Our work

The ME/CFS Research Foundation is committed to the promotion of biomedical research into ME/CFS. Our goal is the sustainable improvement of diagnostic and treatment options. In order to achieve this goal, **we fund scientific research projects** in the areas of basic research (e.g., biomarkers and disease mechanisms) as well as healthcare research.

Additionally, a major part of our work is **international networking of researchers**. Through regular conferences and networking meetings, we enable an active scientific exchange between leading experts to generate shared knowledge and to develop new solutions.

Transparency and dissemination of information are central values of the foundation. With the ME/CFS Research Register on our website and public symposia, we deliver current information about research projects and scientific developments.

In addition, we carry out intensive **educational and public relations work** in order to sustainably increase societal awareness and acceptance of ME/CFS. To this end, we conduct actions and campaigns — such as our recent social media campaign #LemonChallengeMECFS.

In cooperation with the initiative “Empty Stands,” we were able to generate a lot of attention and donations for ME/CFS, as well as raise awareness of the need for more research funding for the disease, during football matches at multiple football clubs in Germany.

As a charitable organisation, we are financed exclusively via donations. Our team is comprised of engaged ME/CFS patients, relatives and supporters. A scientific advisory council of internationally renowned experts supports us in identifying research approaches and in securing the scientific quality of our work.

Support our work!

Would you like to help? **Your donation goes 100% to ME/CFS research!**

Recipient:	ME/CFS Research Foundation
IBAN:	DE35 2004 0000 0628 5316 00
BIC:	COBADEFFXXX (Commerzbank Hamburg)

Alternatively, you can support us directly via **PayPal**:

t.ly/paypal-mecfs

On our **website** you will find further opportunities to get active: For example, start your own donation campaign among friends and family.

Visit us online and learn more about our supported **projects**, **events** and **activities** concerning ME/CFS. Sign up for our **newsletter** and follow us on **social media**:

mecfs-research.org

ME CFS
Research Foundation

ME/CFS Research Foundation gGmbH
Ballindamm 27
20095 Hamburg (Germany)
contact@mecfs-research.org

Support ME/CFS research.

For better diagnostics and treatments.

ME CFS
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What is ME/CFS?

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a severe multi-system illness, which usually occurs after an infection, but can also be triggered by other factors. Some patients with post-Covid syndrome (Long Covid) suffer from ME/CFS. People with the disease have a very low quality of life and often a high degree of disability. Inclusion and quality of life are often extremely limited, even among very young people with the disease.

The **main symptom** of ME/CFS is **post-exertional malaise (PEM)** — a disproportional worsening of state of health after minor physical, mental or emotional exertion. This occurs on a delay (12 to 72 hours after exertion) and can last for days, weeks, or even months. Each “crash” carries the risk of long-term deterioration in health.

Further **common symptoms** include:

- Fatigue (persistent, pathological exhaustion)
- Flu-like illness (malaise)
- Non-restorative sleep and sleep disorders
- Cognitive impairment, such as concentration and memory disorders (“brain fog”)
- Orthostatic intolerance (e.g., dizziness upon standing)
- Heart palpitations, arrhythmia
- Pain (e.g., in muscles, head, nerves, throat or lymph nodes)
- Sensory disorders (e.g., tingling or numbness)
- Hypersensitivity to light, noise, scent or touch
- Gastrointestinal problems (e.g., nausea, irritable bowel or food intolerances)
- Temperature regulation disorders (e.g., cold or hot spells)

ME/CFS is divided into **four degrees of severity**:

- **Mild**: those affected are able to take care of themselves and possibly work or go to school to a limited extent, but they need more periods of rest
- **Moderate**: mobility is significantly limited, daily activities are only possible with considerable effort
- **Severe**: predominantly bedridden, those affected need help caring for themselves and are often dependent on a wheelchair
- **Very severe**: bedridden, extreme sensitivity to light and noise, need complete nursing care

In 2025, **more than 656,000 people in Germany** were affected by ME/CFS. Worldwide, this number is over 40 million. About two thirds of those with ME/CFS are unable to work. A quarter of all ME/CFS patients can no longer leave their homes, and many are bedbound and dependent on nursing care.

According to studies, ME/CFS is among the diseases with the lowest quality of life, lower than cancer, multiple sclerosis, rheumatism or depression.

Photo credits: Lea Aring / Deutsche Gesellschaft für ME/CFS

Why research is the solution

ME/CFS was classified by the World Health Organization (WHO) in 1969. However, the illness was ignored by medicine and society for a long time, and was incorrectly psychologised.

To date, there is still no causal therapy. Diagnosis is complex, and clear biomarkers are lacking. Many of those affected experience a years-long odyssey through the healthcare system until they receive the diagnosis of ME/CFS.

The current healthcare situation is very poor. As of the end of 2024, there were only two specialised ME/CFS clinics in all of Germany. Many medical practitioners are not sufficiently familiar with diagnosis and symptomatic treatment of the disease. Available off-label medications for symptom relief are rarely prescribed and seldom reimbursed by insurance.

Care of ME/CFS patients is therefore performed mostly by family or private care providers, sometimes under precarious circumstances. Access to social and medical benefits (e.g., degree of disability, assistive devices) is extremely difficult for many ME/CFS patients. Many medical assessors are not familiar with ME/CFS.

ME/CFS causes considerable suffering to those affected and to their families. **In 2025, the resulting social losses in Germany amounted to about 33 billion euros** (according to a study jointly conducted by the ME/CFS Research Foundation and Risklayer).

Research is the crucial starting point, in order to sustainably improve diagnostics, care and treatment.

ME/CFS research will:

- further uncover causes of the disease
- identify reliable biomarkers for diagnosis
- develop medications and therapies that provide a cure or better symptomatic treatment

ME/CFS research creates the conditions for effective medical care for those affected by the disease.