

PAIS research in Germany – on the cusp of breaking through?

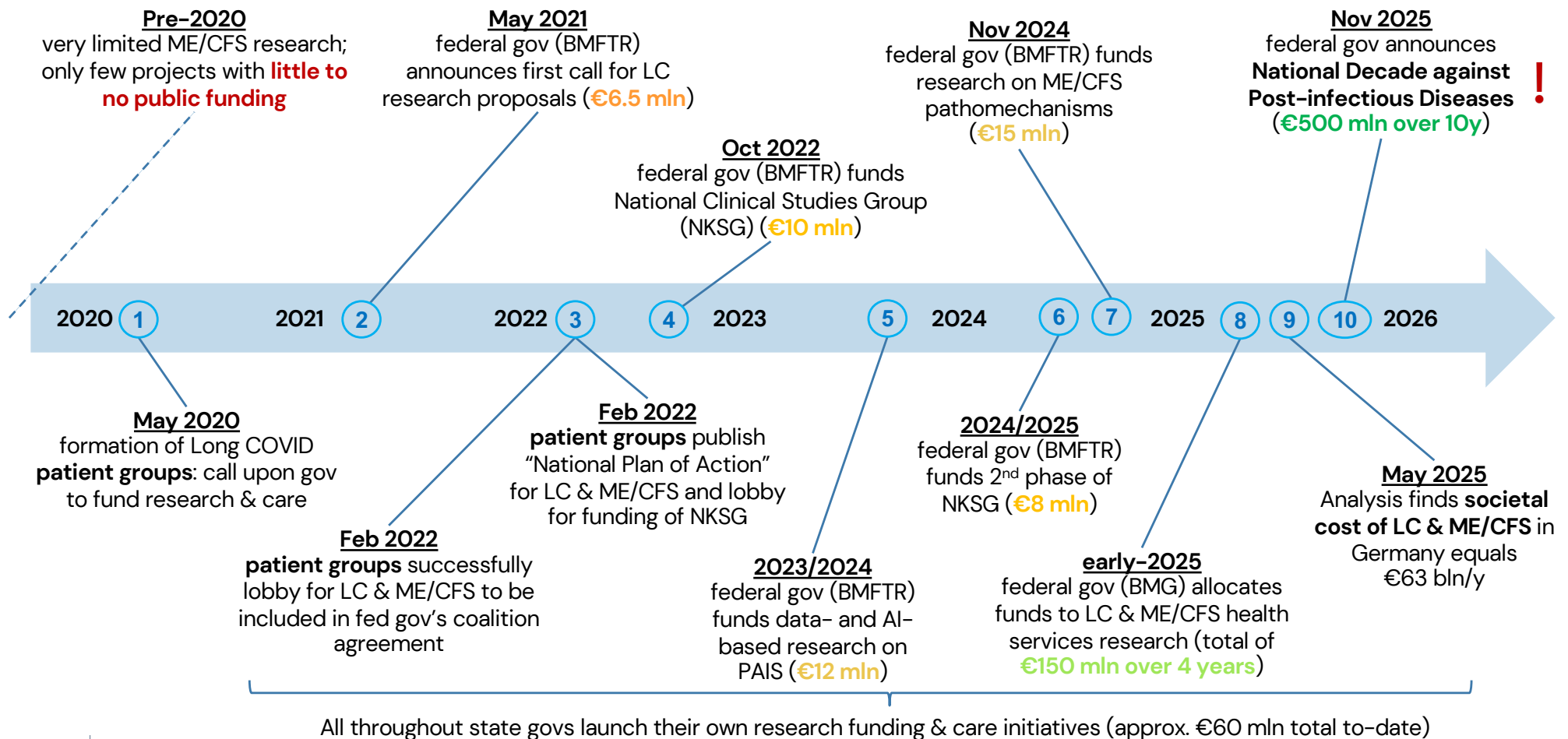
Long COVID Web – Monthly Webinar

15 September 2026

Agenda

1. PAIS research landscape in Germany
2. National Decade against Post-infectious Diseases
3. Societal Cost of Long COVID and ME/CFS in Germany
4. International ME/CFS Conference
5. ME/CFS Research Foundation

1. PAIS research landscape in Germany



1. PAIS research landscape in Germany

Institutionally funded research infrastructure



German Centres for Health Research (DZG)



Network of University Medicine (NUM)



Non-university research institutions

Government and state bodies



Federal Ministry of Health (BMG)



Federal Ministry of Research, Technology and Space (BMFTR)



16 state governments (13 of which directly fund PAIS research/healthcare)

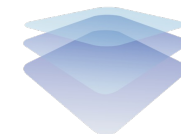
Private funders



ME/CFS Research Foundation (non-profit/charity)

