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International Association for IACFS/ME

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Chronic Fatigue Syndrome

*Dedicated to Promotion of
Scientific Research and
Improved Patient Care*

Public Testimony to the CFS Advisory Committee

As president of the IACFS/ME, representing over 500 biomedical and behavioral professionals, I thank the CFSAC for this important opportunity to present testimony.

Several weeks ago, the Centers for Disease Control issued a job announcement for Chief, Chronic Viral Diseases Branch. This includes primary responsibility for the direction and substance of the CFS research program. The program contains the largest single US budget for CFS research (\$5 million/yr).

This is a critically important position that can influence science, practice, and health policy related to CFS. As such, we need a highly qualified individual to fill the position. According to the head of the search committee at CDC, several candidates will be recommended for further consideration. A new chief will probably be appointed in the next several weeks.

Apart from the necessary scientific credentials, I would like to excerpt a key job requirement from the job announcement:

---- The ability [of the candidate] to deal effectively with the scientific community, national and international medical and health-related organizations, and the public at large.

This critical dimension of leadership has been and still is lacking at the CFS program at CDC. To date, the leadership of the Chronic Viral Diseases Branch has conveyed an attitude of dismissal bordering on arrogance toward the external scientific and professional communities. This attitude has generated mistrust and skepticism of the CFS research program - a mistrust which has been ongoing for the past decade.

IACFS/ME would like to see the position of Chief filled by someone who constructively engages with the scientific community. This important ability would preferably include a shared vision of the direction of biomedical research in CFS--- particularly in the challenging new domains of retrovirology and molecular medicine. These emerging areas of scientific inquiry may lead to new models of intervention that can offer hope and help for long suffering CFS patients.

Overall, we need open communication with the CDC/CFS program and fresh perspectives from their leadership--the qualities that could *elevate* this position to one that is viewed with renewed respect and credibility.

In keeping with the stated job requirements for the Chief, Chronic Viral Diseases Branch, IACFS/ME recommends the following:

2. All candidates should be required to demonstrate their past experience and future potential to deal *effectively* with the external scientific community -- especially professional organizations which look to the CDC for enlightened leadership and scientific progress.
3. When appointed, the new Chief should post a statement of intent on the CDC website with the following objectives:
 - to *develop* cooperative relationships with the external scientific community.
 - to be open to external input in the planning and implementation of studies *relevant* to CFS.
 - to publish detailed abstracts of their planned and ongoing CFS research in order to inform the scientific community and other stakeholders.
3. The CFS program should schedule regular meetings with scientists and clinicians in order to *develop* productive relationships on research and clinical management issues. Such regular meetings were part of the CDC's 5 yr. research plan in 2009. It's now 18 months since the release of the 5 yr. plan and no such meeting has been held.
4. The CDC should initiate an extramural grants program so that independent labs can generate *innovative* research that complements CDC-based studies.

These recommendations are consistent not only with job requirements but also with the Mission Statement of the CDC, which first and foremost emphasizes collaboration and partnerships to create the expertise, information, and tools that communities need to protect their health. The CDC mission statement also pledges to the American people to treat all persons with dignity, honesty, and respect.

<http://www.cdc.gov/about/organization/mission.htm>

In sum we ask that the candidate selected to head the CFS program at CDC be prepared to follow its own mission statement as well as the job's requirements: that is, to demonstrate the important ability to deal *effectively* with the scientific and professional communities.

Thank you.

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President
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