

Declaration of interests form

Instructions: You should declare and describe any financial interest relevant to your Cochrane advisory board role falling into one or more of the below categories that you have held within the time period beginning 36 months prior to submission of this declaration.

An interest is relevant for this role if you have received payment from a commercial organization with an interest in the topic of the review(s) you advise on. This means that the organization has developed (or is known to be developing), or distributes (anywhere in the world), an intervention or potential comparator related to the topic of the review(s). This applies even if the payment was made for work or advice that did not relate to the topic of the review(s).

Further details can be found in Cochrane's policy on [Conflict of Interest for Cochrane Library Content](#)

Name: Lily Chu, MD, MSHS

1. Financial interests

a) Received research funding: any grant, contract or gift, commissioned research, or fellowship from any organisation related to health care or medical research (for example Cochrane, a non-governmental organisation, a pharmaceutical or medical device company, a healthcare charity or a patient advocacy group) to conduct research?

Yes

No

If yes, please provide details:

Towards the end of 2019, I and colleagues at Stanford University (California, USA; Drs. Kegan Monaghetti and Jeff Christie) received a grant from the non-profit, patient advocacy/research organization Solve ME to examine how the autonomic nervous system reacts to physical activity. I serve as an unpaid Co-Investigator.

I serve as an unpaid consultant on a project examining long-term outcomes of SARS-CoV-2 infection including development of ME/CFS in the state of Florida, USA. This project is funded by the US Centers for Disease Control and Prevention (CDC) and led by Dr. Nancy Klimas of the Institute for Neuro-Immune Medicine based at Nova Southeastern University (Fort Lauderdale, Florida).

b) Had paid consultancies: any paid work, consulting fees (in cash or kind) from an organisation related to health care or medical research?

Yes

No

If yes, please provide details:

c) Received honoraria: one-time payments (in cash or kind such as travel expenses) from an organisation related to health care or medical research?

Yes

No

If yes, please provide details:

d) Served as a director, officer, partner, trustee, employee or held a position of management with an organisation related to health care or medical research?

Yes

No

If yes, please provide details:

e) Possessed share-holdings, stock, stock options, equity with an organisation related to health care or medical research (excludes mutual funds or similar arrangements where the individual has no control over the selection of the shares)?

Yes

No

If yes, please provide details:

f) Received personal gifts from an organisation related to health care or medical research?

Yes

No

If yes, please provide details:

g) Had an outstanding loan with an organisation related to health care or medical research?

Yes

No

If yes, please provide details:

h) Received royalty payments from an organisation related to health care or medical research?

Yes

No

If yes, please provide details:

2. Non-financial interests

Do you have any other interests that would reasonably appear to be related to the primary interest? Such interests could include, but are not limited to, publicly declaring any strong opinions about this health area, unpaid membership of committees, advisory boards or patient advocacy groups in this health area, and being a named author of a study that might be included in this review.

Yes

No

If yes, please provide details:

I have been personally affected by ME/CFS since 2006.

I was a member of the Community Advisory Board for the Stanford ME/CFS Initiative from 2012 - 2021. I occasionally advised clinicians and researchers about ME/CFS.

I have been a Board Member of the International Association for Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (IACFS/ME) since 2011 and Vice President since 2014. Since 1990, IACFS/ME has served as the professional organization for researchers and clinicians dedicated to ME/CFS.

IACFS/ME advocates for science-backed care, research, education, and health policy. The IACFS/ME Board and the majority of our members do not believe ME/CFS is due to deconditioning or an irrational/ exaggerated fear or avoidance of physical activity. Our examination of the science leads us to believe neurological, immunological, metabolic, and other abnormalities cause or contribute to ME/CFS. These ideas are reflected in our activities and our materials: we have not supported graded exercise therapy (GET) or cognitive behavioral therapy (CBT) for every ME/CFS patient for well over a decade. We do support [careful activity/ exercise programs](#) that take into account the health/ values/ preferences of individual patients and CBT for psychological/ psychiatric conditions and [problems coping with the effects of ME/CFS](#).

IACFS/ME's views are well-known via prior [letters to editors](#), our [2014 Clinician Primer](#), and various past position statements.

From 2012-2020, at various times, I was invited by the US Centers for Disease Control and Prevention (CDC), Food and Drug Administration (FDA), National Institutes of Health (NIH), and the National Academy of Medicine (NAM) to give input on projects. For the 2013 FDA Drug Development Workshop for ME/CFS, the [online survey](#) I conduct with colleagues showed that between 42%-64% of respondents reported worsening with exercise programs. In 2015, under the auspices of the NAM, I co-authored the report "[Beyond Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: Re-defining an Illness](#)" which made post-exertional malaise a required criteria for diagnosing ME/CFS. For the 2017-2018 NIH Common Data Elements Working Group, whose mission was to establish and promote standardized outcomes across studies, I was the Co-Chair for the Post-exertional Malaise Subgroup. [This is the document](#) summarizing our recommendations.

I assisted in compiling and writing materials for the US ME/CFS Clinician Coalition, in particular, the [short diagnostic and treatment summary](#) on their website. A paper elaborating on the summary, "[Myalgic Encephalomyelitis/ chronic fatigue Syndrome: Essentials of Diagnosis and Management](#)", was published in the Mayo Clinic Proceedings in August 2021.

Trusted evidence.
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Better health.

I do not know if the papers I have co-authored will be included in this project. They are not clinical trials of exercise or cognitive behavioral therapies. My papers have focused on the role of cytokines, use of case definitions, epidemiology of ME/CFS, and characteristics and pathophysiology of post-exertional malaise. I also recently co-authored a paper on environmental accommodations for university students disabled by ME/CFS. [This is my bibliography.](#)

In [2016](#) and [2018](#), along with many other clinicians and researchers, I signed letters requesting the Lancet to appoint experts to perform an independent re-analysis of the 2011 PACE study. The same standards that are applied to other studies, regardless of the medical condition, intervention, setting, etc., must be applied to ME/CFS studies as well if we are to solve this condition. My life and millions of other lives depend on excellent science.