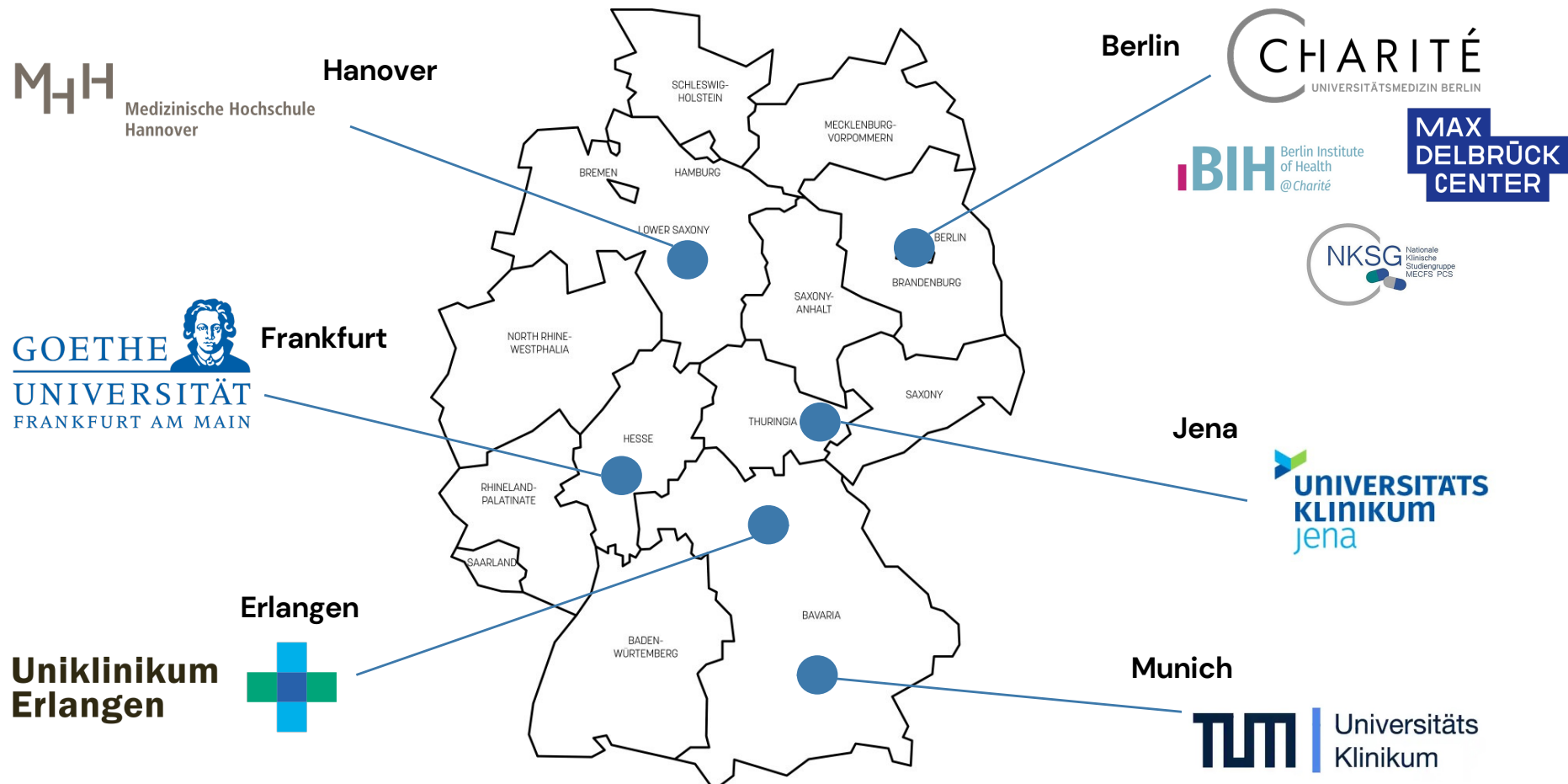


German ME/CFS Association (patient organisation with dedicated funding programme)



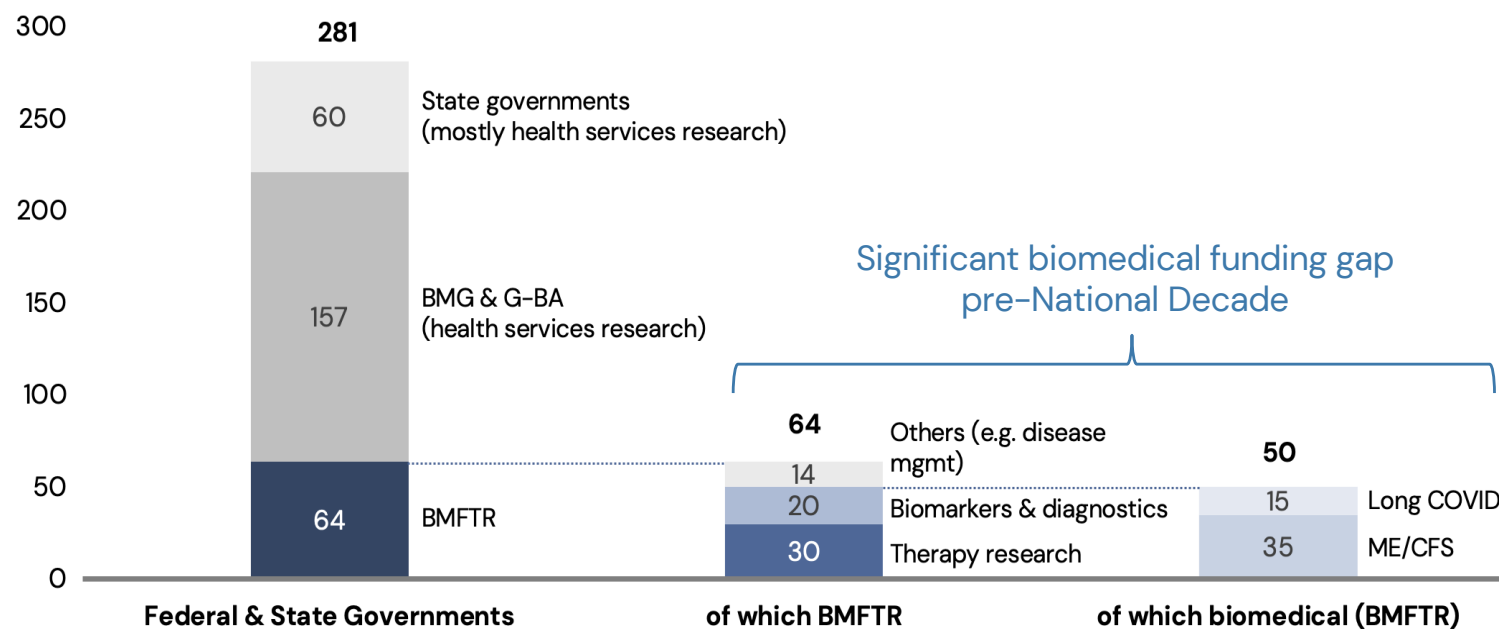
Lost Voices Foundation (patient organisation with dedicated funding programme)

1. PAIS research landscape in Germany



1. PAIS research landscape in Germany

Public funding for ME/CFS and Long COVID research^{*} in € mln, preliminary figures from ongoing analysis



Sources: BMFTR, BMG, state governments – websites and enquiries; analysis by ME/CFS Research Foundation
Figures are preliminary and partly estimated.

^{*} as of end-2025, pre-National Decade and excl. institutionally funded research infrastructure

2. National Decade against Post-infectious Diseases

Background & Vision

- Germany needed a long-term research strategy to combat post-infectious diseases. For this reason, the Federal Ministry of Research, Technology and Space (BMFTR), together with its partners in health research, launched the "National Decade Against Post-infectious Diseases"—an initiative spanning ten years. Its initial planning and parliamentary initiation was led by former Minister of Health Prof. Dr. Karl Lauterbach and the Research Committee of the German Bundestag.
- Representatives from politics, research, the healthcare sector, the health industry, and civil society are working together in this initiative. They are united by the goal of mobilising all resources in Germany to combat post-infectious diseases in a targeted and successful manner.

"Understand. Cure. Care.

Germany is embracing the challenge posed by post-infectious diseases as a national health priority.

With the National Decade Against Post-infectious Diseases, we are creating a long-term, integrative research platform to systematically investigate the causes, mechanisms, diagnostics, and effective treatments for these complex diseases, as well as approaches to prevention—with the aim of ensuring effective care for those affected.

We aim to rapidly bring research findings to those affected and to utilise the experience and insights gained from patient care to inform research, ultimately leading to further improvements."

