

Public Comment
Craig Maupin

CFSAC Members,

The following article is the result of a year-long inquiry into adherence to the federal records schedule and FOIA Act for the CFS program at the NIH. The article was posted on the CFS Report in May 2012 (<http://www.cfidsreport.com>)

The queries for requisite records occurred across three agencies with primary responsibilities for the administration of the CFS research program. Agencies were graded on recordkeeping (or adherence to the federal records schedule) and FOIA responsiveness.

Throughout the last decade, it has been my pleasure to deal with many committed people at the NIH -- staff who are committed to medical research and high standards. This report is designed to pinpoint possible areas of improvement, and provide my thoughts and findings on recordkeeping for the CFS program at the NIH.

Sincerely,

Craig Maupin

Recordkeeping and FOIA Compliance For the CFS Program Within the NIH

(May 2012) The CFS Report recently completed a year-long analysis into recordkeeping and FOIA compliance for the chronic fatigue syndrome (CFS) research program at the National Institutes of Health (NIH). The program was examined for several criteria: recordkeeping and adherence to the federal records schedule, FOIA responsiveness, and consistency in its application of federal guidelines and codes.

Why Examine Recordkeeping?

Recordkeeping matters. Recordkeeping demonstrates three things:

1. Agency commitment. Records are evidence of action. If meetings are missed or disinterest is widespread, apathy often is reflected in poor recordkeeping, disinterest in recordkeeping, or gaps in record schedule.
2. Appropriate recordkeeping allows agency leaders to evaluate, assess, and manage a program's progress. Without appropriate recordkeeping, little oversight is possible.
3. Appropriate recordkeeping and FOIA compliance signals to the public, the scientific community, and Congress that an agency is secure in its efforts, its decisions, and its commitment to a given issue.

By federal law, federal agencies are required to retain correspondence regarding a program's activities, decisions, and actions. Relevant correspondence to agency actions must be kept without program files for 10 years before transferred to the National Archives. Committees nested within agencies that have an advisory role or planning task must also maintain appropriate records, including minutes and correspondence.

Recordkeeping for CFS

The Office of Research of Women's Health (ORWH), which operates under the Office of the Director, is the agency where the CFS program has resided since 2001. The ORWH oversees the Trans-NIH ME/CFS Research Working Group (CFSWG), a group that is purported to meet monthly. A director for the CFS research program at the NIH, appointed by the ORWH, maintains an office in the ORWH.

The ORWH was able to provide 41 pages of meetings for the Trans-NIH CFS Research Working Group, covering roughly two dozen meetings in a ten-year period. However, from

2007-2010, the ORWH could produce records for one meeting of the Trans-NIH Working Group.

According to officials at the NIH, the CFS WG does not "make recommendations to the agency", nor does it "serve in an advisory capacity to the NIH". NIH officials also maintain that the CFS WG is "not mandated to meet regularly, and in fact, not many formal meetings have taken place in the last few years" (2). According to a unnamed source with knowledge of the NIH, the Working Group's activities languished with disinterest and apathy from 2007-2010. NIH officials assert that because the ME/CFS WG has no advisory or planning role in regards to the program, the ORWH need not maintain minutes or records of activities.

At the Center for Scientific Review (CSR), current CFS Special Emphasis Panel chair was able to produce records of both correspondence with the CFS Research Working Group and reviewers. The CSR also maintains appropriate rosters, total grant submissions, and total dollar amounts of grants received by past CFS SEP review panels.

The Center for Scientific Review could produce no records for internal or external correspondence to and from retired chair Terrell Hoffeld from 2001-2010. Such files are required to be kept in the CFS SEP program office at the CSR. The NIH made a determination on September 28, 2011 that "no records exist" (1).

The NIAID administered the NIH extramural and a small intramural program, headed by Dr. Stephen Straus, before 1999. An examination of available records turned up various records before 1995. However, for the period of 1995-1999, Straus' last years managing the CFS program, the NIH could find no internal or external correspondence relating to activities of the intramural CFS program.

Recordkeeping Grades

Current recordkeeping seemed acceptable at the CSR; however, huge holes in recordkeeping at both institutes. The NIH insists the Trans-NIH CFS Research Working Group is not required to meet or keep records, having no advisory or planning capacity.

CSR -- D+

ORWH -- D-

NIAID -- D+

FOIA Responsiveness and Consistency

Overall, I found some of the FOIA officers both helpful and willing to collaborate with the requester. A collaborative relationship between the requester and FOIA officer can cut response times and streamline the process. The NIAID received the highest scores for FOIA

responsiveness. The FOIA officer at the NIAID was consistent, well-informed of the records schedule, and willing to extend the search to the National Archives, when necessary.

The most troubling aspects of FOIA compliance were in the areas of consistency. For instance, one request to the ORWH was denied based on Exemption 5, an exemption intended to promote open and frank discussion among those responsible for making government decisions. Despite invoking this exemption, the NIH claimed, in another response, that the committee subject of the request had no decision-making, advisory, or planning role. Contrary to these claims, a webpage on the ORWH site in 2008 asserted that "the ORWH leadership role is exercised through the Trans-NIH Working Group for Research on Chronic Fatigue Syndrome".

Several denials were based on the idea that the NIH would not be able to locate files pertaining to any broad topic without undue burden. These denials are based on a broad interpretation of common law, rather than federal code. However, such denials were also plagued by inconsistency. For instance, a request for files required was denied because the files were "not found"; however, a response to an appeal made no mention that the files were stated to not exist in the earlier denial. The "too broad" defense only seemed to appear when the requester demonstrated awareness of the records schedule and location of the files. When the location of the files was agreed upon by the requester and the FOIA supervisor, the office remained unwilling to retrieve the files.

Potential problems with inconsistent justifications are twofold. First, according to the record schedules, certain files must be kept in the program office of each institute. In each case, the request was able to pinpoint the location of the files. Second, after responding to a request that "files could not be found", several appeals seemed to fall back on the "too broad" defense. Inconsistency between initial denials and appeals could raise speculation as to whether required records are missing, lost, destroyed, or simply not applied to FOIA, particularly, as an earlier request was denied on the basis that the records were not available.

FOIA Compliance and Consistency Grades

NIAID -- A-

OD (ORWH) -- D+

CSR -- C

Conclusion

The most glaring gap in the records schedule for CFS is a gap in records for Dr. Stephen Straus from 1995-1999. It would be unusual for the administrator of an intramural program to

create no records pertaining to the administration of the program for a period of five years. However, this appears to be the case.

Similar gaps in the records schedule occurred with Dr. Eleanor Hanna and Dr. Terrell Hoffeld, though requests for records that were originally determined to be "not found" or destroyed records were later denied based on a tentative broadness defense. Problems with gaps in the record schedule for CFS appear to occur across agencies.