

The CFIDS Association of America

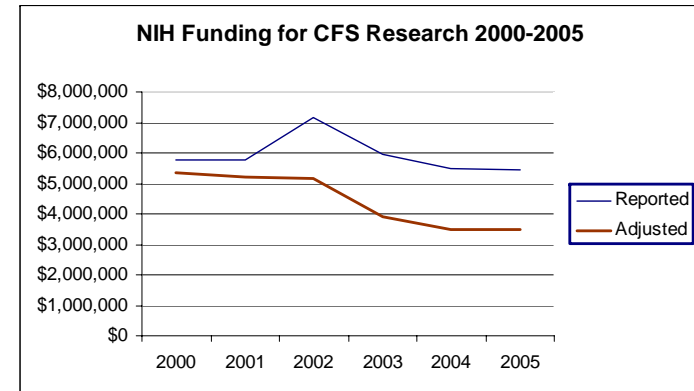
Working to conquer chronic fatigue and immune dysfunction syndrome

Updated Analysis of NIH-Funded Research on Chronic Fatigue Syndrome Shows Continued Trend of Diminishing Support Fiscal Years 2000-2005

Prepared by the CFIDS Association of America and presented to the Department of Health and Human Services Chronic Fatigue Syndrome Advisory Committee on July 17, 2006

Overview

In July 2006, the National Institutes of Health reported to Congress on its activities related to chronic fatigue syndrome (CFS, also known as chronic fatigue and immune dysfunction syndrome or CFIDS). The report from NIH includes as appendices lists of funded grants classified as CFS for FY2000-2005, as well as instructions for coding grants as CFS and an accounting for the number of CFS-related applications received and funded by NIH.



The CFIDS Association performed a careful analysis of NIH-related CFS grants from FY1999-2003 and presented it to the CFS Advisory Committee and Congress in September 2004. Based on discussions with principal investigators, NIH program officers and searches of NIH's CRISP database and the published scientific literature, we demonstrated that \$5.2 million did not appear to have direct relevance to CFS and another \$1 million were studies of conditions similar to CFS, but diagnostically distinct. Adjusting for both types of misclassification of research funding, the amount NIH spent on CFS research between FY1999-2003 dropped by 18%, from \$31.6 million to \$25.9 million. Updating this analysis to include grants reported for FY2004 and 2005, our findings are similar, as indicated on Tables 1 and 2 (attached). **For 2004-2005, 35% of reported funds relate to grants for which the relevance to CFS is limited.** Of the \$35.6 million reported to have been spent on CFS between 2000 and 2005, only 75% (\$26.7 million) appear to be directly related to CFS. Therefore, the new coding instructions for CFS grants issued by NIH allow the inclusion of studies which may have very limited application to CFS, and for which the principal investigator claims no active interest in CFS. While studies investigating various biologic mechanisms can lead to advances for many diseases and conditions, it is essential to have an accurate accounting for studies specific to CFS as a measure of progress in the field. Agreement about what constitutes CFS research is an important foundation for assessing other federally-supported research activities.

CFS warrants a considerably more robust research investment from NIH, the world's largest biomedical research institution. CFS affects at least one million American adults and costs the U.S. economy \$9.1 billion a year in lost productivity. Although CFS is severely disabling, 80% of Americans who have the illness are not appropriately diagnosed or cared for by medical professionals. There is still no diagnostic marker and treatment is limited to symptom relief, largely as a consequence of insufficient research. The lack of progress as demonstrated by NIH support since our 2004 funding analysis is alarming and must be vigorously addressed.

**Table 1:
Analysis of NIH Grants for CFS Research
Projects of Questionable Relevance to CFS
Fiscal Years 2000-2005**

Prepared by the CFIDS Association of America

Project abstracts have been reviewed for information that would support classification as CFS research. No such support was found for the projects listed below. Only two of these grants were reviewed by the CFS Special Emphasis Panel, ZRG1. Projects are listed in chronological order of the year funding begins.

