The Case for Ramping Up ME Research

Rory Preston • Jan 2025



CrunchME

ME/CFS is a hellish condition, with amongst the worst quality of life of any illness

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A study by Hvidberg et al. (2015) found ME/CFS to have the worst health-related quality of life for any illness group, including cancers, sclerosis, and chronic renal failure.

Life is worse still for people at the severe end of the ME/CFS spectrum.

ME/CFS is one of the most underfunded conditions relative to its disease burden

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A study by Mirin et al. (2022) found that NIH funding in the US to be 3% of the level required to be commensurate with similarly burdensome diseases.

This is a picture that is mirrored around the world.

The economic cost of ME/CFS is massive and due to COVID, continues to worsen

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Mirin et al. (2022) estimate the annual economic burden of ME/CFS in the US has increased from $44bn pre-COVID, to $255bn now - a nearly 6-fold increase.

Estimates of the percentage of long COVID patients meeting the diagnostic criteria for ME range from around 10% to ~50%

World-class researchers have found many biomedical abnormalities in patients

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These include autonomic nervous system dysfunction, cardiac pre-load failure & significantly reduced oxygen extraction, the presence of micro-clots in the blood, and a complete lack of metabolic adaption to exercise.

ME/CFS research is inherently multi-disciplinary, and provides an incredible opportunity to understand how different systems within the body interact.

We must support & grow the networks of researchers at the forefront of this condition

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Examples can be found through Open Medicine Foundation in the US, ME Research UK in the UK, ME/CFS Research Foundation in Germany, and WE&ME Foundation in Austria

The goal must be harnessing this research to develop treatments for people desperately in need.

‘I’m optimistic… we’re posed for a breakthrough. I think this disease is curable’

- Prof Ron Davis, Stanford University, IIMEC15 Conference 2023