

Offener Brief zur Finanzierung biomedizinischer Forschung zu Myalgischer Enzephalomyelitis in der Europäischen Union

Myalgische Enzephalomyelitis (ME), auch Chronisches Fatigue Syndrom (CFS) genannt, ist eine schwere chronische Krankheit, die durch extreme pathologische Erschöpfung, kognitive Störungen und sogenannte *Post-Exertional Malaise* (Zustandsverschlechterung nach Anstrengung/Belastung) gekennzeichnet ist. [1] ME-Patienten sind häufig nicht in der Lage zu arbeiten, zu studieren oder an sozialen Aktivitäten teilzunehmen. Viele sind hausgebunden oder bettlägerig und vollständig auf die Pflege durch Familienangehörige angewiesen.

In den Vereinigten Staaten wird der durch ME verursachte direkte und indirekte wirtschaftliche Schaden auf 17 bis 24 Milliarden Dollar pro Jahr geschätzt. In der Europäischen Union, mit etwa zwei Millionen ME-Erkrankten, ist von noch größeren Folgen für die Gesellschaft auszugehen.

Trotz der hohen persönlichen sowie gesellschaftlichen Kosten war und ist ME ein vernachlässigter Bereich in der Medizin. Es gibt derzeit keine erfolgversprechende Behandlung, die Prognose ist schlecht und viele Patienten bleiben jahrzehntelang krank. Obwohl die medizinische Forschung Fortschritte macht, ist die Pathologie der Krankheit noch sehr wenig verstanden.

Angesichts der hohen Krankheitslast ist eine deutliche Erhöhung der Mittel für die biomedizinische ME-Forschung dringend erforderlich. Mit diesem Brief fordern wir die EU auf, über geeignete Regelungen im *Horizon Europe* Programm eine verbesserte Förderung der Forschung zu vernachlässigten chronischen Krankheiten wie ME sicherzustellen.

In den USA, Australien und Kanada haben die Regierungen eigene Mittel für die ME-Forschung bereitgestellt; eine Strategie, die neue Wissenschaftler anzieht und hilft, das Gebiet weiterzuentwickeln. Medizinische Forschung zu ME findet an renommierten Instituten statt, so zum Beispiel in Stanford, Cornell und an der Columbia University. Auch an den mit Harvard verbundenen Krankenhäusern wurde vor kurzem eine neue ME-Forschungskoooperation etabliert. Das vordringliche Ziel ist die Entwicklung eines diagnostischen Tests, um die Genauigkeit der Diagnose zu erhöhen und zuverlässige Ergebnisse in Behandlungsstudien sicherzustellen.

Leider hinkt Europa in der ME-Forschung hinterher. In der Tat finanziert die EU – ein globaler Vorreiter im Gesundheitswesen und in der medizinischen Forschung – derzeit fast gar keine Forschung zu ME. Die wenigen in Europa angesiedelten Forschungsprojekte werden oft von Selbsthilfeorganisationen, Patienten und ihren Angehörigen finanziert.

Wir fordern, dass die EU sich den internationalen Entwicklungen anschließt und sich langfristig verpflichtet, in die biomedizinische ME-Forschung zu investieren. Eine Maßgabe im *Horizon Europe* Forschungsprogramm zur Bekämpfung vernachlässigter chronischer Krankheiten würde eine wesentliche Hürde für die europäische Forschung zu ME beseitigen. Nur so wird es möglich sein, zu einem besseren Verständnis dieser verheerenden Krankheit zu kommen und schließlich zu einer wirksamen Behandlung.

[1] Institute of Medicine (IOM). *Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness*. Washington, DC: The National Academies Press; 2015. https://www.ncbi.nlm.nih.gov/books/NBK274235/pdf/Bookshelf_NBK274235.pdf

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