

The ME/CFS SEP isn't just any panel. Dig down into the 225+ grant review panels at NIH and you'll find (except for those on HIV/AIDS) only one devoted to another disease - the ME/CFS SEP one.

Look more closely at the titles of those panels and you'll find specific diseases mentioned (other than HIV/AIDS) only a handful of times. With the exception of HIV/AIDS and ME/CFS virtually all of the hundreds of grant review panels focus on processes -- not diseases.

How did chronic fatigue syndrome (ME/CFS) get its own review panel? My understanding is that the panel was created several decades ago in the wake of the CDC fiasco. Recognizing that systemic bias against ME/CFS existed, the NIH produced a panel specifically for ME/CFS in order to give ME/CFS researchers a leg up in the grant review process.

Unfortunately, it didn't always work out that way. In fact, the ME/CFS SEP panel and its makeup would be a sore spot for ME/CFS advocates for at least a decade.

One of the reasons may have been the panel's initial focus. Although the panel was putatively on chronic fatigue syndrome, [Craig Maupin of The CFS Report](#) reported in 2004 that the CFS SEP's original mandate called for it to examine the "causes, manifestations and treatments of the Chronic Fatigue Syndrome, the Fibromyalgia Syndrome and other chronic polysystemic morbidity syndromes."

After Dr. Hoffield, a dentist, was appointed to lead the review panel, he tended to fill the panel with pain and jaw specialists, who, ME/CFS researchers asserted, tended to rate immune or pathogen grants poorly. Hoffield maintained that he simply produced panels that reflected the nature of the grant applications before him: the panel had a lot of pain researchers because it received more pain grant applications.

Pain and TMJ researchers applauded as immune researchers stewed at reviewer comments indicating the reviewers didn't know the first thing about their topic.

An analysis made by Craig Maupin [in 2004](#) found that less than 20% of the reviewers had even a minimal interest in chronic fatigue syndrome. In 2007, Ron Glazer, at that time a CFS federal advisory committee (CFSAC) member, reported that only 15% of the CFS grant review panel members over the previous three years had a [background related to ME/CFS](#) (and none of them had a background related to ME/CFS **etiology**).

[Pat Fero's analysis](#) pegged ME/CFS grant acceptance rates at about six percent from 2006-2008. She concluded that two-thirds of the grants awarded by the panel during those years went to diseases other than chronic fatigue syndrome.

At one point the researchers began to go public. Andrew Lloyd of the [Dubbo studies](#) described a grant he'd twice altered to accommodate the reviewers' critiques which then didn't make it past the first round on the third try. Ron Glazer, a well-published

researcher, described the ineptitude of the people reviewing his grant. Glazer said he'd never, in his decades of research, "seen anything like it". (Glazer finally did get his ME/CFS grant funded, ironically, by going to a non-ME/CFS panel.)

The low number of grant applications for ME/CFS has been a concern for decades, but it's possible that something of a vicious circle began. Believing their applications had little chance of being accepted, ME/CFS researchers may have submitted fewer of them while applications for research on pain and fatigue on other diseases such as fibromyalgia increased.

Pat Fero reported that in May 2008, the CFSAC research subcommittee concluded that the inability of the CFS SEP to give ME/CFS grants a fair review would likely lead researchers to pursue other research areas that would give them a better chance to advance their career goals.

Years of advocacy appeared to pay off in 2010 with the appointment of a new panel administrator, Dr. Leutke. Kim McCleary of the CFIDS Association of America signaled relief when she stated Dr. Leutke "is obviously more receptive to the recommendations that we've been submitting for years for reviewers with knowledge of CFS". That 2010 panel was packed to the gills with ME/CFS experts such as Gordon Broderick, Maureen Hanson, Nancy Klimas and Mary Fletcher.

- [The Stars Begin to Align at the NIH: A CFS Review Panel.... For CFS!](#)

Half of the next June 2011 panel had experience in ME/CFS, and from 2012 to the present the CFS SEP review panel has been staffed almost entirely by ME/CFS experts.

Two Freedom of Information Act (FOIA's) requests suggest, however, making the panel more ME/CFS friendly has made little difference in grant application rates.

In fact, 2011 showed a dramatic drop in applications (n=20). Grant application rates rebounded a bit in 2012 (n=30) but then tanked again. Instead of increasing the number of grant applications to the panel, they have plummeted since Leutke began packing the panel with ME/CFS experts. The thirteen grant applications received in 2016 were the lowest the panel has received since at least 1999. Nancy Klimas called the number of applications given to a panel she was on "pitiful".

Grant Application - Pre-Leutke

2005 - 40
2006 - 66 (includes Neuroimmune RFA)
2007 - 41
2008 - 45
2009 - 36

Number of Grant Applications - Past Five Years

2011 - 20
2012 - 30
2013 - 16
2014 - 18
2015 - 26
2016 - 13

It's possible that the recent dramatic decline seen in the number of grant applications may have resulted from a decision to refocus the panel entirely on ME/CFS. The last pain researchers appeared on the panel around 2011. From then on the panel would devote itself entirely to ME/CFS - making the number of ME/CFS-specific grant applications clear.

"SEP Mandate: The Myalgic Encephalomyelitis/Chronic Fatigue Syndrome recurrent Special Emphasis Panel [ME/CFS SEP] reviews applications in the multiple disciplines applied to studies of the potential causes, diagnosis, pathogenesis, clinical manifestations, epidemiology, and treatments of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. "

For many years the NIH has said that if they get more "good" grant applications they will fund them. That idea has largely been scoffed at by the ME/CFS patient community which has assumed that poor reviewers were thwarting the success of ME/CFS grants. That may have been true in the past but is not true anymore. The ME/CFS SEP panel has clearly been open for business for the past five years but the number of grant applications has not reflected that.

- [FOIA Indicates Lack of Interest Dogs Chronic Fatigue Syndrome Field](#)

It's possible that other roadblocks in the process remain. The Institutes, for instance, may not have been funding well-scored ME/CFS grants. A NIH Reporter search using the term "chronic fatigue syndrome" for active projects from 2012 to 2016 suggests, however, that ME/CFS grant applications were being funded at a good clip. If the results are accurate, in fact, they suggest ME/CFS applications success rates are at least similar to that found in the [neurological and immunological Institutes](#). (NINDS - 20%, NIAID - 24%).

(The search included all grant rewards in the results including those which involved multiple rewards for the same study. Five multiple awards for the same study were found. I assumed that the few studies which did not list the grant review panel the studies were reviewed in were reviewed by the CFS SEP.)

ME/CFS Grant Success Rates

Year	# of Grants	# of Grants	Success
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	Submitted	Funded	Rate
2011	18	4	22%
2012	30	6	20%
2013	16	5	31%
2014	18	8	45%
2015	26	5	19%
2016	13	5	38%

The NIH-funded ME/CFS research centers will help, but in his recent talk Dr. Koroshetz noted that most of the NIH funding comes from investigator-initiated grants, making it critical for the field and for the ME/CFS community that the number of investigator-initiated grant applications increase substantially.

This short survey suggests that the ME/CFS grant review panel is open for action. While grant application success rates at the NIH will probably never be high, this survey, if correct, suggests that bias is not a major issue for grants proceeding through the CFS SEP either.

Grant Applications Per Year to the ME/CFS SEP

1999 - 17
2000 - 32
2001 - 19
2002 - 25
2003 - 30
2004 - 39
2005 - 41
2006 - 68 (Neuroimmune RFA)
2007 - 41
2008 - 45
2009 - 36
2010 - 45
2011 - 2