneficial to our community of CFS patients.*

#4: CFSAC Transition. As of this date, it would appear that the CFSAC does not have its full complement of members. A timely and publicly disclosure of incoming Advisory Committee members is important: Patients need to know who is advising the U.S. Secretary of Health with regard to their illness, and how to contact them. Committee members need to be brought onboard in a timely fashion so as to maintain the uninterrupted flow of recommendations to the U.S. Secretary of Health, and to maintain the continuity and institutional history of the Committee. While we take the opportunity to thank the administrative staff for its ongoing work, *P.A.N.D.O.R.A. asks for the public announcement of the new Advisory Committee members as soon as possible and certainly no later than the next CFSAC meeting.*

Finally, P.A.N.D.O.R.A. requests an expeditious reply to this letter. We are cognizant of the changes that have taken place in the past few years with regard to the priorities at the D.H.H.S., and the ranking of CFS amongst them. P.A.N.D.O.R.A. asks that CFS and other neuroendocrineimmune illnesses remain at the forefront of future D.H.H.S. initiatives. For far too long have CFS and related neuroendocrineimmune illnesses suffered from inadequate research funding and under-representation of dedicated researchers capable of unraveling the complexity of their illness and of providing effective, therapeutic modalities.

In Good Health and In Beauty,

Marly C. Silverman

Marly C. Silverman
Founder
P.A.N.D.O.R.A, Inc.

cc: Dr. John Agwunobi
CFS Advisory Committee Members
Senator Bill Nelson, FL
Senator Mel Martinez, FL

Rep. Ileana Ros-Lehtinen, FL
Rep. Ron Klein, FL
Rep. Robert Wexler, FL
Rep. Alcee Hastings, FL
Rep. Debbie Wasserman-Schultz, FL, Member, Appropriations Committee
Rep. Allen Boyd, Florida, Member, Appropriation Committee
Rep. C. W. Bill Young, Member, Appropriations Committee
Rep. David R. Obey, WI, Chair Appropriations Committee,
Rep. Dave Weldon, FL, Member, Appropriation Committee, Subcommittee,
Health, Labor & Education
Rep. Ander Crenshaw, FL, Member, Appropriations Committee, Subcommittee,
Health Labor & Education.
Senator Tom Harkins,
Senator Edward Kennedy, MA,
Senator Hillary Clinton, NY
Senator Barak Obama, IL
Senator Orrin Hatch, UT
Senator Bernard Sanders, VT
Senator Christopher Dodd (CT)
Senator Harry Reid, NV

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