2. National Decade against Post-infectious Diseases

Concept

- **Funds:** €500 mln over ten years (2026–2035)/€50 mln in annual funding to be allocated.
- **Goal:** research the causes, underlying mechanisms, and new treatment options for people living with post-infectious diseases—such as ME/CFS and Long COVID—as well as other post-viral diseases.
- **Planned/ongoing measures include:**
 - Additional funding for **research projects** on pathophysiology, immunology, diagnostics, and biomarkers, incl. ME/CFS.
 - Strengthening of **clinical trials/clinical trial platforms** (adaptive platform trials).
 - Structural measures, such as **funding for early-career research groups**, to increase the number of scientific experts long-term.
 - Establishment of a **new patient database to serve as a foundation** for research projects and the evaluation of new treatment approaches (building up on existing Network of University Medicine (NUM) infrastructure).
 - Genome sequencing: Using existing data from the NAKO Health Study (Germany's largest long-term health study investigating common diseases in over 200,000 participants) and the NAPKON cohorts (National Pandemic Cohort Network) within NUM, **genome sequencing of both patients and controls** will reveal genetic differences. Findings should provide the basis for a better understanding of the disease mechanisms underlying PAIS.
 - **Optimised data environment** to be established that guarantees the secure storage and protected sharing of all resulting data (incl. with the help of AI-based applications).
 - **Networking and training initiatives** for scientific community, as well as evidence-based outreach for professionals.

2. National Decade against Post-infectious Diseases

Organisational set-up

▪ **Steering committee**

- **Function:** central expert body for the National Decade guiding and shaping its implementation. It advises on the thematic priorities, potential funding needs, and key scientific questions and knowledge gaps regarding post-infectious diseases. Members of the steering committee carry out these tasks jointly. Overall, it serves as an advisory body; it does not possess decision-making authority.
- **Members:** Federal Ministry of Research, Technology and Space (BMFTR), Federal Ministry of Health (BMG), state ministries, Federal Joint Committee (G-BA) (highest decision-making body of the joint self-government of physicians, dentists, hospitals and health insurance funds), German Association for ME/CFS (patient organisation), NAKO Health Study, NUM, DZG, Helmholtz Health, Leibniz Association, Berlin Institute of Health (BIH), and the Association of Research-Based Pharmaceutical Companies (vfa).

▪ **Working groups**

- **3 groups:** (1) translation, (2) research infrastructure/data and biosamples, and (3) healthcare-centered research
- **Function:** develop recommendations for potential funding measures, based on their thematic focus and in coordination with the steering committee.

▪ **Expert advisory**

- Additional expertise and perspectives from scientists, patients, and carers are incorporated on a needs-based basis (within both the working groups and the steering committee).

2. National Decade against Post-infectious Diseases

First funding measures

- Funding for **clinical research/trials highly relevant to patient care (project start expected in mid-2027):**

- Close evidence gaps and generate new findings on how patients can be better diagnosed and which drugs can be used for targeted treatment. Call for proposals focuses on PAIS, specifically mentioning Long COVID and ME/CFS.
- Selected projects will be funded across three modules:

- **Module 1 (duration of up to 5 years): RCTs**

Funding for confirmatory and **exploratory multicentre, prospective, randomised, controlled clinical trials (Phase IIb) designed to demonstrate the efficacy of diagnostic procedures and/or treatments (e.g. drugs)**. Also supports exploratory clinical trials involving a small number of patients, provided trials serve as a preparatory basis for subsequent, larger-scale projects with a greater number of patients. All trials must involve at least two study sites, although justified exceptions are possible.

- **Module 2 (duration of up to 2 years): Systematic reviews**

Supports the development of review articles—specifically, **scientific papers (including updates) covering clinical trials on PAIS**. Module aims to foster the compilation and systematic synthesis of findings at a theoretical level.

- **Module 3 (duration of up to 18 months): RCT concept development with close patient involvement**

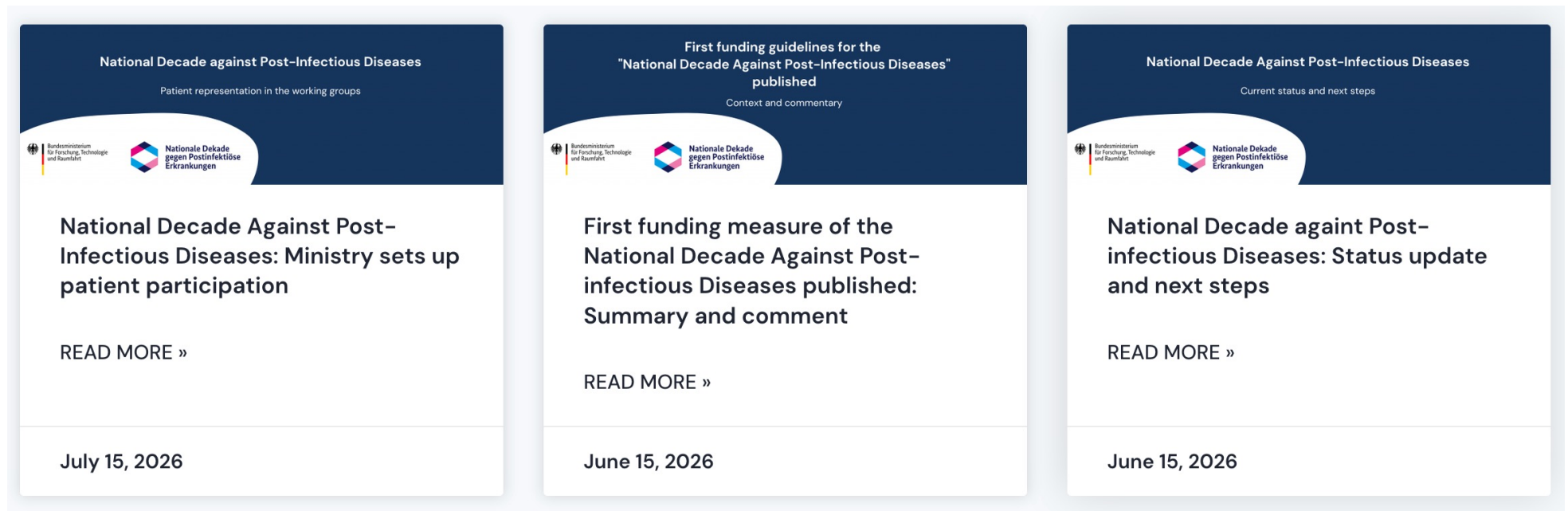
Funds **conceptual phases during which patients (and other relevant target groups) play an active role in planning and designing future clinical trials** (as outlined in Module 1). This encompasses, for example, the collaborative design of future research projects or the participatory development and/or piloting of drug trials. Following the conceptual phase of a funded proposal, the planned project undergoes a prompt review. Project outlines that receive a positive assessment may be implemented as clinical trials with funding under this module, provided that close cooperation with patients continues.