| Project Title | Institution | Principal Investigator | Funding Institute/ IRG | Fiscal Year | Amount | Total |
|---|------------------------------|------------------------|------------------------|-------------|-----------|-------------|
| Clinical neurocardiology: catecholamine systems in stress and disease | NIH Intramural Research | David Goldstein | NINDS (n/a) | 2000 | \$391,603 | |
| <i>Note: The abstract for these studies mentions reflex sympathetic dystrophy, Shy-Drager syndrome and Parkinson's Disease. A review of the literature finds no CFS-related publications by this investigator from 1999 to present.</i> | | | | 2001 | \$426,260 | |
| | | | | 2002 | \$410,246 | |
| | | | | 2003 | \$523,056 | |
| | | | | 2004 | \$531,506 | |
| | | | | 2005 | \$559,424 | \$2,842,095 |
| Coordinating center for clinical and epidemiology studies in infectious diseases | Technical Resources, Inc. | Hugh Klein | NIAID (unnamed) | 2000 | \$2,685 | \$2,685 |
| <i>Note: There is no abstract available for this study.</i> | | | | | | |
| Pathophysiology of neuroimmune communication | Ohio State Univ. | Ning Quan | NINDS (ZRG1) | 2001 | \$128,661 | |
| <i>Note: This investigator has stated that he is not studying anything directed related to CFS.</i> | | | | 2002 | \$128,625 | |
| | | | | 2003 | \$128,625 | \$385,911 |
| Transcriptional regulation of E-selectin | Children's Hospital (Boston) | Tucker Collins | NHLBI (PTHA) | 2002 | \$177,750 | |
| <i>Note: The abstract states that the project may "provide novel strategies for therapeutic approaches to the important problem of vascular disease." NHLBI program officers have confirmed that this is not CFS-</i> | | | | 2003 | \$177,750 | |
| | | | | 2004 | \$177,750 | |

| Project Title | Institution | Principal Investigator | Funding Institute/ IRG | Fiscal Year | Amount | Total |
|--|------------------------------------|-------------------------------|-------------------------------|--------------------|---------------|--------------|
| <i>related research.</i> | | | | 2005 | \$177,750 | \$711,000 |
| Reactive species in vascular disease-injury mechanisms | Children's Hospital (Philadelphia) | Harry Ischiropoulos | NHLBI (LBPA) | 2002 | \$170,000 | |
| <i>Note: The project abstract states, "Overall the proposed experiments will evaluate in a systematic manner the critical role of endogenously generated nitrous oxide as a mediator of cellular metabolism and respiration that enables cells to resist oxidative stress." NHLBI program staff have confirmed that this is not CFS-related research</i> | | | | 2003 | \$170,000 | |
| | | | | 2004 | \$170,000 | |
| | | | | 2005 | \$170,000 | \$680,000 |
| Molecular basis for protein-phospholipid interaction | Northwestern Univ. | Jon Lomasney | NHLBI (ZHL1) | 2002 | \$148,583 | |
| <i>Note: NHLBI program staff have confirmed that this is not CFS-related research and the investigator has confirmed that he is not studying CFS. The project abstract contains nothing specific to CFS.</i> | | | | 2003 | \$149,000 | |
| | | | | 2004 | \$148,500 | |
| | | | | 2005 | \$148,500 | \$594,583 |
| Mechanisms by which IGF-1 stimulates smooth muscle cells | UNC Chapel Hill | David Clemmons | NHLBI (END) | 2002 | \$194,028 | |
| <i>Note: The project abstract concludes with the statement, "The results [of this study] may suggest novel strategies for interfering with these processes to alter the progression of atherosclerosis." NHLBI program staff have confirmed that this is not CFS-related research.</i> | | | | 2003 | \$199,455 | |
| | | | | 2004 | \$203,694 | |
| | | | | 2005 | \$209,541 | \$806,718 |
| Endothelial cell dysfunction in oxidative stress models | Med. Coll. of Georgia | Robert Caldwell | NHLBI (PTHA) | 2002 | \$125,562 | |
| <i>Note: The abstract refers to the study of "cardiovascular disease including diabetes mellitus"; NHLBI program staff have confirmed that this is not CFS-related research.</i> | | | | 2003 | \$125,562 | |
| | | | | 2004 | \$125,562 | |
| | | | | 2005 | \$125,562 | \$502,248 |
| Viral dsRNA as a mediator of chronic muscle diseases | Univ. of Minnesota Twin Cities | Patricia Tam | NIAID (ZAI1) | 2002 | \$329,987 | |
| <i>Note: A review of the literature finds no CFS-related publications by this investigator from 1999 to present and she has indicated that her research has no direct relationship to CFS.</i> | | | | 2003 | \$334,125 | |
| | | | | 2004 | \$334,125 | |
| | | | | 2005 | \$349,860 | \$1,348,097 |

