

Public comment on the P2P Draft Report on ME/CFS

Dear Sir/Madam,

I would like to contribute with a public comment from outside of the US. I live in Queensland, Australia, and I want to share the experience we have here of the successful establishment of a biomedical Centre of Excellence for ME/CFS.

I refer to these lines of the report:

Lines 111-112: Future studies must be collaborative, multicenter efforts and must include large, diverse samples across the lifespan.

Lines 328-329: Create a network of collaborative centers working across institutions and disciplines, including clinical, biological, and social sciences.

I know the ME/CFS community (the medical ME/CFS community as well as the patient community) have long called for the establishment of ME/CFS Centres of Excellence in the US, since the previous CFS Research Centres were shut down.

In your draft report, you do not mention the term “Centres of Excellence”, but maybe the recommendations in the lines above mean something similar?

I would request that you, in the final version of the report clarify this further, making a prioritized recommendation with a set time-target that NIH establish Centres of Excellence for ME/CFS across the US focused on biomedical bench-to-bedside research.

I offer this good example from Australia:

In Queensland, a Centre of Excellence called National Centre for Neuroimmunology and Emerging Diseases (NCNED) has been established within Griffith University. It is a combined research hub and clinic, designed to perform world-leading research as well as provide adequate medical care for ME/CFS.

ME/CFS patients in Queensland, Australia, are certainly lucky, since this is one of the very few proper ME/CFS clinics in the world. Other examples would be the US clinics participating in the US Centers for Disease Control and Prevention’s multi-site study, such as Center for Neuro-Immune Disorders (FL), Open Medicine Clinic (CA), Fatigue Consultation Clinic (UT) and Sierra Internal Medicine Associates (NV). I estimate that there are less than a dozen places in the world where ME/CFS patients can get proper biomedical care.

NCNED at Griffith University focuses its research on the key area in ME/CFS, the neuro-immune system. It aims to find biomarkers and immune-modulating treatments. It staffs 20 people: clinicians, researchers and a nurse.

One important feature of this COE is that it is designed to meet the needs of the severely ill patients. As you may know, this is a part of the ME/CFS population which is even more blatantly underserved than the rest. A significant proportion of ME/CFS patients are severely affected and debilitated, many are house-bound, some are completely bedridden and in need of 24-hour care. Many are very sensitive to sensory input such as light, noise, touch, interaction with other people. Almost nowhere in the world do these patients get to see physicians, since they are unable to make it to clinics.

NCNED caters for patients with severe ME/CFS by making house calls both for clinical and research purposes. The clinic is also built to suit the severely affected, with specially adapted hospital beds in single rooms, shielded from lights and sound, and with staff educated in the needs of severely ill ME/CFS patients.

From the website of NCNED:

#### NCNED Mission

Our mission is to perform world class biomedical research that will contribute to the understanding of myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) through the identification of physiological mechanisms and biomarkers.

#### NCNED Aims:

To be recognised for world-class clinical and population based health and medical research.

To collaborate with local, national and international research institutes and researchers.

To translate research into preventative medicine, social and clinical care and public health outcomes.

To create sustained improvements in health and health care for individuals with ME/CFS

In conclusion: I suggest that the final P2P report be strengthened by

- a prioritized recommendation with a set time-target that NIH establish Centres of Excellence for ME/CFS across the US focused on biomedical bench-to-bedside research

- inclusion of a section mentioning the severely ill ME/CFS patients and their specific needs: house calls, inclusion in research studies via collection of blood and other samples etc in the home environment, especially adapted hospital beds in single rooms (no strong lights, no sounds, staff educated in the needs of severely ill ME/CFS patients)

Reference:

NCNED website:

<http://www.griffith.edu.au/health/national-centre-neuroimmunology-emerging-diseases>

Thank you for taking my comment into consideration.

Kind regards,

Sharon Light

Australia