2. National Decade against Post-infectious Diseases

First funding measures

- Funding for **expansion of the database** for research into post-infectious diseases (project duration 2026–2028):
 - To improve the data basis for research, drawing on existing patient cohorts from the NAKO Health Study and NUM/NAPKON. Funded consortia genome and RNA sequencing, immune profiling, protein analysis, and autoantibody screening. A comprehensive database is being created that links patients' clinical presentation with their genetic predisposition and immune function.
 - Reference dataset will be made available to additional research projects. Aim is to facilitate the identification of pathomechanisms and therapeutic targets, lay the groundwork for future clinical trials, and enable integration with national and international reference cohorts.
 - Sub-projects cover:
 - Genome sequencing
 - Biosamples and DNA- & RNA-extraction
 - Proteomics and scRNA-seq
 - Case definitions
 - Clinical epidemiology
 - Serolomics, autoantibodies
 - Total RNA sequencing
- Additional funding is provided to **enable continuation of ongoing basic, translational, and clinical research projects.**

2. National Decade against Post-infectious Diseases



Regular updates on the Foundation's website: <https://mecfs-research.org/en/news-events>

3. Societal Cost of Long COVID and ME/CFS in Germany

Approach

- **Number of SARS-CoV-2 infections:** Underlying data basis stems from a corrected modelling of the number of monthly SARS-CoV-2 infections in Germany since the start of the COVID-19 pandemic.
- **LC & ME/CFS prevalence:** In order to generate data on active LC & ME/CFS cases over time, the model makes use of both the corrected number of SARS-CoV-2 infections as well as a range of existing findings from scientific literature. These cover assumptions on how many of the people who contract SARS-CoV-2 go on to develop Long COVID, how many of these Long COVID cases remain ill for more than a year and how many of the Long COVID cases transition to ME/CFS. The model also takes into account the estimated share of people recovering from Long COVID and ME/CFS over time. All depending on virus variants, immunisation/vaccination status etc.
- **Societal costs:** Based on this, the costs arising from the modelled disease cases are calculated. These costs result from reduced value-add and increased expenditure, calculated according to standard economic parameters, specifically: production disturbance costs, human capital costs, medical costs, administrative costs, travel costs, support and assistance costs, deadweight costs of transfer payments, and quality of life and well-being costs. These are then multiplied by different severity multipliers for Long COVID and ME/CFS. The Cost modelling is based on a Monte Carlo Simulation (frequently used to model e.g. the cost of environmental/climate disasters).



3. Societal Cost of Long COVID and ME/CFS in Germany

SARS-CoV-2 infections in Germany (monthly)