| Project Title | Institution | Principal Investigator | Funding Institute/ IRG | Fiscal Year | Amount | Total | |
|---|--|------------------------|------------------------|-------------|--------------|--------------------|-----------|
| Biobehavioral randomized trial for patients on interferon | Oregon Health Sciences Univ. | Anna Schwartz | NCRR (n/a) | 2002 | \$5,555 | \$5,555 | |
| <i>Note: No abstract is available on CRISP. Note: A review of the literature finds no CFS-related publications by this investigator from 1999 to present.</i> | | | | | | | |
| Immunoneuroendocrine response to tetanus toxoid | Brigham & Women's Hospital | Gail Adler | NCRR (n/a) | 2002 | \$6,029 | | |
| <i>Note: A review of the literature finds a 1999 paper on tetanus toxoid stimulation by this author, although the study was of healthy subjects. This author has several publications on fibromyalgia, but none on CFS.</i> | | | | | 2004 | \$4,821 | \$10,850 |
| Heat stress and circulatory control | Univ. of Texas SW Med. Center - Dallas | Craig G. Crandall | NHLBI (RESP) | 2004 | \$61,066 | | |
| <i>Note: The abstract makes no mention of CFS and CFS is not listed in the key words.</i> | | | | | 2005 | \$47,164 | \$108,230 |
| International symposium on motor control using TMS | East Carolina Univ. | Tibor Hortobagyi | NINDS (ZRG-1) | 2004 | \$2,250 | \$2,250 | |
| <i>Note: No abstract available; CFS is not listed in "key words"</i> | | | | | | | |
| SPECT & DNA binding of naphtylimido imidazoacridone WMC79 & related compound | Univ. of Mary. Baltimore | Sergey G Tarasov | NCRR (n/a) | 2004 | \$43,966 | \$43,966 | |
| <i>Note: No abstract available</i> | | | | | | | |
| Neuro-Rehab measurement | [Loan Repayment Institutions] | Catherine Frantom | NINDS (n/a) | 2005 | \$3,058 | \$3,058 | |
| <i>Note: No information available</i> | | | | | | | |
| | | | | | TOTAL | \$8,047,246 | |

**Table 2:
Analysis of NIH Grants for CFS Research
Projects Focused on Conditions “Related” to CFS
Fiscal Years 2000-2005**

Prepared by the CFIDS Association of America

Project abstracts have been reviewed for information that would support inclusion as CFS studies and have been found to have limited application to the study of CFS. In recognition that research on related conditions may have bearing on studies of CFS, an adjustment of 50% of the yearly total for these projects has been made. Projects are listed in chronological order of the year funding begins.

| Project Title | Institution | Principal Investigator | Funding Institute | Fiscal Year | Amount | Total |
|---|--------------------------------|-------------------------------|--------------------------|--------------------|---------------|--------------|
| Neuroendocrinology of masticatory muscle disorders | Univ. of Michigan Ann Arbor | Elizabeth Young | NIDCR | 2000 | \$10,698 | \$10,698 |
| <i>Note: Abstract refers to temporomandibular joint disorder and fibromyalgia</i> | | | | | | |
| Chronic fatigue in Lyme disease | SUNY | Lauren Krupp | NCRR | 2001 | \$2,473 | |
| <i>Note: No abstract available, although CRISP does list CFS in grant's list of key words</i> | | | | 2002 | \$1,743 | \$4,216 |
| Skin cooling to improve orthostatic tolerance | Univ. Texas SW Med. Ctr. | Craig Crandall | NHLBI | 2002 | \$134,750 | |
| <i>Note: Some CFS patients demonstrate orthostatic intolerance; the percentage varies greatly by investigator</i> | | | | 2003 | \$131,500 | |
| | | | | 2004 | \$131,500 | |
| | | | | 2005 | \$131,500 | \$529,250 |
| Response to light in patients with delayed sleep phase syndrome | Northwestern Univ. | Susan Bencoulif | NCRR | 2002 | \$532 | \$532 |
| <i>Note: No abstract available</i> | | | | | | |
| Autonomic function in patients with syncope and normal controls | Columbia Univ. Health Sciences | Daniel Bloomfield | NCRR | 2002 | \$252 | \$252 |
| <i>Note: No abstract available</i> | | | | | | |
| Mechanisms in chronic multisymptom illnesses | Georgetown Univ. | Daniel Clauw | NCRR | 2002 | \$436,360 | |
| <i>Note: No abstract available</i> | | | | 2003 | \$222,438 | \$658,798 |