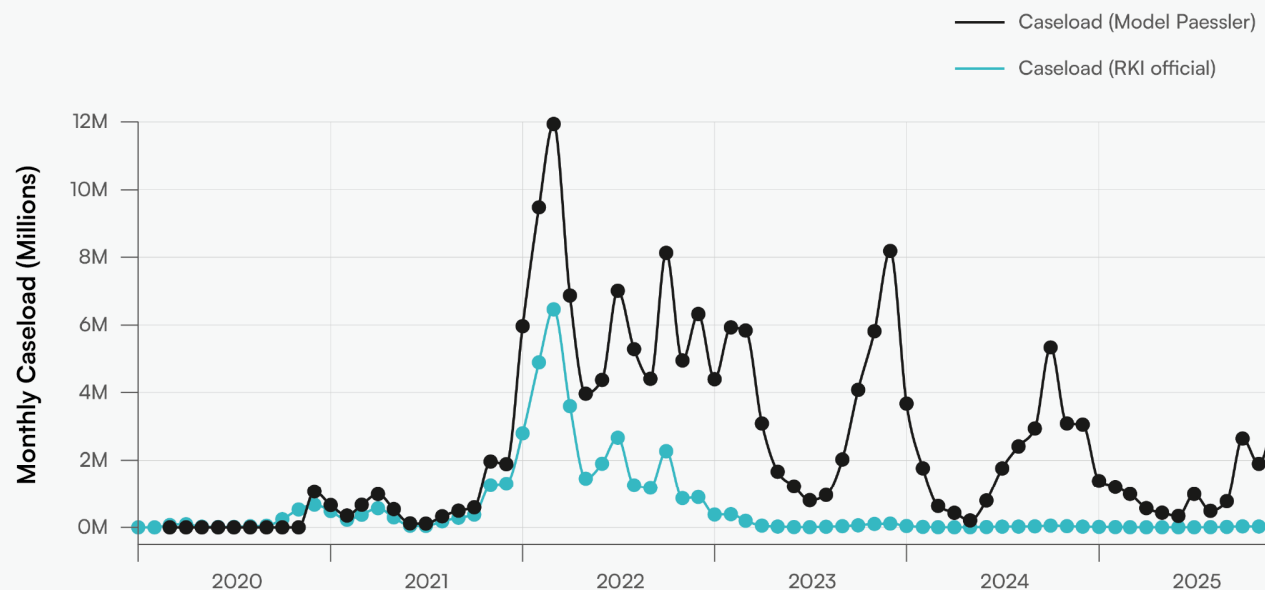
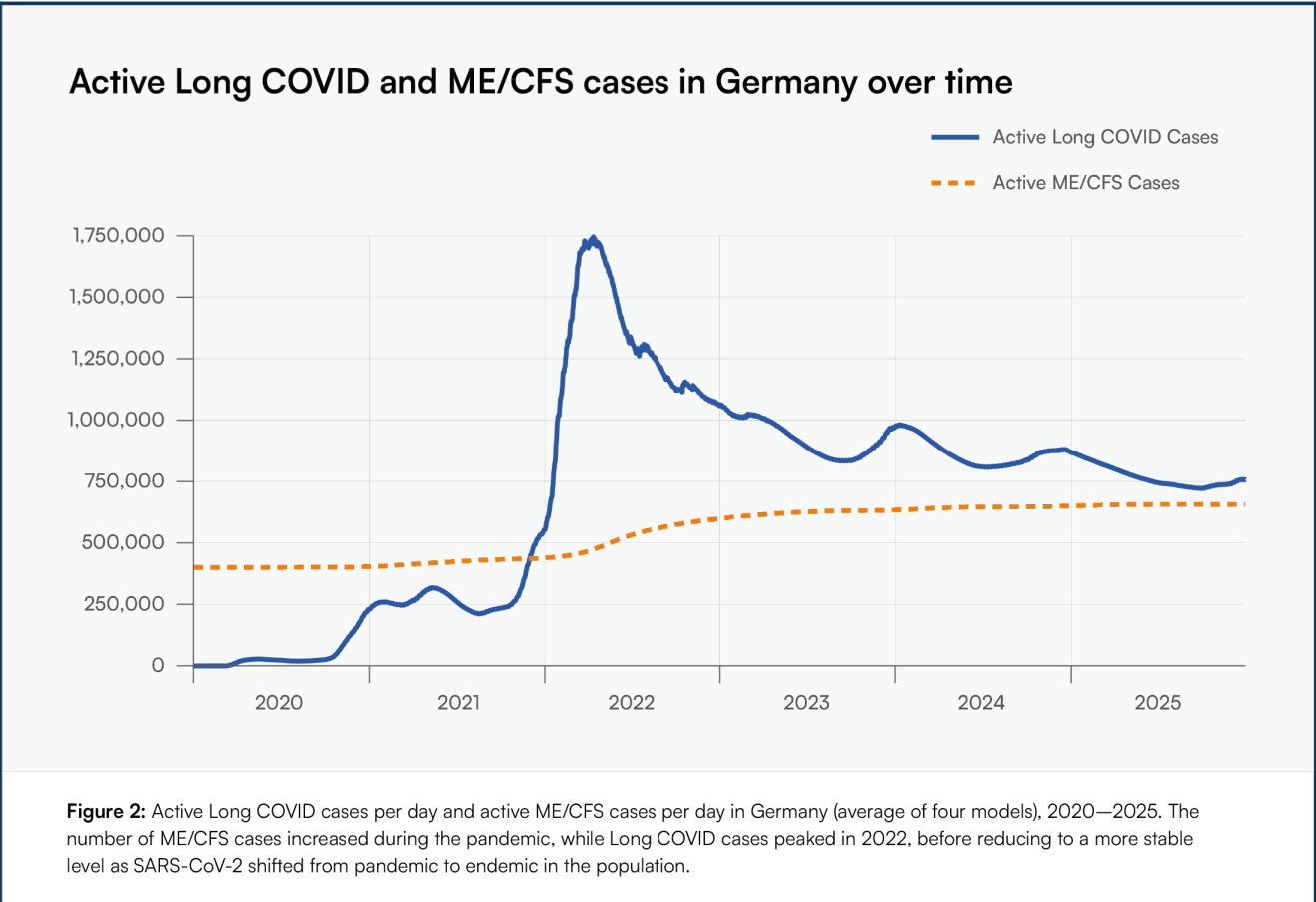
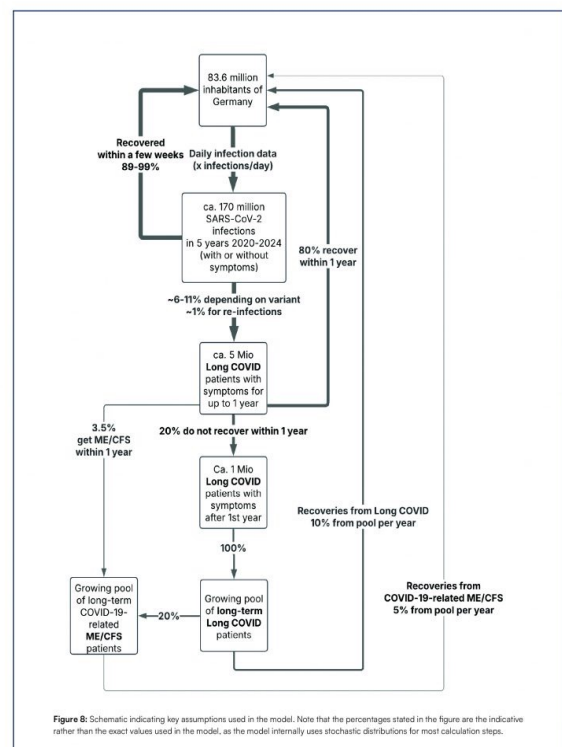


Figure 1: SARS-CoV-2 infection caseload in Germany, official data from Robert Koch Institute (RKI) compared to corrected model data from Paessler et al. (2026). Official data do not capture all cases; modelling suggests that in 2025, the actual number of infections was between 13 and 15 million, which was 80-200 times higher than the officially recorded figures.

Data basis: Corrected modelling of the number of monthly SARS-CoV-2 infections in Germany. This alternative model is available as a [preprint](#).

It indicates that in 2024-2025, the **number of SARS-CoV-2 infections was likely 80-200 times higher than official data** by the Robert Koch Institute (the federal public health institute in Germany) suggests. In 2025, the number of SARS-CoV-2 infections was likely between 13 and 15 million.

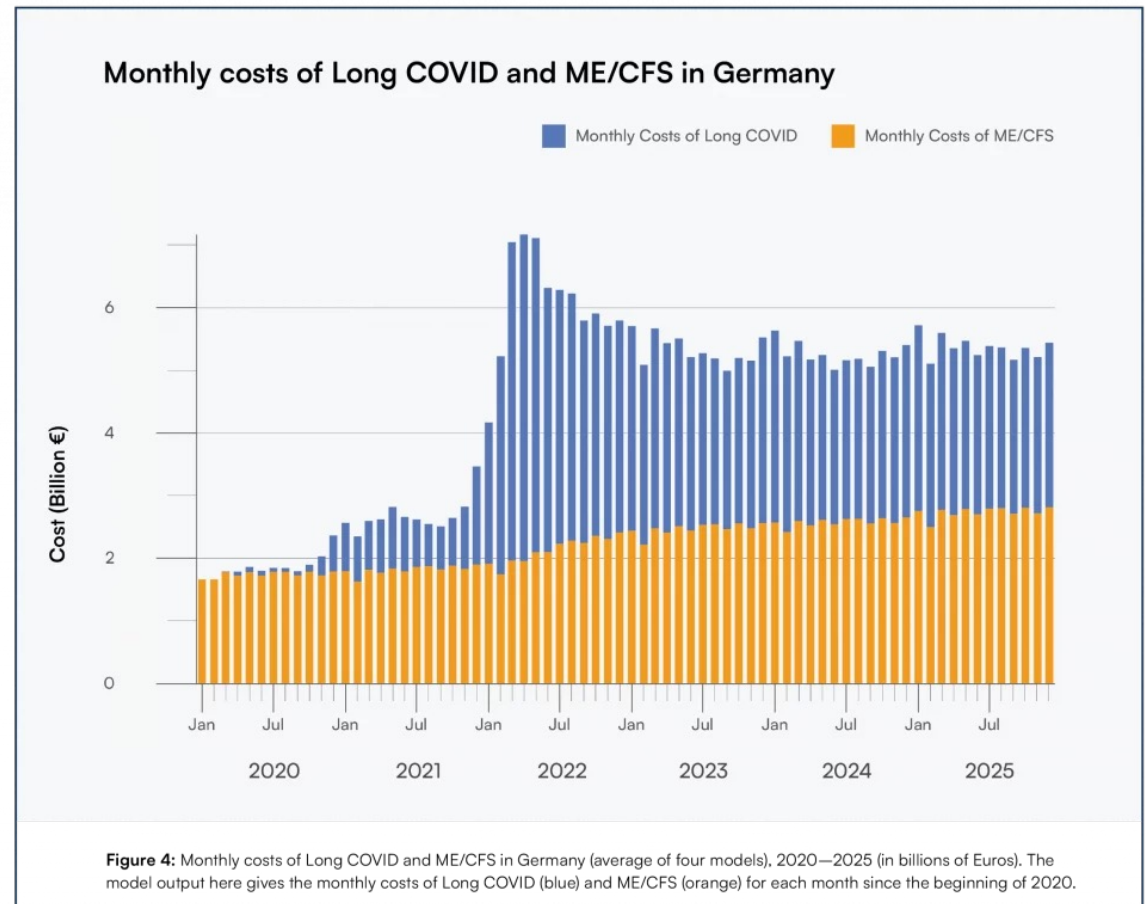
3. Societal Cost of Long COVID and ME/CFS in Germany



3. Societal Cost of Long COVID and ME/CFS in Germany

At the end of 2025, more than 750,000 people in Germany were living with Long COVID, while an additional 650,000 people were living with ME/CFS (the latter includes ME/CFS diagnosed as a result of COVID-19/Long COVID).

The number of ME/CFS cases (and associated monthly costs) increased compared to the previous year, while the number of Long COVID cases (and monthly costs) slightly decreased.



3. Societal Cost of Long COVID and ME/CFS in Germany

Results

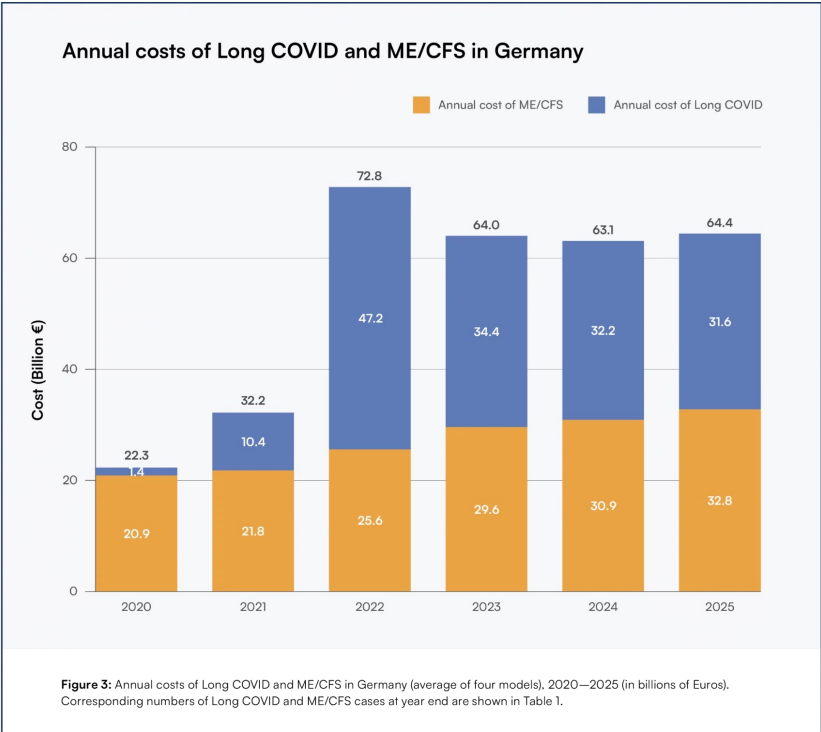


Table 1: Cases and costs of Long COVID and ME/CFS in Germany, 2020–2025. Average of the four variations of the model developed.

Year	Long COVID			ME/CFS			Long COVID & ME/CFS
	New cases	Cases at year end	Cost (€ billion)	New cases	Cases at year end	Cost (€ billion)	Combined cost (€ billion)
2020	272,829	227,560	1.4	3,481	403,432	20.9	22.3
2021	805,773	547,306	10.4	36,593	438,896	21.8	32.2
2022	2,743,384	1,064,373	47.2	165,849	598,620	25.6	72.8
2023	527,594	970,917	34.4	46,168	635,838	29.6	64.0
2024	282,381	871,086	32.2	28,792	650,183	30.9	63.1
2025	164,976	756,808	31.6	20,870	656,951	32.8	64.4
Total			157.2			161.6	318.8

Daniell J, Brand J, Paessler D, Heydecke J, Schoening S, Nikoloudis ML, Manser V, McLennan AK. 2026. **The rising cost of Long COVID and ME/CFS in Germany: 2026 update.** April 2026. Hamburg and Karlsruhe: ME/CFS Research Foundation and Risklayer.



In total, more than 1.4 million people in Germany were living with either Long COVID or ME/CFS at the end of 2025.

In 2025 alone, Long COVID and ME/CFS cost €64.4 billion, equal to 1.44 % of Germany's gross national product (GDP).

3. Societal Cost of Long COVID and ME/CFS in Germany

More information on the Foundation's website: <https://mecfs-research.org/en/costreport-long-covid-and-mecfs>

2026 update out!

Long COVID and ME/CFS prevalence and cost
in Germany modelled for the period 2020—2025



Model data publicly available on GitHub: <https://github.com/risklayer/long-covid-mecfs-costs-germany>

4. International ME/CFS Conference

About the event

- Annual hybrid event jointly organised by Charité Fatigue Center (lead Prof. Dr. Carmen Scheibenbogen) and the Foundation.
- Directed at medical professionals, researchers and interdisciplinary experts in the fields of medicine and biology.
- Held in 2023, 2025, and 2026 (last brought together 7,000 participants on-site and online).
- 2026 Conference centred on the latest findings from research on disease mechanisms; ranging from insights into genetics, biomarkers, and imaging, to vascular, neuronal, immune and metabolic dysfunction. Day two of the Conference was centred on showcasing recent data and results from clinical trials investigating treatments, with a focus on interventions targeting immune dysregulation. An afternoon Symposium summarised ongoing research in German for patients and the wider public.
- Contributions focussed on ME/CFS, while also highlighting research on Long COVID.
- Conference featured a poster gallery (online and offline). Posters available online for registered participants for up to six months after the Conference.
- Videos and list of speakers available on the Foundation's website: <https://events.mecfs-research.org> or directly via Youtube: <https://www.youtube.com/@MECFResearchFoundation>