| Project Title | Institution | Principal Investigator | Funding Institute | Fiscal Year | Amount | Total |
|--|-----------------------------|------------------------|-------------------|-------------|-----------|-----------|
| Role of fatigue in rheumatic diseases | UMDNJ | Gudrun Lange | NIAMS | 2003 | \$49,704 | \$49,704 |
| <i>The abstract states: "The primary objective of the proposed workshop is to establish a knowledge base of current information on fatigue in rheumatic illness that will be compared with the state of knowledge gained from studies of fatigue in cancer, HIV/AIDS, stroke, and MS." CFS does not appear in the abstract or list of key words.</i> | | | | | | |
| Pain perception in fibromyalgia | Univ. of Ala. At Birmingham | Laurence Bradley | NCRR | 2003 | \$4,978 | \$4,978 |
| <i>Note: No abstract available</i> | | | | | | |
| Disordered responses to orthostatic stress in Gulf War Syndrome symptoms | Johns Hopkins Univ. | Peter Rowe | NCRR | 2002 | \$433 | |
| <i>Note: No abstract available</i> | | | | 2003 | \$9,870 | |
| | | | | 2004 | \$7,991 | \$18,294 |
| Are fibromyalgia and Chiari 1 malformation related? | Univ. of Washington | Dedra Buchwald | NIAMS (ZRG-1) | 2003 | \$146,712 | |
| <i>Abstract indicates that fibromyalgia patients recruited to the study will be assessed for CFS.</i> | | | | 2004 | \$146,712 | |
| | | | | 2005 | \$127,983 | \$421,407 |
| Subject Registry: Interdisciplinary studies of chronic multi-symptom illnesses | Univ. of Mich. Ann Arbor | David A. Williams | NCRR | 2004 | \$9,149 | |
| <i>Note: No abstract available</i> | | | | 2005 | \$77,197 | \$86,346 |
| Factors in arthritis, CFS, fibromyalgia & TMJ disorders | Univ. of No. Car. | Kathleen C. Light | NCRR | 2004 | \$74,144 | |
| <i>Note: No abstract available</i> | | | | 2005 | \$17,907 | \$92,051 |
| Movement restriction and fatigue in cancer survivors | Johns Hopkins Univ. | Cindy Schwartz | NCRR | 2004 | \$157 | |

| Project Title | Institution | Principal Investigator | Funding Institute | Fiscal Year | Amount | Total |
|------------------------------------|--------------------|-------------------------------|--------------------------|--------------------|---------------|--------------------|
| <i>Note: No abstract available</i> | | | | 2005 | \$1,246 | \$1,403 |
| | | | | | TOTAL | \$1,877,929 |

Adjustment Detail:

| | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | Total |
|--|-------------|-------------|-------------|-------------|-------------|-------------|------------------|
| Total support for conditions related to CFS | \$10,698 | \$2,473 | \$574,070 | \$565,202 | \$369,653 | \$355,833 | \$1,877,929 |
| Amount of adjustment | \$5,329 | \$1,237 | \$287,035 | \$282,601 | \$184,826 | \$177,917 | \$938,964 |

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**Table 3:
Analysis of NIH Grants for CFS Research
Adjusted Funding Summary by Year
Fiscal Years 2000-2005**

Reported funding amounts are adjusted by the value of studies inappropriately classified in full as CFS, as described on Tables 1 and 2

| | 2000 | 2001 | 2002 | 2003 | 2004 | 2005 | Total |
|--|-------------|-------------|---------------|---------------|---------------|---------------|----------------------------|
| Reported by NIH | \$5,769,075 | \$5,759,731 | \$7,157,974 | \$5,940,874 | \$5,482,957 | \$5,457,921 | \$35,568,532 |
| Adjustment for projects of questionable relevance to CFS (Table 1) | <\$394,288> | <\$554,921> | <\$1,696,365> | <\$1,807,573> | <\$1,803,240> | <\$1,790,859> | <\$8,047,246> |
| Adjustment for projects focused on conditions “related” to CFS (Table 2) | <\$5,329> | <\$1,237> | <\$287,035> | <\$209,245> | <\$184,826> | <\$177,917> | <\$865,589> |
| Adjusted Total | \$5,369,458 | \$5,203,573 | \$5,174,574 | \$3,924,056 | \$3,494,891 | \$3,489,145 | \$26,655,697 |