4. International ME/CFS Conference

Selection of previous speakers



Rob Wust

Vrije Universiteit (VU)
Amsterdam, Netherlands



David Systrom

Brigham and Women's Hospital
and Harvard Medical School,
Boston, USA



Michael Peluso

University of California San
Francisco (UCSF), USA



Keyla Sá

Yale University, USA



David Putrino

Icahn School of Medicine at
Mount Sinai, New York, USA



Takashi Yamamura

National Center of Neurology
and Psychiatry (NCNP), Tokyo,
Japan



Chris Ponting

University of Edinburgh, UK



Michelle James

Stanford University, USA



Jeroen den Dunnen

Amsterdam University Medical
Center (UMC), Netherlands



**Christopher
Armstrong**

University of Melbourne,
Australia



Øystein Fluge

University of Bergen, Norway



Gunnar Gottschalk

Simmaron Research, USA



Alain Moreau

University of Montreal, Canada



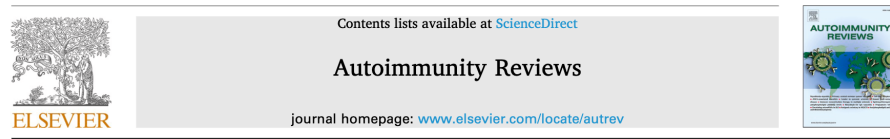
Luis Nacul

University of British Columbia,
Canada

4. International ME/CFS Conference

Conference summaries

Autoimmunity Reviews 25 (2026) 104043



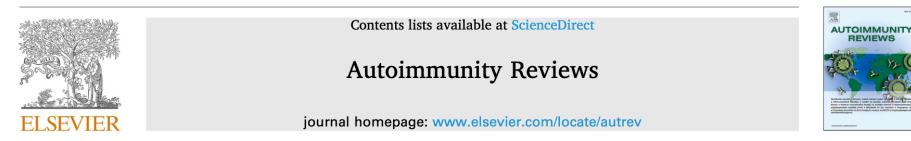
Expert perspectives on Myalgic encephalomyelitis/chronic fatigue syndrome – Insights from the 3rd International Conference of the Charité Fatigue Center

Annick Fehrer^{a,*}, Lara Windzio^{a,1}, Simon Schoening^{b,1}, Sophie Steiner^{a,1}, Anna C. Aschenbrenner^c, Nina Babel^{a,d,e}, Uta Behrends^{f,g}, Judith Bellmann-Strobl^{h,i}, Guido Cammà^j, Alan Cash^k, Wolfram Doehner^{d,i,m,a}, Jeroen den Dunnen^o, Øystein Fluge^{p,q}, Christiana Franke^l, Kathryn Hoffmann^r, Claudia Kedor^a, Laura Kim^a, Wiebke Löhden^s, Olav Mella^{p,q}, Lorenz L. Mihatsch^f, Michael J. Peluso^t, Christian Puta^{u,v,w}, David Putrino^x, Anuradha Ramoji^{y,z}, Wakiro Sato^{aa}, Birgit Sawitzki^{ab}, Georg Schlieper^{ac}, Yehuda Schoenfeld^{ad}, Martina Seifert^{a,m}, Fridbjörn Sigurdsson^{ae}, Anouk Slaghekke^{af}, Kristian Sommerfelt^{ag}, Franziska Sotzny^a, Elisa Stein^a, Juergen M. Steinacker^{ah}, Michael Stingl^{ai}, David M. Systrom^{aj}, Karl J. Tronstad^{ak}, Klaus Wirth^{al,am}, Bernhard Wörmann^{an,ao}, Rob C.I. Wüst^{af}, Takashi Yamamura^{ap}, Carmen Scheibenbogen^a

2025 Conference doi: [10.1016/j.autrev.2026.104043](https://doi.org/10.1016/j.autrev.2026.104043)

2026 Conference article submitted for publication

Autoimmunity Reviews 22 (2023) 103452



Understanding, diagnosing, and treating Myalgic encephalomyelitis/chronic fatigue syndrome – State of the art: Report of the 2nd international meeting at the Charité Fatigue Center

Sophie Steiner^{a,1}, Annick Fehrer^{a,1}, Friederike Hoheisel^{a,1,*}, Simon Schoening^{b,1}, Anna Aschenbrenner^c, Nina Babel^{a,d,e}, Judith Bellmann-Strobl^{f,g,h,i}, Carsten Finke^f, Øystein Fluge^{j,k}, Laura Froehlich^l, Andreas Goebel^m, Bettina Grandeⁿ, Johannes-Peter Haas^o, Bettina Hohberger^p, Leonard A. Jason^q, Anthony L. Komaroff^r, Eliana Lacerda^s, Max Liebl^t, Andrea Maier^u, Olav Mella^{j,k}, Luis Nacul^{s,v,w}, Friedemann Paul^{g,h,i}, Bhupesh K. Prusty^x, Christian Puta^{y,z,aa}, Gabriela Riemekasten^{ab}, Wolfgang Ries^{ac}, Peter C. Rowe^{ad}, Birgit Sawitzki^{ae}, Yehuda Shoenfeld^{af}, Joachim L. Schultze^{c,ag,ah}, Martina Seifert^{a,e,ai}, Nuno Sepúlveda^{aj,ak}, Franziska Sotzny^a, Elisa Stein^a, Michael Stingl^{al}, Friederike Ufer^{am}, Christian Veauthier^{an}, Francisco Westermeyer^{ao,aw}, Klaus Wirth^{ap}, Bernd Wolfarth^{aq}, Pawel Zalewski^{ar,as}, Uta Behrends^{at,au,av,2}, Carmen Scheibenbogen^{a,2}

2023 Conference doi: [10.1016/j.autrev.2023.103452](https://doi.org/10.1016/j.autrev.2023.103452)

4. International ME/CFS Conference

2027 Conference

- **Save the date: International ME/CFS & PAIS Conference on 11–12 May 2027 online and at Hotel MOA Berlin**
- Confirmed keynote speaker: Prof. Dr. Akiko Iwasaki, Yale University
- Jointly organised with DZG (BMFTR-funded) and LongCare (BMG-funded)
- Organised as part of a 2-day PAIS Summit with 3 thematic sessions held in parallel
- Increased capacity for participants (target: 10,000) and poster contributions (up to 100)
- **Call for poster abstracts (hybrid exhibition) to be published in Dec 2026/Jan 2027**



Sign up for our newsletter to get notified:
<https://mecfs-research.org/en/news-events/newsletter>

5. ME/CFS Research Foundation

Core activities

▪ **Research funding**

- More than 15 research projects directly funded/indirectly supported since 2022.
- Projects focus on the development of biomarkers, diagnostics, and treatment options.
- Initial focus was to support of established centres of excellence for ME/CFS research in Germany: Charité Fatigue Center (CFC) and Munich Chronic Fatigue Center (MCFC). 2026 saw first open call for funding (€2.5 mln).

▪ **Networking of researchers**

- International ME/CFS Conference (public event).
- Informal working group meeting (“PAIS Research Consortia Meeting on Clinical Trials”) (closed to public).

▪ **Facts and resources**

- ME/CFS Research Register (MRR) (data registry).
- Societal Cost of Long COVID and ME/CFS (data modelling).

▪ **Advocacy and policy outreach**

- Statements at Parliamentary Hearings, informal/formal discussions with Ministries and MPs, National Decade patient representation.

▪ **Fundraising and awareness**

- Social media campaigns, collaborations with sport’s clubs (Bundesliga), fundraising events.

5. ME/CFS Research Foundation

Research funding

Charité Fatigue Center (CFC)

Disease mechanisms

Biomarkers

CHARITÉ

MAX PLANCK INSTITUTE
FOR THE SCIENCE OF LIGHT

Cell Morphology, Cell Deformability and Microclots in ME/CFS

Funding period: January 2024–December 2026

View project →

Biomarkers

CHARITÉ

UNIVERSITÄT
DUISBURG
ESSEN

Investigation of Brain Changes in ME/CFS

Funding period: January 2026–June 2026

View project →

Biomarkers

CHARITÉ

Comparative Study of Healthy Control Subjects and ME/CFS Patients

Funding period: January 2026–June 2026

View project →

Munich Chronic Fatigue Center (MCFC)

Disease mechanisms

Biomarkers

TUM

Universitäts
Klinikum

Model Ward for Severely Affected Children and Young People

Funding period: January 2024–December 2025

View project →

Biomarkers

TUM

Universitäts
Klinikum

MCFC Research Laboratory

Funding period: January 2025–December 2025

View project →

Biomarkers

TUM

Universitäts
Klinikum

ME/CFS Registry and Biobank

Funding period: January 2025–December 2025

View project →

Biomarkers

TUM

Universitäts
Klinikum

Healthy Control Population for PAIS–ME/CFS (HeIP)

Funding period: January 2025–December 2025

View project →

5. ME/CFS Research Foundation

Research funding

Research Funding Programme 2026

Treatment

CHARITÉ

TAME – CD19-Targeted B-Cell Therapy for Post-Infectious Autoimmune ME/CFS

Funding period: September 2026–December 2029

View project →

Disease mechanisms

MHH
Medizinische Hochschule
Hannover

Genetic Determinants of Post-Infectious ME/CFS

Funding period: September 2026–March 2029

View project →

Disease mechanisms

Biomarkers

CHARITÉ

DRFZ

STRAT4PAIS — Immune Endotypes of Paediatric Post-Acute Infection Syndromes

Funding period: September 2026–August 2028

View project →

Disease mechanisms

HELMHOLTZ MUNICH

TUM

CHARITÉ

Molecular Dissection of Cell Death-Mediated Inflammation

Funding period: September 2026–August 2028

View project →

Treatment

Disease mechanisms

Biomarkers

GOETHE
UNIVERSITÄT
FRANKFURT AM MAIN

MYOFLAME-19 Autoimmune Substudy

Funding period: September 2026–August 2028

View project →

Biomarkers

Uniklinikum
Erlangen

Single Cell RNA Sequencing Analysis of the Immune Cell Receptor Repertoire

Funding period: September 2026–August 2028

View project →

Biomarkers

IBH
Institute of Biomedical
Histochemistry

MARK-ME – Minimal Biomarker Panels for Diagnosis and Stratification of ME/CFS

Funding period: September 2026–August 2028

View project →

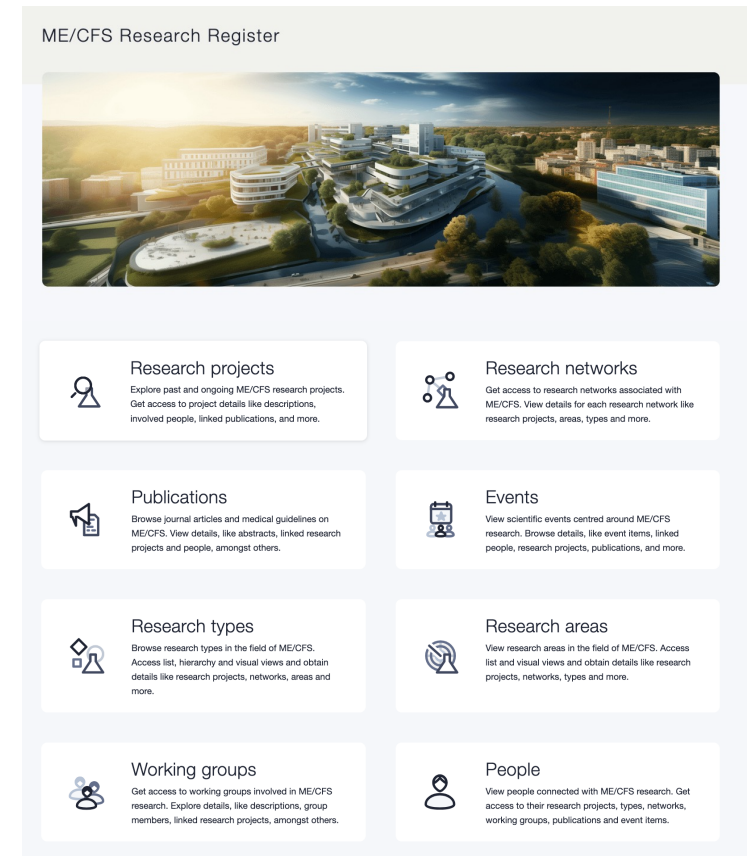
Details on all funded projects, incl. lectures, interviews etc. are available online: <https://projects.mecfs-research.org>

5. ME/CFS Research Foundation

ME/CFS Research Register (MRR)

- First-of-its-kind data register on ME/CFS research.
- Holistic overview of medical research on ME/CFS, detailing research projects, research networks, publications, scientific events, research types, research areas, working groups, people and organisations.
- Covers research conducted in Germany, Austria, Switzerland, the Netherlands, Norway, and Iceland.
- Currently lists around 150 research projects and 260 publications.
- Features detailed search filters and visualised overviews.
- Country coverage and technical features to be expanded.

Register is publicly available at: <https://mrr.mecfs-research.org>



Thank you for your attention!

Questions?
